

ANGLIA RUSKIN UNIVERSITY

FACULTY OF HEALTH, SOCIAL CARE AND
EDUCATION

PRIMARY PERCUTANEOUS CORONARY
INTERVENTION FOR ACUTE MYOCARDIAL
INFARCTION: EXPLORING THE EXPERIENCES
OF PATIENTS, CARERS AND CARDIAC NURSES

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A thesis in partial fulfilment of the requirement of Anglia
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ABSTRACT

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DOCTOR OF PHILOSOPHY

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A narrative inquiry approach was used to compare and contrast the experiences of ten patients who received Primary Percutaneous Coronary Intervention (PPCI) for Acute Myocardial Infarction. Eight carers and ten cardiac nurses in one Heart Attack Centre were also recruited. The purpose of the study was to understand what mattered to these individuals from their different perspectives. Patients and carers were interviewed within 14 days of hospital discharge. Vignettes were developed from participants' direct quotations to convey their experiences of different events surrounding the PPCI. Two artificial stories from patients and carers were presented in the nurses' interviews. Using Labov's structural analysis, participants' narratives portrayed the travelling experiences, routes and journeys encountered. The emotional responses depicted how patients felt when they were ill and then suddenly well and of how carers were initially helpless and then able to manage. Different to previous literature on the experience of PPCI was the inclusion of nurses' experiences. Their narratives revealed a preoccupation with making patients well again. An intriguing finding was the manner in which nurses expected sick patients to respond to their caring actions. When patients were ill, the nurses' role was clearly defined. When patients felt well, their caring actions were fraught with difficulty. The nurses' emotional responses provide new understandings about how nurses actively managed the challenges and rewards of working in a Heart Attack Centre. The voices of the patients, carers and nurses heard in this research revealed the compelling and diverse ways in which strategies were taken to protect the self or others from harm and the reasons for these active behaviours. This study has drawn attention to the ways patients, carers and nurses work together and against each other. These experiences will be useful for improving nursing practice.

Keywords: PPCI, patients, carers, nurses, experiences, narratives

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Glossary

Acute Myocardial Infarction (AMI)	Blood flow is abruptly blocked in one or more coronary arteries causing tissue damage.
Angioplasty	A balloon used to stretch open a narrowed or occluded coronary artery.
Carer	Term to describe the patients' spouse, partner or children.
Cardiac arrest	Electrical activity in the heart is unable to sustain cardiac output.
Catheter laboratory	A room containing diagnostic imaging equipment to visualise the coronary arteries.
Defibrillation pads	Applied to the chest and attached to a device that gives an electrical shock to the heart when a person has a cardiac arrest.
Electrocardiogram (ECG)	A non-invasive diagnostic test used to check heart rhythm and electrical activity.
FemoStop	Mechanical device used to compress femoral artery/vein for reducing bleeding and complications from the puncture site.
Primary Percutaneous Coronary Intervention (PPCI)	Emergency non-surgical procedure used to open up occluded coronary arteries for patients who have had an Acute Myocardial Infarction.
Percutaneous Coronary Intervention (PCI)	Elective non-surgical procedure used to open up occluded/narrowed coronary arteries using angioplasty and/or stents.
Percutaneous Transluminal Coronary Angioplasty (PTCA)	Elective non-surgical procedure used to open up occluded/narrowed coronary arteries using angioplasty
Stent	A small mesh tube placed in coronary artery.
Thrombolysis Therapy	Intravenous drug administration to dissolve the blood clots occluding the coronary artery.
Vasovagal	A fainting episode caused by an abrupt slowing of heart rate and blood pressure.

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Copyright declaration

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Chapter 1

Motivation for this research

1.1 Introduction

Primary Percutaneous Coronary Intervention (PPCI) is now the preferred choice of treatment for an Acute Myocardial Infarction (AMI) since 2008 in the United Kingdom (UK). The implementation of PPCI as a first line treatment has significantly decreased mortality, time spent in hospital and risk of further complications (Department of Health, 2008; Hall, et al., 2016). The PPCI is performed in an angiographic suite which has the appearance of a theatre. The patient is positioned flat on a trolley and under local anaesthesia, a coronary angiography is performed. This involves contrast being injected into the coronary artery under x-ray guidance (Peacock, et al., 2007). When the occlusion is identified, a wire is passed down the artery passing beyond the occlusion. A balloon is then temporarily inflated and deflated at the site of the blockage to widen the narrowed artery and restore blood flow (Leahy, 2006; Bowden, 2009; Cooper, 2015). A stent which acts like a scaffold is placed permanently to support the artery wall from closing. The entire procedure usually lasts around 60 minutes but is dependent upon the number of coronary arteries affected and the number of stents required. High dependency care lasts between 12-24 hours. Patients are then transferred to a ward and discharged home, 2-3 days after admission.

A large number of patients now receive PPCI (Hall, et al., 2016) but there is still little known about patients' experiences during the hospitalised phase. The short trajectory from the onset of the AMI through to being discharged from hospital deserves further study as does the recognition of the physical and psychological experiences that may be encountered. To date, reported studies examining PPCI experiences have tended to concentrate on aspects such as perceptions developed about the AMI and overall satisfaction of the choice of treatment. The carers' (family members) perspectives and experiences also remain under explored. Whilst literature has documented the roles of cardiac nurses, little is currently known about nurses' experiences of caring for patients before, during and after PPCI. This qualitative research study utilised narrative methodology to inform and progress understanding of the experiences of patients, carers and nurses surrounding PPCI.

1.2 Problem statement

It is not a coincidence I have chosen to study the experiences of patients, carers and nurses. My research interests were driven by my own personal and professional experiences. I worked as a coronary care nurse for 15 years and completed a research study exploring the lived experience of five patients with an AMI. I then moved to Anglia Ruskin University to become a Senior Lecturer, teaching and leading modules for post-registration nurses on cardiac care.

In 2008, following recommendations of the Department of Health, a decision was taken to set up and deliver a PPCI service in East Anglia. This change in the treatment pathway for AMI required a significant service reorganisation for patients and health care professionals because the success of PPCI is dependent upon being performed expeditiously and by an experienced team. Prior to 2008, the hospital which then became the Heart Attack Centre had mainly dealt with patients transferred from other hospitals, patients who required elective PCI to diagnose Coronary Heart Disease and patients who required follow-up treatment (angioplasty, surgery). The health professionals were less familiar with treating emergency patients who had experienced a 'new' cardiac event. The PPCI service meant different working hours and workloads, having to rapidly respond to emergency situations, changes in role boundaries, finding beds for unplanned admissions (Carter, et al., 2010), dealing with patient's and family member's emotional reactions and providing patient education.

Following the announcement, I became aware of positive and negative perceptions from nurses in response to the service reorganisation. As a cardiac lecturer, I listened to the voices of coronary care nurses who felt frustrated they would no longer be able to care for AMI patients. This was an aspect of the job they had enjoyed and thrived in doing. Historically, patients with AMI were managed and cared for in Coronary Care Units (CCU). As many did not have the necessary 'high-tech' environment and resources required for PPCI, patients were taken directly to the Heart Attack centre; bypassing their local hospital. Skills that had taken years to develop in coronary care settings were now required by the nurses in this Heart Attack Centre. My inner voice wondered whether patients, carers and nurses experiences would be affected.

1.3 Significance of this research

Thinking about the voices from the nurses working in CCUs and the Heart Attack Centre enhanced the 'why' of my doctoral inquiry and strengthened my focus. It made me think about things I was not necessarily conscious of beforehand. I wanted to seek the experiences of patients, carers and nurses to find out what mattered to these individuals before, during and after the PPCI. To discover more about the ways in which patients and carers managed themselves when receiving a PPCI or being closely associated to someone who was receiving the PPCI. I also wanted to know about the caring experiences of the nurses and the ways in which they managed the patients, carers and themselves within the short illness trajectory. By paying close attention to the emotional aspects of these experiences I would be able to understand which aspects were important and the reasons for these being so.

This study utilised a narrative inquiry approach to address the gap in knowledge. Listening to individuals' experiences can promote understanding about the experience of PPCI and the systems of care that surround the patient, carer and nurse. Narrative inquiry does not focus just on the stories of others but also involves recognition and engagement of the self in the research process. As this thesis has progressed, I too have encountered personal experiences which revealed new understandings about my 'self'. Unexpectedly, I was diagnosed with a severe episode of sciatica. I became suddenly unwell with a pain that left me feeling helpless, trapped and dependent on others. I wanted this pain to go away as quickly as it had come. I had always seen myself as a 'well' person. It was only when the pain and associated sensations were gone, I no longer felt vulnerable. It was only then, I felt I could return, to being me. The second experience, involved my father-in-law suffering a significant stroke. I had one foot in the world of a carer and the other foot in the world of the nurse. I had my nursing knowledge about the stroke but I was powerless. I just had to sit and wait. Thinking about these emotions made me realise the meanings I had made from and about these experiences. These were my stories and they played a critical role in guiding my thinking during this thesis.

1.4 Research aim/purpose

The purpose of this study was to explore the stories of patients, carers and nurses surrounding their experiences of PPCI (before, during and after) from their different perspectives. Understanding these experiences has the potential to target interventions that will promote satisfaction, quality of care and recovery. The stories gathered will be analysed as wholes and then related to other stories to uncover what is shared or different. This narrative study brings to the fore, the voice of the individual experience to:

- 1) Explain the experiences surrounding Primary Percutaneous Coronary Intervention for Acute Myocardial Infarction from the perspectives of patients, carers and cardiac nurses.
- 2) Understand the responses, reactions and concerns of the patients, carers and cardiac nurses' before, during and after Primary Percutaneous Coronary Intervention.
- 3) Develop further understanding to enhance care and caring experiences.

1.5 Organisation of thesis

This thesis is divided into eight chapters:

Chapter one provided the purpose, the study aims and an overview of the thesis.

Chapter two has mapped the primary research and identified different types of voices heard in the literature surrounding experiences of patients, carers and nurses. There was a notable absence of cardiac nurses' experiences with the literature mostly concentrating on their roles rather than experiences with caring. The voices identified from the literature are presented in the conceptual framework.

Chapter three presents the philosophical stance of the thesis followed by an explanation of narrative inquiry. The data collection and data analysis methods, ethical considerations and steps taken to enhance rigour are also presented.

Chapter four presents the research findings of the patients' experiences of having an AMI, then receiving and recovering from having a PPCI. These findings are discussed in relation to their emotional responses and behaviours to certain events that occurred.

Chapter five presents the research findings for the carers revealing how they managed their experiences. It concludes with a comparison of the patients' and carers' experiences.

Chapter six presents the nurses' experiences of caring encounters with patients and carers. It reveals the occasions when the nurses' role was clearly defined but also when caring actions were fraught with difficulty. The experiences reflect how the nurses actively managed the challenges and rewards of working in a Heart Attack Centre. These experiences are aligned with the patients and carers experiences.

Chapter seven brings together the literature and theoretical influences to explore the different mechanisms that produced the voices heard in the participants' narratives.

Chapter eight assesses the findings against the aims and questions of this study. The conceptual framework is re-presented to reflect the journeys and voices identified from the findings. The implications for clinical practice, education, research and the strengths and limitations of the study are presented. The originality and contribution of new knowledge gained from the three essential groups are also discussed. The chapter concludes with final reflexive statements.

1.6 Summary

The advent of Primary Percutaneous Coronary Intervention has revolutionised the way in which patients recover following an Acute Myocardial Infarction. Nurses are in a unique position to improve the experiences of patients and carers. This research study will be of interest to nurses working in heart attack centres, managers and service user groups. The following chapter examines the literature on the experiences of patients, carers and nurses surrounding emergency and elective Percutaneous Coronary Interventions and presents the conceptual framework emerging from the review.

Chapter 2

Voices emerging from the literature review

2.1 Introduction

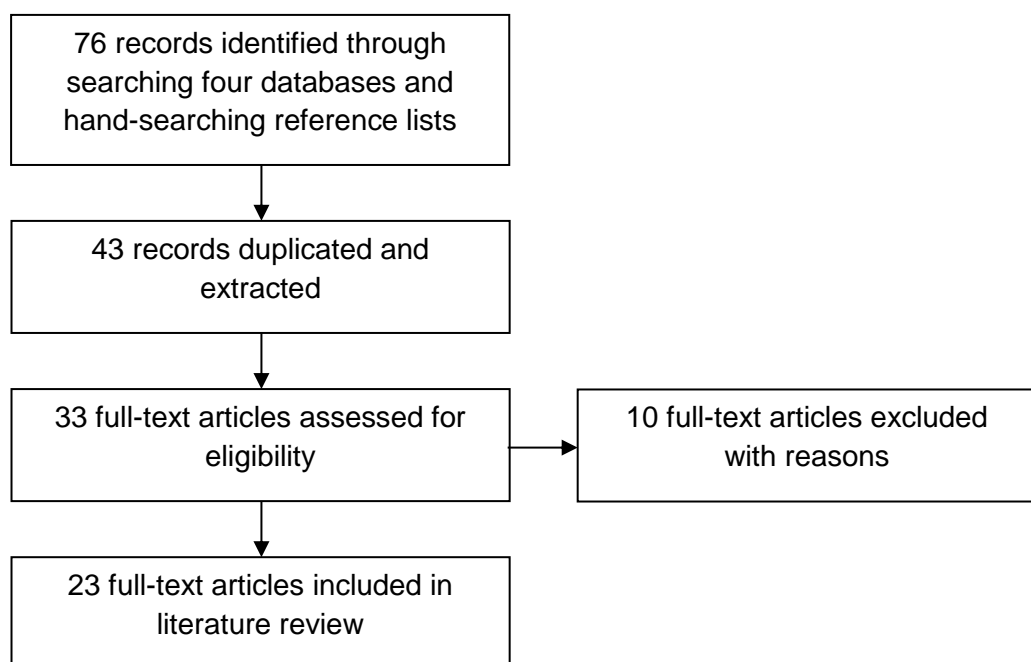
The literature in this chapter was reviewed to understand the experiences of patients who have received either an emergency (PPCI) or elective Percutaneous Coronary Intervention (PCI) and the experiences of family members (carers) and nurses working in the cardiac environment. While the numbers of studies in this review are relatively small, the emotionality of the experience was notable. The chapter begins with the approach taken when searching the literature for this thesis. Relevant themes from studies in the review were extracted and are represented as types of voices. These voices reflect the journeys taken by patients, carers and nurses surrounding experiences of PPCI. This is followed by discussion of the concepts included within the conceptual framework for this study. The review informed the development of the research questions and study.

2.2 Literature review methods

The literature review was undertaken in order to map out, interpret, critique and find gaps to underpin the development and rationale for this research thesis. The literature on PPCI experiences was limited so a decision was taken to also include experiences surrounding elective PCI. The procedure is performed in the same manner for both emergency and planned patients. An extensive literature search was performed in November 2009 and repeated at regular intervals. The search strategy involved searching four electronic databases: British Nursing Index, CINAHL, Medline and Google Scholar. These searches were supplemented by hand-searching reference lists. The search included publications which related to PCI experiences (1999 to 2014) and PPCI experiences (from 2008) because of the changes in the treatment pathway for AMI. The search was limited to papers published in or translated into English. The keywords/search terms used were: patient's experiences and/or patient's perceptions, family, carers, relatives, significant other's experiences and/or perspectives, nurse's experiences with primary angioplasty, angioplasty or coronary angioplasty, primary percutaneous coronary intervention, PPCI, percutaneous coronary intervention, PCI, coronary angiography or angiogram, angiogram, cardiac or coronary catheterisation and percutaneous coronary transluminal coronary angioplasty or PTCA.

Thirty-three papers were found after duplicates were removed. The majority of the papers met the inclusion criteria but ten papers were removed because after the whole paper was examined these publications did not focus specifically on patients', carers' and nurses' experiences surrounding PPCI and/or PCI. This reflects Flemming and Briggs' (2006) observations that there can be difficulties with literature searching because keywords/search terms vary between databases. A total of twenty-three research papers were selected for this review. These were critiqued for strength of evidence and methodological rigour. Figure I shows the process and results for the literature search.

Figure I PRISMA flow chart



Due to the comparatively small number of papers located through the searches, literature exploring different types of experiences was also drawn in to add knowledge and insight. The experiences of cardiac surgical patients, relatives of critically ill patients, partners of sudden cardiac arrest survivors and healthcare professionals involved in providing medical/interventional cardiac treatment enabled further understanding in relation to receiving, needing and providing care in the cardiac or critical care setting.

2.3 Types of voices

The decision to present the experiences of patients, carers and nurses as types of voices was conceptualised after I became aware of different emotional states triggered by feeling ill (vulnerability) and feeling well (safe). As I interpreted and mapped the research papers I heard different voices emerging or being connected to certain aspects encountered by patients, carers and nurses. Sampson, O’Cathain and Goodacre (2009) described participants who were satisfied with their treatment surrounding PPCI as having ‘positive voices’. In contrast, negative views were associated with dissatisfaction, often expressed in an apologetic manner and harder to obtain. Focusing on types of voices facilitated a deeper exploration of why certain voices were present. This was a novel and unique methodology for bringing together the three participant groups (patients, carers and nurses). Linking the literature together by voice types enabled this review to provide a more complete picture. This was a process that continued into the data analysis and findings chapters. The six voices identified in the published literature reflected different emotional responses, reactions and behaviours. The studies informing the types of voices are summarised in Appendix I.

The **‘feeling fixed’** voice was a common theme in research papers examining PPCI experiences. This voice revealed the misalignment patients had concerning the PPCI in that many believed this had fixed the AMI. The **‘uncertain’** voice was evident in both PPCI and PCI experiences. It reflected the mismatch between expectations of the procedure and the reality of what happened to them. This voice was coupled with variations in how patients’ and carers’ information needs were met at different times as they made their way through their experiences. The **‘quiet’** voice demonstrated how patients struggled with different influences forced upon them as they participated as an emergency or elective patient, in an unknown world. The **‘anxious’** voices was a common voice in the PCI research papers and strongly related to not knowing outcome, perceived risks during the procedure and fears about future well-being. The **‘satisfied’** voice was only heard in the PPCI research studies. It was associated with speed of treatment, rapid relief from symptoms and feeling well earlier than expected. Patients and carers were highly satisfied with the outcome and care received. Finally, the **‘knowing’** voices provided an insight into nurses’ experiences as they diagnosed, treated symptoms and promoted a good outcome for patients. Knowing patients were in the right place was important to patients, carers and nurses. All of the voices except the ‘knowing’ voice, were frequently noted. This was possibly due to the small number of research papers exploring nurses’ experiences.

2.4 'Feeling fixed' voices

There was a strong indication in the literature that patients believed the PPCI had 'fixed' the heart attack. These beliefs were influenced by the rapid change in feeling seriously ill to suddenly feeling well. In a mixed method exploratory study, Astin, et al. (2009) recruited 16 males and 13 female patients admitted for a first-time PPCI. The intention was to understand patients' experiences of PPCI and perceptions about the AMI. A pre-designed questionnaire called the Illness Perception Questionnaire (IPQ-R) was given to participants (3-12 days after discharge) to self-report their level of agreement on 38 pre-written statements about their heart attack.

The IPQ-R (Moss-Morris, et al., 2002) was theoretically derived from the Cognitive Model of Illness Perception developed by Leventhal, Meyer and Nerenz (1980). The model assesses five main components: identity, timeline, cause, consequences and control or cure. The model proposes that in response to events such as illness and treatment experiences, people generate perceptions for understanding what has happened to them. Illness perceptions can be described as the mental ideas or images people have about illness. They function as a template in which symptoms previously experienced are compared against current symptoms. These perceptions can influence subsequent behaviours and coping strategies which in turn may influence how the experience is then managed by the individual.

The results of the self-reported questionnaire revealed mixed perceptions about the heart attack. The scores indicated that participants viewed the heart attack as a serious condition believing it was an acute rather than chronic illness. The trends in the scores indicated the PPCI was understood as curative and an effective way to control the illness. These findings suggest there was a lack of coherent understanding about the heart attack and PPCI. The results also identified perceptions were strongly influenced by speed of the PPCI and the positive outcomes. Whilst the sample size of 29 was small for a mixed method study, this was an important study that led the way in recognising issues faced by those who had experienced a PPCI and for nurses caring for patients receiving PPCI.

Sampson, O'Cathain and Goodacre (2009) explored the experiences of both carers and patients' surrounding PPCI. This study was part of a wider evaluation to assess the feasibility of ten pilot heart attack centres who were implementing a primary angioplasty service in the UK (2010). In phase one, interviews were used to explore positive and negative views of patients and carers from two PPCI hospitals. The sample consisted of 10 patients (5 men and 5 women) and 6 carers. The gender and

relationship of the carers to the patients was not specified. Although the specific timing of the interviews was not stated it was indicated that participants were interviewed within four weeks of the hospital admission. The authors acknowledged the findings may have been different had they interviewed sooner.

Similar to Astin, et al. (2009), participants were amazed at how quickly they were treated and recovered from their heart attack. Again there was a strong theme that the PPCI had 'fixed' them. In witnessing the PPCI happening to them in the catheter laboratory there was a high level of confidence. Many participants felt so well they could not believe they had actually experienced a heart attack. This wellness was in complete contrast to how they had felt prior to the PPCI.

Astin, et al. (2009) and Sampson, O'Cathain and Goodacre (2009) recognised that if patients felt well sooner than they expected and had misconceptions about the heart attack this combination could greatly influence behaviours adopted during recovery. These two studies highlighted relevant concerns about whether patients would continue to seek cardiac rehabilitation services and in light of this whether current service provision would need to be revised.

Another study closely aligned with and highly relevant is the study by Radcliffe, et al. (2009). This study was designed to explore patients' experiences and perceptions of PPCI. Using purposive sampling, 11 men and 4 women who had experienced an AMI were interviewed between 13 to 90 days. Despite a wide variation in data collection times, this qualitative descriptive study provides useful results. The researchers used semi-structured interviews to gather data about experiences surrounding the PPCI, including treatment received prior to PPCI, patients' understanding of the AMI, discharge and after-care, perceptions of health status, treatments and information needs.

Echoing the results of previous studies, participants were very positive about their experiences and amazed at how quickly they felt better. The PPCI was deemed less stressful than anticipated. In addition, the shorter recovery and subsequent hospital stay led participants to believe they must be well. The wide data collection period of up to 90 days meant the authors were able to follow on participants several months later. However variability in recall was acknowledged as a potential issue. This was attributed to different illness states of patients during hospitalisation because it was noted some patients had been sedated or experienced cardiac arrest.

More recently, Dullaghan, et al. (2014) compared illness perceptions with particular attention on how these perceptions change future behaviours. Patients were recruited to three different AMI groups: 5 received PPCI, 5 received thrombolysis therapy and 5 were either treated with a PCI and/or medications. Rather than using the questionnaire as in Astin, et al. (2009), an interview guide based on the self-regulation model was developed. This framework was used to understand people's responses to the threat from the illness and the perceptions developed about the illness and treatment. Participants were interviewed between one and four weeks after an AMI. Similar to other papers, the study lacked specific details about recruitment and interview timings.

The results concluded that for the PPCI and thrombolysis patients, the speed of being rapidly treated signalled the seriousness of the AMI. Similar to Astin, et al. (2009) perceptions regarding the rapid recovery made participants question about what had actually happened to them. However these PPCI patients recognised they had a responsibility in controlling the nature of the illness, viewing it as a chronic and long-term condition. The patients who received thrombolysis believed lifestyle changes were important but the authors found a wider variation in their illness perceptions. Many participants viewed the illness as either short or long-term. In contrast, the non-AMI group held a different view. Compared to the other two groups, they had to wait longer for the blood results which meant it took longer to confirm a definite diagnosis. They then had to wait to receive treatment. Curiously, it was the waiting that led these participants to believe their illness was less life-threatening. This created a sense of ambiguity about the illness making participants less certain about whether lifestyle changes would make any difference (Dullaghan, et al., 2014).

Hirani, Pugsley and Newman (2006) assessed illness representations in 214 patients treated with different types of treatment medical therapy, PCI and cardiac surgery. These findings also revealed patients' subjectivity about the illness and the treatment options. Patients treated by PCI and CABG believed it was the intervention that had cured them in a significantly shorter time period than had they been treated with medications. Bowling, et al. (2008) also investigated patient preferences in treatment options for angina (medications, PCI, surgery) and found PCI was highly favoured because people believed it would improve well-being and prolong life. For others, it was a quick fix; one that would put an end to treatment and ongoing symptoms. However some reticence was noted, in that patients admitted to being frightened and would only consider an intervention if their condition worsened.

Astin and Jones (2006) also examined the differences in the way people perceived their heart disease before and after elective angioplasty. Pre-angioplasty, there was a strong belief that the intervention had offered a cure for their illness. Post-angioplasty, most participants experienced fewer symptoms or symptoms shorter in duration. In some cases, the result of having almost total symptomatic relief convinced people the angioplasty had considerably improved their quality of life. These studies appear to suggest that treatment choice may be based on perceived benefits and personal candidacy. This reveals the variability and effects of emotions within experiences.

The studies conducted by Astin, et al. (2009), Radcliffe, et al. (2009), Sampson, O'Cathain and Goodacre (2009) and more recently, Dullaghan, et al. (2014) all offer valuable insight of patients' viewpoints. These studies suggest participants found it difficult to understand they had experienced a heart attack. Speedy resolution of symptoms in conjunction with believing they had been fixed made participants feel almost back to their 'normal' self. The rapid change in physical well-being was contrary to how participants expected they would feel (Astin, et al., 2009; Radcliffe, et al., 2009; Dullaghan, et al., 2014). There was a sense of disbelief because expectations did not match reality. Many patients felt confident and hopeful for the future. They believed they were well again (Astin and Jones, 2006; Hirani, Pugsley and Newman, 2006; Astin, et al., 2009).

Astin, et al. (2009) presented their results using Leventhal, Meyer and Nerenz's (1980) Cognitive model of Illness Perception. The Dullaghan, et al. (2014) study was guided by the Leventhal, Brissette and Leventhal (2003) Self-Regulatory model of illness behaviour. This was a fitting choice for both research papers. Both theoretical perspectives are appropriate for understanding cognitive and emotional representations during an illness event. As Dullaghan, et al. (2014) demonstrated patients can experience initial uncertainty about the diagnosis (illness) regardless of whether they feel rapidly well after treatment. Exploring patients' misunderstandings of the illness and identifying risks from poor secondary prevention remain important aspects for cardiac care. However, understanding about patients' treatment experiences and the impact upon the self as they recover in hospital is also important and necessary. Nurses need to understand what issues are important and matter to patients.

The arrival of PPCI has led to changes not only in saving lives but also in the boundaries for health, illness and wellness. It can no longer be assumed that an AMI will evoke an expected set pattern of behaviours and responses usually associated with sick patients. Instead patients' interpretations are being influenced by the effects from the PPCI and their prompt return to wellness. The length of time spent in hospital is also affecting patient's understanding of the illness because patients believe they must be well if they are being discharged from hospital.

Capturing patients own reported outcomes are important for understanding the full picture. Knowing more about how patients coped when they felt well (fixed) are important aspects for this study and deserve further exploration. It would be interesting to understand whether individuals acted in a certain way when feeling sick and then in another when well and what these behaviours are influenced by or based upon. The motivation to get well, become well and have a complete recovery requires the help of others such as carers and health professionals. Not all patients undergoing PPCI will experience a good outcome straightaway; some may have complications meaning they do not have the rapid resolution documented in the studies. Only Radcliffe, et al. (2009 p.219) cited any problems or complications arising with participants recruited into their studies. Understanding different experiences surrounding PPCI are important aspects for this study.

2.5 'Uncertain' voices

This voice was noted when patients did not know what had happened to them during the PPCI and afterwards. This voice was also influenced by the amount of information given to the patients and carers and how this information was understood after they were discharged from hospital and managing themselves. A number of studies revealed there was a mismatch between patients' expectations of what would happen and what actually happened. In addition to the IPQ-R, there was a qualitative arm in the Astin, et al. (2009) study. This was used to understand patients' experiences of the PPCI from symptom onset through to early recovery at home. Participants were interviewed 3-12 days after hospital discharge. The reason for the time interval was explained as patients needing time to settle and deal with the illness event that had occurred. The authors were wary of a longer period because of the risk of poor recall. The topic guide centred upon questions relating to their recent hospital admission and whether patients had any worries or concerns. The interviews lasted between 30 to 90 minutes.

Using framework analysis, a detailed conceptual model was produced which highlighted how the speed of events contributed to feelings of uncertainty about what had happened to them. Some participants had expected a general anaesthetic and surgery as opposed to the local anaesthetic they actually received. Expectations of surgery were often preceded by patients believing they were in a 'theatre' environment because they were met by staff wearing theatre gowns and caps. This was reinforced when patients were asked to sign a consent form further giving the impression a serious procedure would happen. Astin, et al. (2009) described how one patient believed access to his heart could only be gained through opening up his chest. The lack of a scar led to a misunderstanding about what had actually occurred. Radcliffe, et al. (2009) found other participants were less forthcoming about what they thought would happen. Knowledge about the procedural aspects were often influenced by what people had read, seen in the media or been told by friends and family.

Two other papers that combined emergency and elective PCI patients in their samples indicated similar findings. Coronas, Coyer and Theobald (2009) interviewed ten participants; two received PPCI with the remaining having received elective PCI. The sample comprised of two female and eight male participants. Motivation for the study had arisen from the researcher's clinical experience because it had been noted patients often had no idea about what they were having done or what the procedure involved. The theme 'about the procedure' highlighted the intervention as a relatively simple procedure. This simplicity was explained by the short length of the procedure, being performed under local anaesthetic, no visible scars and only required a short hospitalisation. For some the lack of pain or minimal pain greatly reduced any stress being experienced. Poor recall again was acknowledged as an issue by the researchers. A 6-week timeframe was selected because this was when participants returned to the clinic making access to interviews less problematic for the researchers.

The second study was Lyons, Fanshawe and Lip (2002) who interviewed seventeen patients (nine males and eight females) about their experiences of elective angioplasty. Initially patients had concerns and uncertainties before the procedure because it was viewed as an operation rather than a procedure. Afterwards the majority felt worrying had been unnecessary. Some were surprised about what they had actually experienced. Details of the sampling method, response rates, withdrawals and justification for final sample size were not clearly provided, reducing the rigour of the study.

Overall, the literature appears to suggest that regardless of whether patients were elective or emergency they had very little understanding about what the procedure entailed. Any concerns experienced beforehand were often eradicated once it was realised no discomfort had been experienced. However, in believing the procedure was relatively simple, understanding about the diagnosis and management was affected. The existing research was unclear about how patients coped immediately after the PPCI and whilst they were in hospital. It was also difficult to determine whether not knowing was a case of just not wanting to know or used as a strategy to protect the self.

The literature also indicated the 'uncertain' voice was present because patients were disappointed with information provision. Once at home, patients were uncertain of what activities to perform. Astin, et al. (2008) collected the responses of 29 patients to understand preferences about how information was delivered, by whom, the content and the time interval. A key issue was the timing of the delivery of information. The fast pace of the treatment and diagnosis seemed to reduce patients' ability to absorb information given to them. In contrast the pre and post angiogram picture enabled patients to make sense about what had happened. This picture was viewed as something that had directly affected them rather than receiving information which was seen as generic and less personalised. Many patients had no particular preference of who provided the information as long as it was understandable.

In comparison the participants in Radcliffe, et al. (2009) simply accepted what they were told, trusting the health professionals who provided information to them. Many were able to recall (during their interviews) lifestyle advice given to them. However in the days and weeks that passed (13-90 days) after the AMI, patients' comments suggest they still had unanswered questions (Radcliffe, et al., 2009). This caused further uncertainty when they reached home. Most patients seemed at odds with their bodies because they felt so well. There was surprise at the extent of limitations placed upon them by the health professionals because in feeling back to normal they expected their bodies to be able to do everything they had done before the AMI. This uncertainty was mostly directed at the General Practitioner.

More recently Astin, et al. (2014) conducted a postal survey with 712 patients scheduled for elective angioplasty at one centre. Patients were sent a DVD, 2-3 weeks prior to their admission and asked to score the content and usefulness in both preparing them for the procedure as well as learning about lifestyle changes necessary for secondary prevention. From a response rate of 36%, participants'

scores reflected that the majority (86%) felt more at ease of making lifestyle changes and 98% felt prepared for the angioplasty with 87% finding the DVD easy to moderately easy to use. The authors recognised that whilst behaviours cannot solely be changed by watching a DVD it was proposed as a useful adjunct for prompting patients to ask questions at the clinic and as a method for reinforcing information.

Lundén, et al. (2013) investigated the information needs of patients requiring elective PCI. Interviews and a questionnaire were used to assess the emotional states for 42 patients from 3 hospitals in Sweden. The results revealed a mixed response to whether information needs were achieved. Information given prior to the procedure was valued but only when patients believed it met their needs. Needs expressed as being important were knowing the scheduled time for treatment, preparation required before the procedure and knowing what to expect during the treatment (how it would feel). Negative feelings related to poor information provision meaning patients felt insecure about what would happen to them during the PCI. Not knowing, led individuals to worry about complications that may be experienced which then led to further fears that the PCI would be unsuccessful. This well designed study uncovers some of the reasoning underlying variability of the PCI experience.

Sampson, O'Cathain and Goodacre (2010) also found in phase two of their mixed methods study that patient and carer satisfaction levels were notably lower in relation to information about medications, their potential side effects and information given about how to manage the condition after discharge. Difficulties to absorb information given at the time of the hospital admission were again given by participants as reasons for being uncertain. Similar to Radcliffe, et al. (2009) poor follow-up by the GP was viewed as a significant contributory factor for poor understanding.

The experiences of relatives with patients in critical care have also reflected the 'uncertain' voice. Similar to AMI, the illness crisis is sudden and unexpected but in contrast the duration is often much longer. One way reported to deal with the uncertainty was to keep close to the patient. Engström and Söderberg (2004) interviewed 7 spouses of patients who had been ventilated for 24 hours or longer. Relatives were constantly fearful about the future and the possibility something else 'bad' would happen. This gave way to feelings of helplessness and losing control. Remaining at the bedside enabled the relatives to regain a sense of personal control. In agreement, Ågård and Harder (2007) described 7 relatives experiencing a constant turmoil as they thought about the past, the unbearable present and unknown future.

Despite experiencing various negative emotions, the relatives developed and used a range of coping mechanisms to adapt to the situation. These included enduring, suppressing anxiety and focussing on the immediate situation. Eggenberger and Nelms (2007) also noted feelings of vulnerability and insecurity in 11 family groups. Experiences were physically demanding and often led to fatigue and exhaustion. The environment was frightening and difficult to understand but being a family unit made the situation more bearable, because they had each other. They felt stronger and able to find ways to protect each other from threats associated with the experience. For relatives who were on their own, the waiting room became a place for seeking comfort. Kutash and Northrop (2007) interviewed six visitors from three different intensive care waiting rooms (neuroscience, trauma and burns) and found comfort was derived from being with other families experiencing the same situation.

Interestingly, papers on PPCI and PCI experiences have not commented on carers needing to seek emotional support from others. This may be partly explained by the manner in which different types of life threatening illness are viewed by carers. Johansson, Hildingh and Fridlund (2002) interviewed 18 family members/close friends visiting patients in a coronary care or intensive care unit. They found coping responses were related to perceptions surrounding the seriousness of the illness. When relatives visited a patient in a coronary care, the experience was easier to endure because relatives could talk to the patients. A conscious patient was viewed as being less critically ill than compared to a ventilated patient who could not talk. This may explain why little was reported by carers surrounding PPCI and PCI.

During the intensive care admission period, insufficient information was also noted to influence and evoke feelings of uncertainty. McKiernan and McCarthy (2010) interviewed six relatives and found different types of information were required at different points. These relatives wanted information which would prepare them for what to expect when visiting the patient. Hughes, Bryan and Robbins (2005) similarly described the importance for relatives to receive specific information. The eight relatives in their study, wanted to speak to the same doctor. In reality, contact with the doctor was variable and the style of information delivery left many relatives feeling uncertain about the future. Furthermore, contradictory information received from the nurses created uncertainty about the patient's condition causing issues and concerns surrounding trust. This study also included the experiences of five nurses. The findings revealed that whilst the nurses were aware of the importance of providing information, they often restricted the amount volunteered, blaming resources and staffing issues as common barriers.

Studies using different approaches have similarly found relatives expressing dissatisfaction with doctors' availability and information provision. Karlsson, et al. (2011) used questionnaires and found 35 relatives wanted and expected regular conversations with doctors throughout different phases. It was not just at the beginning of the illness episode but also towards the end when the patient improved. Auerbach, et al. (2005) used a survey approach to assess 40 relatives' perceptions of health professionals providing information. The results demonstrated how relatives responded less favourably to the doctors when the doctors' attitudes were viewed as controlling and unfriendly. In contrast, nurses were appraised as friendly and presented as the primary sources of information. Perhaps not unsurprisingly, Chien, et al. (2006) found satisfaction increased significantly when families believed health professionals had made a conscious effort to improve the way in which they delivered information about the patient.

Even after hospitalisation, carers remain uncertain as they attempt to make sense of what has actually happened and what the impact means for them. Dougherty, Pyper and Benoliel (2004) explored the experiences of partners of sudden cardiac arrest survivors who had an internal cardio-defibrillator (ICD) implanted. Whilst the partners looked forward to the future they remained fearful of the things that could happen or the possibility that the ICD could malfunction. Feeling uncertain about the future was also confirmed in Larsson, et al. (2013). This study interviewed 20 relatives of patients who had survived a cardiac arrest. Initially relatives found it extremely difficult to comprehend what had happened, describing the situation as feeling 'unreal'. Uncertainty about whether they would be able to manage was influenced by the possibility of a repeated episode. Consequently, as Holm, et al. (2012) found, partners felt frightened about the patient returning home. Symptoms associated with stress such as sleeplessness, anxiety and needing to keep the family member in sight at all times was frequently reported. The partners felt unprepared for the situation that faced them.

These studies reflect the emotionality of carers' experiences and the factors which can influence and reduce the 'uncertain' voice during and after critical illness. They provide an insight to the way carers try to guard and protect themselves from uncertainty. Issues relating to the completeness and consistency of information and the courtesy, compassion and friendliness of information providers may explain the difficulties with processing information. It is therefore important to identify these factors and the impact they may have upon the coping responses of carers.

For patients who felt 'fixed', the speed of treatment acted as a barrier for absorbing and retaining information (Astin, et al., 2008). Information provided as an in-patient often proved to be unhelpful after hospital discharge. Many patients and carers were uncertain about what the patient could and could not do (Sampson, et al., 2009). It can only be assumed the participants in the studies by Astin, et al. (2008; 2009), Radcliffe, et al. (2009) and Dullaghan, et al. (2014) were also uncertain about the information received. It is anticipated my research study will add to these studies to understand more about patients' and carers' information needs. The inclusion of the nurses' experiences will provide a different dimension to understand the how, what and why of information delivery. The admission, unknown outcome, disequilibrium and lack of information can all cause feelings of uncertainty. Together they raise aspects of interest for this research in terms of how the carers of PPCI patients may manage themselves and the implications for cardiac nurses in relation to caring for family members.

2.6 'Quiet' voices

Participant's voices were notably dampened by events happening to them and around them. People expressed feeling shocked, not believing what had happened and anxious (Astin, et al., 2009). The heart attack was barely mentioned, something else was clouding their reactions. They were contemplating the possibility they could die (Astin, et al., 2009) and they felt vulnerable (Bowman, Watson and Trotman-Beasty, 2006; Astin, et al., 2009; Radcliffe, et al., 2009). From the onset of the AMI through to having the PPCI and then to feeling well there was a common sense of incomprehension. Afterwards emotions swung from feeling hope and then anticipation. The situation felt 'surreal, like being in a dream', they felt 'stunned', 'unable to comprehend what had happened' (Astin, et al., 2009; Sampson, O'Cathain and Goodacre, 2009; Radcliffe, et al., 2009). The beginnings of their experience were highly emotional but so too were subsequent transition points. It is possible the quiet voices were attempting to defend the self passively. They may have been indicating an unconscious fear of death. There may have been an acceptance or realisation they were powerless to manage a situation of this magnitude.

The need and importance for the self to be in the hands of others was also reflected in the key studies. The PPCI studies reported patients as passive recipients of care with no desire to participate. Participants accepted what they were told would happen with very few questioning or realising they had a choice (Sampson, O'Cathain and Goodacre, 2009). The literature indicated it as wanting to be treated as quickly as

possible by doctors who had the necessary knowledge (Astin, et al., 2009; Radcliffe, et al., 2009; Sampson, O’Cathain and Goodacre, 2009; Dullaghan, et al., 2014). The participants trusted the competence and authority of the medical personnel. They purposively placed themselves in the care of experts and allowed others to make the ‘right’ decisions. In doing so, they believed there was a stronger possibility of a good outcome. Rather than viewing this choice as lack of participation it could be viewed as a valid form of participation. These perceptions were then confirmed when people felt well. Radcliffe, et al. (2009) found patients tended to accept what they had been told to do (taking medications at prescribed times) rather than taking an active role in their treatment (did not question why they required medications).

A different reason for passivity was offered by Lundén, Bengtson and Lundgren (2006) in their sample of elective PCI patients. Patients were aware of restrictions at different stages of the treatment but in contrast to the previous studies it was the thought of being dependent on others that made them feel exposed and weak. Having to rely on others for personal needs was an activity that sick patients required. Whilst some struggled with this concept, others just accepted this was what happened when being a patient. It was a matter of finding a way to deal with the situation. The authors do not acknowledge whether these were first time hospital experiences or whether participants had previous experiences.

Throughout the PCI participants valued the competence and caring approach of the conduct of the staff. The net result was that even when patients felt susceptible to risk, they still felt safe. In believing they would be kept safe from potential harm patients went along with decisions made by others even when it meant experiencing discomfort (Lundén, Bengtson and Lundgren, 2006). This implies that when high levels of trust exist the preference of many patients is to adopt a passive role. Similar findings were noted by Higgins, Dunn and Theobald (2001) in a study of non-urgent PCI patients. Interviews conducted one month post-elective angioplasty found participants placed all responsibility with the doctor, letting the health professionals take control. The authors concluded a coping strategy was formulated which enabled participants to deny any thoughts of complications associated with the procedure.

One strategy adopted by the participants in the Astin, et al. (2009) study was to disconnect themselves from the events happening around them. They just seemed to endure the situation letting health professionals get on with their job. There was an awareness of the machinery and equipment around them but they were uncertain of its effect on them or to them. Sampson, O’Cathain and Goodacre (2009) described participants being impressed by the ‘modern technology’. The presence of the

technology meant something significant was happening. The equipment enabled them to see what was being done to them, for them. This reinforced a sense of security, comfort and ultimately optimism that there would be a good outcome for the patient. However, as Blaxter (2009) highlighted radiographic images are just a reflection of the reality at that moment. How the result is reported and how it is perceived are not the same. If considered the same this can lead to differing realities, in that the world of the body and the world of the image exist in two separate spaces.

Literature reflecting upon cardiac patient's experiences of machines has indicated that technology can provide a sense of security (Doering, McGuire and Rourke, 2002; Gardner, et al., 2005; Lapum, et al., 2010). As such it can change the way a person views the self at certain point of their journey. In a narrative study, Lapum, et al. (2010) interviewed 16 cardiac surgical patients about the influence of technology on their recovery. Despite initial worries about complications from the surgery, the technology was perceived as a fix that would result in a positive outcome. Many of the experiences began with an acknowledgement that their body was attached to the technology. In being 'plugged in' participants experienced a number of different emotions; a sense of security, fear and passivity. Rather than seeing themselves as a person (self-identity), they described their bodies in terms of what the technological devices were doing for them. There was reliance on the technology and of those caring for them to protect them from danger. It only became problematic when the patient felt they were being neglected by a health professional. Temporarily giving control to someone else was accepted as part of the course. However, the accounts noted this also had a positive side in that there was a sense of relief that the responsibility for what happened to the patient was placed firmly in the hands of the health professional. It meant they could remain quiet and passive.

This sense of the individual's agency being suppressed has been found in other research studies concerning patients who have undergone cardiac surgery. Leegaard and Fagermoen (2008) described how patients treated the period of cardiac surgery as a non-being; they simply allowed what had to happen to happen; it became part of their identity. It could also be proposed the environment fostered passivity. Almerud, et al. (2007) interviewed 9 patients shortly after discharge following an admission to critical care lasting 1-7 weeks. They found that people who previously were fully in control were now reduced to a dependency on others. That control was mainly influenced by the presence of machinery, equipment and the nurses performing their various activities. As such, the technology infiltrated being at a certain point of their journey. The technology ruled their surroundings and the environment they were

forced to be within and the person (who they became whilst ill). It induced a sense of distance between the patient and nurses. Patients felt alienated because the nurses used information collected from the machinery to talk to them rather than asking the patients about their experiences. They felt reduced to being an object in which their clinical status and disease process took the presidency. Consequently, patients could feel lost, vulnerable and invisible.

Overall the evidence appears to indicate a sense of co-operation and legitimisation with the health professionals (Astin, et al., 2009; Radcliffe, et al., 2009; Sampson, O'Cathain and Goodacre, 2009). There was a perception that in receiving treatment, something was being done about the undesirable situation of experiencing a heart attack; a situation that for many was beyond their personal control. Patients calmly withdrew their responsibilities and relinquished control to others. They were happy to place themselves in the 'expert's hands' (Astin, et al., 2009; Radcliffe, et al., 2009; Sampson, O'Cathain and Goodacre, 2009; Dullaghan, et al., 2014). Many preferred to leave a decision of this serious nature to the doctors; it was viewed as a medical decision rather than a patient decision. The extent to which this decision was accepted by the patients was unclear. Rier (2000) and Blaxter (2009) reflected on their experiences of being a patient that there are times in acute illness when patients cannot always be active players. On these occasions control over their body and personal space was lost as they were cared for by staff whom they had never seen before. In being in a temporary state of illness, patients have to comply with the expected (or unexpected) rules of behaviour, rituals, hierarchies, culture and language within the hospital setting. The research in this thesis will attempt to understand how patients made sense of their surroundings and in being a patient.

2.7 'Anxious' voices

Several studies have reported patients experienced anxiety before, during and after elective PCI (Higgins, Dunn and Theobald, 2000; 2001; Lenzen, Gamel and Immink, 2002; Astin, Jones and Thompson, 2005; Lundén, Bengtson and Lundgren, 2006; Caldwell, et al., 2007; Page, Jackman and Snowden, 2008; Trotter, Gallagher and Donoghue, 2011; Lundén, et al., 2013). In contrast to emergency patients, elective patients often have to wait varying amounts of time for their treatment. As a result, patients have to mentally prepare themselves for potential distress, discomfort and the potential threat that if the treatment is unsuccessful it will mean additional treatment is required.

Higgins, Dunn and Theobald (2000; 2001) noted the individual's coping style was a key influence in how the situation was managed. Participants tended to view the elective angioplasty as something 'they just had to get through'. Several factors helped participants prepare themselves; acquiring knowledge from healthcare professionals to make sense of what was going to happen; having confidence in the doctors' expertise and having support from family members. Lundén, Bengtson and Lundgren (2006) also indicated that patients went through a 'balancing act' as they tried to keep it together by keeping a distancing from the situation in a protective stance.

Lenzen, Gamel and Immink (2002) surveyed levels of anxiety in 46 patients waiting for a first coronary angioplasty and 40 patients waiting for a repeat procedure. Participants completed three self-reporting questionnaires before the procedure. Five participants who had received a repeat procedure were interviewed the day after the procedure. They were selected by either having a low well-being score or a high well-being score. The sample was predominantly male. Waiting times for the first-timers and repeaters were relatively similar (3-6 weeks). The anxiety score showed a trend of being slightly worse in patients having a repeat procedure. This was attributed to previous experience of the procedure but also a realisation that the condition was worse. The presence or return of symptoms and reflecting on their prospects for the future were important elements in preparing the self for the procedure. It was acknowledged by the authors that current preparatory information did not focus on these aspects. Therefore emotional support and tailored preparation were indicated as key aspects to be addressed post-study.

Another relevant study was a descriptive, repeated-measures investigation by Astin, Jones and Thompson (2005). This study was designed to describe the levels of anxiety at three time points (pre-admission, 6-8 weeks after, and 6-8 months after). The 140 participants completed a self-reported questionnaire (State-Trait Anxiety Inventory) to assess anxiety. In addition, patients reported the frequency of symptoms experienced. The investigators found state anxiety scores for men and women pre-procedure were high but similar to other studies at the time of the study. The results were put down to procedural uncertainty and dealing with the ongoing potential threat to the self. Trait scores decreased significantly at 6-8 weeks reflecting the manner in which individuals coped with the PCI. A reduction in symptoms was also a major influence. The study indicated females experienced more anxiety than men but was not considered an unusual finding by the authors.

Trotter, Gallagher and Donoghue (2011) measured anxiety using the Spielberger State Anxiety Inventory (STAI) at three different time points. These were before the PCI, the first day post-PCI and 1 week post-discharge. One hundred participants completed all three surveys. Anxiety scores were highest pre-procedure but then had decreased significantly post-procedure and even further by the post-discharge time. The most frequently reported concern was the outcome of the PCI and the possibility of requiring surgery. Other concerns were fear of discomfort, followed afterwards by uncertainty and fears about the progression of the CHD. The researchers reported that participants who were more anxious pre-PCI continued to have anxiety. Other reasons for anxiety included having a first-time PCI or if participants had experienced chest pain prior to the PCI. Predictors of anxiety were highest in patients undergoing PCI for the first time, experiencing chest pain and those already prescribed medications for anxiety. These findings highlight the importance of nurses interacting with patients and the need to recognise the presence and impact of anxiety.

Using a grounded theory approach, Caldwell, et al. (2007) interviewed ten men and ten women in their study prior to a scheduled PCI. The purpose was to find out about the fears and beliefs of participants requiring a PCI. One notable key concern found was participants worrying about having to maintain their body in a certain position on the stretcher. Participants were aware they were responsible for the behaviours of their own body. Some worried about remaining still, not moving, conscious that if they did it may cause problem for the doctors. Fears centred on what may happen if they could not maintain control and the subsequent embarrassment for the individual. More women than men feared losing control during the PCI. Their response or attempt to cope with the situation led to further anxiety. In contrast, the men derived a sense of comfort from watching the technology and valued its input in the procedure using this as a form of distraction during the intervention. The perceived level of control was also influenced by information given to the participants' pre-PCI. Rather than seeing the information as a reassurance, they believed this meant they would experience complications such as bleeding, heart attack and stroke. These fears put them at odds with the need to have the PCI. They knew it was necessary to receive a diagnosis and for improving the quality of their lives but they felt anxious.

In contrast, Lundén, et al. (2013) found elective angioplasty patients reported both positive and negative emotional states. Initially there was relief because the treatment offered a sense of hope. There was an opportunity to regain control of their lives because often the symptoms had taken control. The study also reflected despair;

there was doubt about the possibility of not getting better. Others were concerned the procedure would be cancelled or postponed. Patients worried whether the procedure would be painful and whether they would cope. The anxious voices mostly related to the outcome of the treatment and the possible need to have invasive surgery.

Important issues such as the extent to which patients managed their fears and expectations surrounding the procedure were highlighted in the findings of Caldwell, et al. (2007). In particular, it was noted patients were more fearful after they were given information about the procedure. In addition to exploring fears, Caldwell, et al. (2007) also ascertained the effects of the waiting period to add to theoretical understanding. They wanted to explore patients' perceptions of risk and how they managed those risks. Initially, the intention was to interview participants within 4 weeks of patients being placed on the waiting list. At this point the procedure date was not known to the patients. However, it became evident that participants believed that by taking part in the study their waiting time could be reduced. So a decision was taken to interview participants after they have been scheduled for the procedure. The result of this was a wide data collection time range of 2 days -11 weeks before the PCI. Interestingly, participants strongly indicated it was not their decision to receive the PCI instead the decision was made by their referring physician. In believing this was a 'routine' treatment it seemed to help dilute fears.

Page, Jackman and Snowden (2008) also found if participants believed a treatment was routine they were less concerned about what would happen to them. The timing of treatment was again highlighted as an influential aspect. Dullaghan, et al. (2014) noted that when patients waited to receive treatment they were less concerned; believing their illness state to be less life-threatening. Perhaps due to being a relatively new intervention, few studies have investigated whether patients undergoing PPCI have similar concerns and fears as elective patients. Understanding the perceptions patients have about their treatment is important because these can influence behaviours when they return home. Nurses caring for patients commonly rely on the behavioural indicators of anxiety. As hospital stays become shortened for elective and emergency patients, anxiety may be under-estimated or missed. Patients' reactions towards PCI and PPCI may be influenced by nurses and doctors opinions. If as suggested by Caldwell, et al. (2007) health professionals are viewing the procedure as low risk and discuss the treatment as 'routine' this may affect how patients perceive the risks for themselves.

2.8 'Satisfied' voices

Patients who felt confident during and after the PPCI described their care as 'first class' treatment. Sampson, O'Cathain and Goodacre, (2010) sent a questionnaire to 682 AMI patients to examine patient satisfaction in hospitals providing PPCI or thrombolysis therapy as the main treatment option. Patients were asked to respond to questions about the skills and knowledge of the medical and nursing staff, time waiting for treatment, communication, treatment experience, pain and comfort management, and ability for family to visit, health information provision, hospital discharge and subsequent care afterwards. In total, 372 patients from the interventional centre and 223 patients for the control sites responded. The research revealed satisfaction was generally good in all hospitals but higher at the PPCI sites. This was attributed to patients feeling notably more well after the PPCI compared to patients who received thrombolysis therapy. Complications tend to be more common with thrombolysis and therefore it was possible that the patients felt unwell for longer if they had received this treatment.

The carer's experiences surrounding PPCI were also brought to the forefront by Sampson, O'Cathain and Goodacre (2009; 2010). In seeing patients change from a critical ill state to a well state, there was an unexpected level of optimism experienced by the carers. The treatment effects far out reached expectations and a high level of satisfaction was expressed. There was a sense of elation and optimism because everything had turned out better than expected (Astin, et al., 2009; Radcliffe, et al., 2009; Sampson, O'Cathain and Goodacre, 2009; 2010).

Only a small number of studies have researched the experiences of patients and carers surrounding PPCI within the UK. Little has been reported about the care received during and after PPCI. Instead Sampson, O'Cathain and Goodacre (2009, pp.5) suggest satisfaction was likely to be 'linked to the whole experience of undergoing PPCI rather than the procedure itself'. The authors concluded that patients and carers were extremely grateful for the life-saving treatment. There was a general consensus from patients that without the PPCI they would have died (Astin, et al., 2008; 2009; Radcliffe, et al., 2009; Sampson, O'Cathain and Goodacre, 2009; 2010; Dullaghan, et al., 2014). The prompt resolution of chest pain signalled the success of the treatment increasing patient's confidence in what had been achieved by the PPCI. The over-riding need and concern for the carers was to have their loved one treated in the right place by the right experts with the best treatment as soon as possible. To do so carers willingly put up with a longer travelling journey to a specialist hospital instead of travelling to a local hospital. Their actions were confirmed by the

patients' perceived speed of recovery and looking so well. These studies suggest satisfaction is created by patients and carers feeling safe and professionally cared for. Understanding more about patients' and carers' perceptions of the situation will be helpful to nurses.

2.9 'Knowing' voices

Throughout the PPCI literature there was a strong hint patients and carers felt managed by healthcare professionals who 'knew' what they were doing (Astin, et al., 2009; Radcliffe, et al., 2009; Sampson, O'Cathain and Goodacre, 2009). This knowing voice was also reciprocated by the nurses. The initial response to the 'crisis' was to initiate and facilitate diagnostic tests to obtain an accurate diagnosis so that the appropriate treatment could be performed. Smallwood (2009) found nurses' initial priorities were to clarify whether patient's symptoms were cardiac. Decision-making during the assessment process was heavily influenced by the medical model. The nurses believed in providing 'treatment' they were making a difference to patients' outcomes. The focus was treating the cardiac disease rather than the experience of receiving the treatment.

In another qualitative study, Smallwood and Humphreys (2007) found nurses had an overwhelming desire in wanting to do their best for patients. Being able to halt the heart attack and reduce further problems made nurses believe their expertise knowledge and skills were worthwhile. The nurses felt proud, excited and respected by others. They considered themselves as the 'ones' who had made sure the patient had a smooth transition from one event to another. They were the 'vehicles of information', feeding back results of diagnostic tests, initiating decisions, keeping the situation moving in the right direction. They co-ordinated the care and the team. Their involvement meant the patient's journey was streamlined, all the necessary components in place. There were times when their roles stopped them performing certain care needs. In such situations, the nurses felt frustrated.

Carter, et al. (2010) employed a multi-method approach with interviews, a questionnaire, focus groups and observation with 222 staff to establish the workforce issues involved in delivering the heart attack pathway. Altogether seven hospitals were involved, although not all delivered a 24 hour PPCI service. Results from the qualitative aspects, highlighted that the majority of the staff voiced pride and an increase in job satisfaction in that the work they were doing made a difference to people's lives. Staff felt fortunate to work as part of a team where they had the opportunity to develop new skills. Some liked the unpredictability and excitement of

the emergency workload. Difficulties in facilitating the treatment was acknowledged because of the adverse effect it had on other aspects, for example, emergency lists often disrupted elective lists meaning longer working hours. There were also concerns about resources for out-of-hours shifts and maintaining standards of care as was the stress of dealing with ill and unstable patients. Whilst these views may not reflect all staff working in regional heart attack centres, this study does highlight some of the concerns raised in chapter one.

Knowing was affected by the extent to which nurses felt in control. In Smallwood's (2009) study, the nurses firmly believed their role was to ensure patients understood information about the cardiac illness and cardiac drugs. Giving information to others meant they decided what knowledge was given and in what format. Knowing when to act and when not to act was also identified by Svedlund, Danielson and Norberg (1999). Thirty four nurses from a coronary care unit in Sweden were interviewed about their experiences of caring for patients with AMI. The findings suggested, nurses relied on clues such as a 'special look' or having a 'feeling' about the situation. It was this knowing, that enabled the nurses to decide which situations demanded their attention.

Similar to previous studies, the nurses wanted patients to feel safe and secure and be pleased with the care *they* had delivered. The nurses wanted a sense of closeness but at the same time they did not want to get too close to their patients. It was implied the nurses distanced themselves from the patients rather than the other way round. In maintaining a 'professional' distance there was a belief they could be more successful in carrying out their nursing work. According to Reeves and Decker (2012) distancing is a technique adopted by health care professionals when handling difficult situations. It was not specified whether the nurses were junior or experienced but if nurses find caring situations problematic this will affect caring encounters and subsequent relationships with patients and carers.

Lundén, Lundgren and Lepp (2012) interviewed 14 nurse radiographers from 3 hospitals in Sweden to discover experiences of caring for patients receiving radiological interventions in catheterisation laboratories. The nurse radiographers worried that distance imposed by equipment would mean patients would not know who was caring for them. The radiographers knew the importance of ensuring nurse-patient interactions were formed quickly. This was a necessity because it helped the nurses assess patients and helped the patient know who was caring for them. These patients were their responsibility and they wanted to create an atmosphere which evoked calmness, trust and security. There was an intense satisfaction from gaining

patient's confidence. Rather than accepting a 'poor connection', they knew what activities could reduce patients' anxieties such as the ability to start up a conversation. By making a connection they knew they could respond to patients' needs. When verbal communication was difficult in emergency situations or when a patient had received a sedative, an attempt was made to hold the patients' hand or read facial expressions and body language from afar to enhance feelings of safety and security. The nurse radiographers knew their role was to watch out for problems, make the patient feel comfortable, prepare the patient and watch for changes in mood or clinical status.

These studies indicate some of the factors effecting nurse-patient relationships. On one hand, nurses feel they are an important component in the patient pathway and central to its smooth functioning. In contrast, emotional distancing caused by the complexity of the environment or nurses not wanting to be close to patients are influencing factors. The findings of Lundén, Lundgren and Lepp's (2012) study provide an intriguing insight surrounding the behaviours of the nurse radiographers. This was the only paper that has specifically focused on practitioners' experiences in the cardiac catheterisation laboratory.

In this specialised environment nurses are frequently faced with complex-changing clinical situations where they have to play a vital role in rapid patient assessment and monitoring. It would be interesting to know what factors are guiding the nurses' actions as they care for patients and the carers. Nurses are influential in bringing comfort and protecting people from anxiety but they may also be influential in how patients estimate their level of risk surrounding the PPCI. The way in which nurses are explaining the heart attack and care after the PPCI may have significant consequences for patients, carers and other nurses. Knowing more about the caring behaviours and the emotional responses of nurses will be useful for understanding the reasons for how care is delivered within a short hospitalisation period and which aspects are important to the nurses.

2.10 The conceptual framework

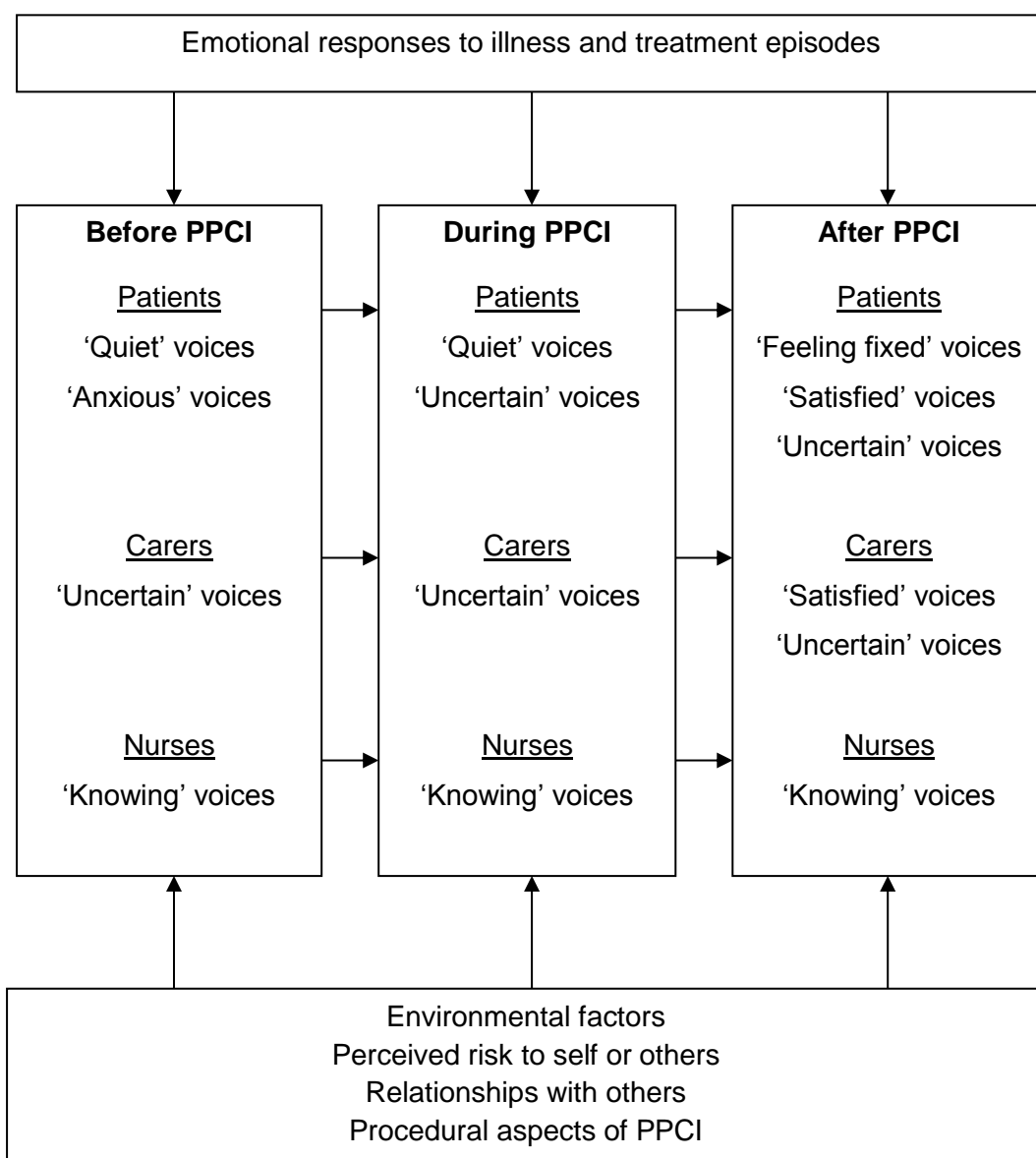
In this literature review, I have used different types of voices to interpret others' work surrounding the experiences of PPCI and PCI. The voices represent the different meanings of participants in particular circumstances. They provide a way for explaining the meaning and the emotionality of the experience. The qualitative, mixed method and quantitative studies used in this literature review have yielded essential, current and relevant issues and in doing so provided a valuable foundation of knowledge for which to base my research study upon.

The voices identified in the literature are:

- **'Feeling fixed'**, this voice reflected patients feeling well after the PPCI. Patients believed the PPCI had fixed the heart attack because the symptoms had gone.
- **'Uncertain'**, this voice reflected the mismatch between patients expectations and actual experiences. There was uncertainty about what had happened surrounding the PPCI. Information needs were unmet causing further uncertainty as patients and carers tried to make sense of what had occurred and what activities could be performed when they had returned home.
- **'Quiet'**, this voice reflected the internal turmoil faced by patients as they tried to deal with the threat from the illness and treatment. Letting others take control was a way of managing the unfamiliar situation. The environment was also a strong influence on this voice.
- **'Anxious'**, this voice reflected patients' experiences of waiting and preparing for the procedure. This voice was influenced by the way in which the self could be managed. There was a constant fear present of losing control, experiencing discomfort and complications. The anxious voice was more vivid when symptoms were present.
- **'Satisfied'**, this voice reflected a good outcome from the treatment. The illness had been managed and there was a sense of optimism. Patients and carers were grateful of where they had been treated; the right place and right people.
- **'Knowing'**, this was the voice that managed the crisis and promoted a good outcome. Providing the right treatment enabled nurses to feel in control and able to do their best.

The conceptual framework (Figure II) portrays the voices of the patients, carers and nurses. This is where this doctoral research will present a novel and unique contribution because of these three essential groups.

Figure II Conceptual Framework



At the beginning of this thesis, my 'nurse eyes' acted as the lens for this study. The PPCI was viewed as a discrete, contained event. Patients required, received and then recovered from the PPCI. Interpretation of the literature has informed my lens that these experiences are more than just about the PPCI. They are about how the patients, carers and nurses responded and managed different events. The journey metaphor became embedded to form a framework for explaining the meaning of the experiences during the analytical phase (Chapters 4, 5 and 6) in this thesis.

The metaphor of a journey is commonly associated with the progression of chronic disease (Frank, 2000; Cleland, et al., 2006; Rolley, 2009) where the illness trajectory is lengthy with ongoing symptoms. As a term, it implies an experience over time with a destination. Stein (2008) describes the journey as being taken into a new landscape. The person travels without invitation where there may be anxiety and risks, some are obvious, but overall the person affected is always hoping for the best. Each step is associated with a constant jangling of emotions, of moods, silences and transitory feelings (Stein, 2008).

The journey through the literature has reflected that initially patients' voices are 'quiet', and 'anxious', indicating the immensity of the heart attack but also the bewilderment of what had happened and could happen next. In contrast, the 'knowing' voice of the nurses was clearly heard as they proceed with their known pathway of nursing activities and responsibilities. During the PPCI, the patients' voices remain 'quiet' but are also 'uncertain' when the experience does not fit with their expectations. For the carers, the 'uncertain' voice was activated as they attempted to manage the situation and remained a constant voice. Whilst the literature indicated many patients adopted a passive-like state by handing control to the health professionals, it was not fully understood whether there are points when passivity was accepted and when it was not and why not. Less was known about the carers' experiences as they waited for the patient to receive the PPCI.

After the PPCI, patients reported 'feeling fixed' voices based on beliefs that the symptoms caused by the heart attack had disappeared. The 'uncertain' voice was heard as patients become muddled about what was happening and why they felt so well so quickly. Ways were found to deal with the situation but it was not evident how this was undertaken and the decisions taken by patients. The 'satisfied' voices for patients and carers reflected a destination reached. The experience had been survived an outcome achieved more easily than initially anticipated. The 'knowing' voice of the nurse remained dominant within the different phases.

The environment was instrumental in influencing people's behaviours and responses. The technology induced a sense of quietness in that patients felt physically unable to do things independently. In contrast, the technology enabled the nurses to 'know' what to do and made carers 'satisfied' that loved ones were treated in the right place. Afterwards carers experienced 'uncertain' voices as they struggled to understand what had happened because of information given by nurses. Other than Lundén, Lundgren and Lepp (2012), the caring encounters of nurses have received little attention. Exploring the different dimensions of cardiac nursing activities will reveal more about the emotionality of nurses' experiences.

2.11 Summary

The voices of the patient, carer and cardiac nurse remain scarce with the literature. The knowledge gained from this research will be useful to health professionals involved in different aspects of the patients' journey from diagnosis through to hospital discharge. It is anticipated that voices not yet heard will lead to explanations about how the three essential groups coped with different events, turning points and transitions. Understanding the issues that matter to and concern patients, carers and nurses means more can still be learnt about the journeys experienced. My research is concerned with conveying the stories of patients, carers and nurses. The stages of the research methodology and methods are discussed in the next chapter.

Chapter 3

Thinking with stories to engage understanding

3.1 Introduction

Tentative explanations for patients, carers and nurses experiences surrounding PPCI were mapped from existing literature in the previous chapter. Whilst this literature provided useful insights and results it was mostly descriptive and often not embedded within a theoretical context. This research study will draw attention to the factors that influence patients', carers' and nurses' experiences before, during and after PPCI. The stories collected will aid understanding about the individual patient, carer and nurse to discover what they thought and felt about different aspects of their experiences. The narrative inquiry approach used in this study will contribute to the existing body of knowledge about PPCI experiences as well as providing evidence to drive the nursing profession towards providing more therapeutic care.

This chapter begins by considering the philosophical stance in which this research is situated. This is followed by a discussion of narrative inquiry and the methodological decisions which have been made to acquire knowledge about different individual's experiences surrounding PPCI. Every stage of the research required meticulous thought and preparation. My role as the researcher, recruitment of the participants, ethical considerations and steps taken to ensure rigour are presented. A structural narrative analysis approach was adopted because the focus was on the individuals' evaluations of their narrated events. Examining the structure and elements of the narratives will provide a window to discover how experiences surrounding the PPCI were interpreted. This will promote understanding about the personal meaning and responses to those experiences. In this way, narrative methodology can be used to generate new knowledge.

3.2 Situating and defining narrative inquiry

Narration is a human activity that contributes to our understanding of ourselves and the world we live in but that understanding can change as we narrate. Bruner (1991) argued there are two different ways in which we know the world; the first is in an abstract and conceptual manner; the second is based on the way in which we communicate and organise our experiences through stories. Narration as an activity is a way of making sense of those experiences and reflecting individuality of human experience. Sandelowski (1991) also described narratives as a way to explore and

explain experiences. Stories are viewed as a portal, through which experience of the world is lived and interpreted and made personally meaningful to the individual.

Human experience was conceptualised by John Dewey (1958) as a 'changing stream' characterised by continuous interaction of human thought with the personal, social and material environment. In his theory of experience, Dewey states there is a necessary continuous and intimate relationship between experience and knowledge. Narrating is an act within a stream of experiences that generates new realities for future experiences. Every experience takes something from the present moment and carries it into the future experience. Events, people and objects are a temporal transition reflecting the past, present and future (Clandinin, 2013). In other words what you hear, see, think and feel grounds and shapes your understanding. As people experience interactions, their feelings, hopes, desires and fears are likely to also be influenced by environmental, social and cultural factors.

In this study, I have used Labov's (1972) definition of narrative as a way of "recapitulating past experience by matching a verbal sequence of clauses to the sequence of events which actually occurred" (Labov, 1972). Polkinghorne (1988) refers to narrative as an 'organisational scheme' that provides a structure for the meanings of events and actions. Clandinin and Connelly (2000) present stories as a detailed organisation of events, arranged in a plot (what the story is about) with a beginning, middle and end. Whilst not all stories are told in chronological order they do generally have characters (other people including the narrator) and reflect personal, emotional and cultural features.

This research study combines a realist ontology and interpretive epistemology (McEnvoy and Richards, 2006). According to Blaikie (2007) this offers an alternative paradigm. It places emphasis on the way in which the world is socially constructed and understood. It acknowledges that whilst things do exist and act independently of our descriptions it is only through particular descriptions that we understand them. It is an approach which appreciates there is more than one way to interpret and make sense of the world. There are three different ontological domains of reality: the '*empirical*' reality which is either experienced directly or indirectly; the '*actual*' (reality that occurs but may not be experienced directly); and the '*real*' (the generative mechanisms that contribute to our understanding of the 'actual'). These generative mechanisms are not fully explanatory but are the 'tendencies' or the factors that contribute. It is this layer that views unobservable structures as 'real' on the grounds that their effects can be experienced (Bryman, 2012).

As noted in Chapter 2, different factors such as the environment, perceived risk to self or others, relationships with others and procedural aspects of the PPCI may contribute to the changes and reactions in people's behaviours. The results of these were the 'different voices'. Realists believe relationships are influenced by external structures and internal subjective beliefs (Wainwright, 1997). Small changes in one factor can cause a larger effect in the three different ontological domains of reality domains. The stories gathered in my research will provide a route to capture the thoughts and emotions of the participants to understand what was meaningful to them and why. How did it feel to receive the PPCI? How did patients receiving PPCI cope with feeling extremely unwell to suddenly feeling better? How did the carers cope with seeing a family member seriously ill suddenly become better? How did nurses cope with sick and well patients in an acute cardiology environment? Which issues affected whether nurses had positive and/or negative experiences? As such people's experiences will be triggered by the interplay of different structures that may or may not be observed.

A realist approach is appropriate for this research because it provides a way to think about the experiences to understand why things 'are as they are'. It does not claim to find the truth but instead recognises a multi-layered reality (Clark, Lissel and Davis, 2008; DeForge and Shaw, 2012; Walsh and Evans, 2014). It is an approach that is able to recognise both the lay person and professional perspective enabling different representations of the truth. This approach will encourage me not to just view events as being a 'product' or 'end point' but to consider how different factors coming together in certain circumstances or in certain combinations generate new events and new journeys (McEnvoy and Richards, 2003; 2006).

On an interpretive level people can have or observe similar experiences but they will relate to it in different ways because of how they view and make sense of their world. Analysis of the data will attempt to tease out and disentangle the factors and relationships involved in the experiences of patients, carers and nurses surrounding PPCI. Moving from the descriptive to the discovery of possible causes will draw attention to the impact of these factors and increase understanding about why events happened in the way they did for the patients, carers and nurses and what they meant and perhaps how they influenced subsequent behaviours.

3.3 Motives for using narrative inquiry

Rather than establishing a fundamental truth, I was seeking to understand the ideas that informed these experiences. My intention was to provide insights about how decisions were taken or what they were influenced by. I wanted to understand the motives, meanings, tensions and reasons that were time, context bound and specific to the participants' experiences. In discovering the factors that contributed, I would be able to provide reasons for the different types of voices and gain a deeper understanding of their experiences.

My approach to this study has differed from more traditional qualitative approaches because I wanted to explore how people talked about their experiences and the ways they constructed meaning within their accounts. This has involved engaging with the concerns and aspects that mattered to patients receiving PPCI, carers closely associated to the patient and the nurses providing care. The narrative method seeks to understand how people think through events and how these past events shape their story (Andrews, Squire and Tamboukou, 2008). Narratives are retroactive constructions of things that happened to, or around, the narrator. Events perceived to be important and significant are selected, organised into a sequence with an attempt to interpret something from those events (Holloway and Freshwater, 2007).

Listening to how people narrate their experiences is common in healthcare. Through using people's stories more can be understood about their views and what is shaping these (Bold, 2011). These experiences can provide a way of knowing because they can uncover the layers of a person's experience (Elliott, 2005). In telling their story, the story teller takes the listener (researcher) on a journey, providing an insight into how they dealt or coped with their experience. These stories can provide new and important information so that we understand how people manage events and interpret their experiences and make sense of their worlds.

Emotions often play a significant role in any experience but in positivist research and sometimes in qualitative research they can become lost. Radcliffe, et al. (2009) and Sampson, O'Cathain and Goodacre (2009; 2010) both concluded obtaining negative experiences was much harder than gathering positive experiences. Emotions can compel the way a story is told and how events are introduced and portrayed, who is featured in the story and why these are included by the narrator. Positive and negative emotions can affect how people process and retrieve memories meaning that certain aspects in a story may be exaggerated or enhanced depending on the significance to the individual. Why such exaggerations exist will be of analytical interest. These features exist for a reason and will contribute to understanding the story being told.

Holloway and Jefferson (2000) also conclude emotions and experiences can colour and influence the stories told. Similarly Carter and Little (2007) argue that in reducing the self to an effect of language, narrative researchers may be tempted to select good or bad stories and by doing so they may overlook elements left out or those that are being concealed by the storyteller. This can make it difficult to view the self as one of wholeness and coherency suggesting that the self is in a constant state of flux as people and their human relationships change (Blaikie, 2007). How a person views the self at any particular point of time is likely to alter their self-identity. They may feel well and confident, or weak and vulnerable. The literature review noted a different relationship with patients' bodies when they felt ill compared to when they felt well.

3.4 Narrative inquiry as a methodology

Narrative inquiry is a methodology that attends to stories as being about experience (Clandinin, 2013). It explores the stories people tell as a result of the social influences on inner life, environment and unique personal history (Clandinin, 2006). It is an approach that honours the lived experience as an important source of knowledge and understanding. It is an inquiry that uses the experiences of others to understand how individuals' experiences have been developed, shaped, influenced, expressed and enacted (Labov, 1997). Rather than obtaining one true account it is about understanding the meaning for those who have experienced them. It draws attention to what events have taken place (Riessman, 2008), revealing the here and now of what those things mean. Webster and Mertova (2007) note it is a methodological approach which supports the enquiry into the complexities, ambiguities and realities of the lives of individuals.

As human beings we are continuously engaged in striving to create meaning of what happens to ourselves in our lives. According to Bolton (2014) we employ reflexive thinking to explore the meaning in an attempt to exert some control over our feelings, thoughts, actions and bodies. The stories we tell ourselves are created through language and interactions with other people, as well as the social and cultural contexts. Individuals create understandings of reality and sustain these perspectives through talk and interaction within the stories they tell to others. Berger and Luckmann (1991) proposed that we know our world not by objectively observing an external reality, but by constructing how we understand this world with others. Clandinin (2013) also argues that stories provide a 'window' into how people make sense or create some sort of order about their experiences. She denotes that experiences and events are reflected upon and organised, as people consider the significance of these

experiences. Moreover as Andrews, Squire and Tamboukou (2008) explain, events are included in stories because of their connections to the main plot and so can only be understood within the context of the whole narrative. People generally recount elements or episodes that they perceive are 'worthy' of narration. Such events will be influenced by how people evaluate or interpret present and past experiences and situations (Webster and Mertova, 2007).

For Crossley (2003), stories provide a vehicle for accessing the personal functioning of an individual. They explore issues about how individuals feel about a particular event and how this relates to their inner selves at the point of telling. However, Polkinghorne (1988) highlighted that access to a person's inner world is based upon the person's ability to reflect and order that experience and communicate it to others. For example, stories shared with friends and family will be different to those they discuss with health professionals. According to Lieblich, Tuval-Mashiach and Zilber (1998) and Ezzy (1998) identity is a story created, told and then re-told.

Stories are, as Bruner (1991) asserted, changeable, a series of events that can be told in different ways to different people and so narratives are always re-constructed. Mishler (1999) also recognised that the story is put together by the context in which it is told. The narratives obtained for this research are based upon the participant's reality of the situation and are told according to how they felt at the time they recalled their memories. Both the telling of the experience (the language used by the narrator) and what is said will be useful for knowing more about the experiences of the participants in this research study.

Polkinghorne (1988) viewed stories as drawing together the beginnings and end points of different episodes. In bringing these temporal elements the story is given 'a point'. An explanation for why happenings have occurred in a particular manner. Linking events together allows the narrator to draw inferences about the characters in the story, events, responses to events and processes surrounding their decision-making. Holloway and Freshwater (2007) describe this as the 'thread' which makes up the story and the element which brings coherence to the telling *after* the telling of the story. Polkinghorne (1988) indicates most stories consist of multiple threads, representing the sub-plots within the whole plot. Narratives can be viewed as a whole story or as a story containing smaller stories. Small stories are often constructed from critical events, responses and behaviours to combine into a 'big' story. It is the telling of the story that brings together and links the fragments to create a coherent whole.

Narrative inquiry studies differ to most qualitative approaches because of the way in which the data is handled during analysis. Narrative analysis focuses on the person whereas thematic analysis examines the broader issues as a set of themes (Holloway and Wheeler, 2010). Narrative analysis refers to a range of methods interpreting storied texts which can include a thematic approach but generally the focus is on the dynamic 'in process' interpretation (Riley and Hawe, 2005). As with other qualitative approaches, narrative researchers need to be mindful when handling their data because a too strong or too weak interpretive role can influence data selection. Some researchers represent the narratives as being authentic however these stories are co-constructed truths at a point of time (Gilbert, 2002). Instead, Polkinghorne (2007) suggests researchers should search for the reasons to understand the 'why' of what the person is saying. Time and context are also important influences in the construction and meaning because individuals gather knowledge from the past, present and future.

3.5 Stories of illness

Influential works by Frank (1995; 2000; 2010) have shown the useful contributions narratives have made for understanding the meanings of illness experiences. Using personal accounts of succumbing to life threatening illness (cancer and heart disease) Frank (2000; 2010) attempted to make sense of illness at an existential and personal level. He argued stories are not simply descriptions of about being ill, rather narratives are a tool which allow people to articulate a sense of their self-identity and how they have come to be what they are now because of the illness. Frank (1995) retells stories and places them in analytical frameworks. This disentangles types of narratives making it easier for the reader to identify the narrative type and to understand how the story proclaims a certain relation of the body to the world. These frameworks are not the truth of the stories rather they are one means to heightening attention to stories that are their own truth.

Frank (2010) outlined three thematic types of illness narrative that he defined as restitution, chaos and quest. Restitution narratives refer to an expectation that the person who has become ill will become healthy again. Chaos narratives are those where the individual imagines they will never get better. These occur when illness persists or when there are difficulties surrounding medical diagnoses. These narratives tell of constant turmoil, lack of knowing, uncertainty and feeling both helpless and hopeless. In the 'quest' narrative, the person has to accept that they are ill or that they have been marked by the illness. Even after treatment has ended,

people with chronic illness still have to live with the illness. The illness is used as a catalyst for changing their life even though it may not necessarily result in resolution of the illness.

Crossley (2000) also developed three categories that closely resemble those of Frank. The analysis of survival narratives from 38 people living with HIV revealed categories with a temporal orientation: living with a philosophy of the present (optimistic); living in the future (falsely optimistic); and living in the empty present (pessimistic).

Similarly, Murray (2008) applied a temporal organisation scheme to the stories of breast cancer survivors; a pattern that can be seen in other progressive illness conditions: regressive, progressive and stable. Accompanying these states were the metaphors: despair, hope and acceptance.

Drawing upon the work of Frank and others, narrative research provides an effective route for analysing the stories of patients and others affected by illness and for finding out how (and why) illness has altered the individual's identity. Whilst these types pose a risk of unifying the view and particularity of individual experience they also encourage closer attention to the stories people tell. As a research methodology, narratives aim to explore meanings within individual narratives and gain an overview of the experiences.

3.6 Key features of stories

An essential ingredient of telling the narrative is its capability to structure events, actions and experiences from memories, prompt reflections, connect with the past, present and future; organising events and actions into a whole (Polkinghorne, 1988). These are personal and social constructions of experiences (Frank, 1995): personal because it is the telling that gives a voice to the body that has coped or, not coped, with the situation and social because they are told to someone. Thus the teller is in a process of deconstructing and reconstructing their identities.

The narratives collected in this research have the following key features:

- They are about an event or sequence of events

The participants presented an interpretation of the events that made sense to them at the 'telling' (Murray, 2008). These events were selected, organised and presented as an accurate description of what happened or could have happened. Participants may have exaggerated the truth, but this was how they had believed it (Riessman and Quinney, 2005). It was not a case of telling one 'big' story but rather lots of smaller stories. According to Andrews, Squire and Tamboukou (2008) stories are repeatedly told and reinvented to explain and justify actions taken by the teller.

- They have temporality and spatiality

The accounts looked back and recalled experiences located in particular times and places. They connected the self with the past, present and future. The experiences told were not just about the 'here and now' but also what they had learnt from the experience and previous experiences. The telling was in part about trying to make sense of what had happened (Polkinghorne, 1988).

- They involve action and a plot

The narratives were linked together by different events, actions and motives which Holloway and Freshwater (2007) described as the 'narrative thread'. Initially I was uncertain about how this 'thread' would present itself because I had not anticipated what I would get from the questions I asked. This thread brought about a level of coherence to the telling and *after* the telling. According to Clandinin (2006) plotlines are continually revised as experiences are re-told.

- They are contextual

Each narrative was considered in the context it was told. According to Fraser (2004) this can be a social, historical, cultural or political context. Narratives were told depending upon how the participants viewed the person they were telling. For the patients and carers, I was viewed as a researcher who was interested in their experiences. For the nurses, I was a University lecturer who had a strong interest in cardiac care and the education of cardiac nurses.

- They have a starting point, middle and an end

Whilst the narratives had each element they often lacked chronology. Instead they were led by the questions asked and the poignancy the events had for each participant. Consequently participants presented their experiences in different orders. Holloway and Freshwater (2007) assert the telling gives access to what the storyteller thinks is important to say or not say. For Crossley (2003), the shape of telling is moulded by the internalising in the self, from families and friends, from the culture around them and from other ill people. A narrative is also shaped by metaphors and imagery.

- They are subject to change and re-interpretation

As the participants narrated they were engaged in their world (Blaikie, 2007). They were continually re-interpreting, producing multiple realities (Holstein and Gubrium, 2008; Hunter, 2010). As such, narratives can change with each telling (Gilbert, 2002), depending on who is doing the telling and who they are telling (Crotty, 1998). These interpretive processes mean there is no one true interpretation because different people construct different meanings about the same phenomenon (Crotty, 1998). The truth of stories is not necessarily what *was* experienced but what was told was *their* truth. I was interested in both the telling and the meaning given to the experience. My interest lay in what they told me at that point in time.

3.7 Research aims and questions

The aims of this narrative-based study were to:

- 1) Explain the experiences surrounding Primary Percutaneous Coronary Intervention for Acute Myocardial Infarction from the perspectives of patients, carers and cardiac nurses.
- 2) Understand the responses, reactions and concerns of the patients, carers and cardiac nurses before, during and after Primary Percutaneous Coronary Intervention.
- 3) Develop further understanding to enhance care and caring experiences.

The key research questions guiding this research were:

1. What can patients' stories tell us when they describe their experiences of Primary Percutaneous Coronary Intervention (PPCI)?
2. What can carers' stories tell us when a person closely associated to the carer requires a Primary Percutaneous Coronary Intervention (PPCI)?
3. What are the experiences of nurses working in a Heart Attack Centre as expressed through their stories of caring for patients requiring Primary Percutaneous Coronary Intervention (PPCI) and carers in the cardiac environment?
4. What can these stories tell us about the meanings of events for patients, carers and nurses surrounding a Primary Percutaneous Coronary Intervention (PPCI)?

3.8 Study setting

The participants for this study were recruited from a regional heart attack centre in the UK. The Heart Attack Centre opened in 2008 and is located within a specialist cardio-thoracic centre in the UK. In 2011/12, during the period of data collection, 372 patients received PPCI (79.3%) within 90 minutes of arriving at the hospital. The cardiac services include three catheterisation laboratories, a 4-bedded high dependency unit (HDU) and a 25-bedded cardiac ward.

Prior to 2008, the cardiac centre had provided elective cardiology procedures and interventions for patients transferred from another hospital. The hospital had a 24 hour, seven days a week PPCI service. At the time of data collection, the hospital had been operating a PPCI service for three years and had undergone a significant re-organisational change to implement the services. This provided the opportunity to explore different people's experiences surrounding PPCI. I chose this hospital because it is a key service provider for people in the East of England. My role as a link lecturer from the University placed me in an ideal position to seek support and co-operation from gatekeepers in the hospital to gain access to potential participants. The lead consultant cardiologist was also keen to understand the experiences of patients and family members in the hospital setting.

3.9 Choosing the participants

I recruited the patient and nurse participants using purposeful sampling. The carers were recruited using convenience sampling. It was important for this research to select and study people who had first-hand knowledge of the PPCI and were willing to talk to me about their experiences. This would serve the purpose of the study and answer the research questions. In a narrative inquiry approach the goal is to accrue a sample that will permit an in-depth understanding of the research interest. It was not about finding one truth but to understand the differences and similarities in experiences (Clandinin, 2006; Riessman, 2008). In the first instance, I used studies from the literature review as a reference point to guide potential sample numbers.

At the point of ethical approval my intention was to recruit between 7-10 participants in each of the three groups. The final sample consisted of 10 patients, 8 carers and 10 nurses; a number I concluded adequate because the methodology concentrates on building a rich understanding of the issue under exploration. Discussions by Elliott (2005) and Bold (2011) indicate narrative research studies generally have smaller numbers, with the key emphasis on depth rather than breadth.

3.9.1 Patient participants

Patients who had received a PPCI for a heart attack and were willing to share their experiences and able to converse in English were included in the research. People with history of a previous AMI and/or PPCI were excluded. Similar to the exclusion criteria of Astin, et al. (2009) I wanted to capture 'fresh experiences' rather than people who had previously experienced the procedure and illness as their stories may have been influenced by these former experiences.

I decided to interview patients within 14 days of their hospital discharge because this time range would enable participants to recall their memories surrounding the PPCI. There was a strong indication within the published literature (Astin, et al., 2009; Radcliffe, et al., 2009; Sampson, O'Cathain and Goodacre, 2009; 2010) that memory recall had at times been an issue for participants. After two weeks of experiencing an AMI, patients are invited to attend a cardiac rehabilitation programmes. It was possible that attendance could have affected recall about the PPCI. Whilst there was still a potential risk of having cardiovascular complications it was considered to be a reasonably safe time as the majority of patients are discharged home after 2-3 days and considered to be well.

I recruited seven male patients and three female patients. A higher number of male participants reflected the typical population who present with an AMI. The number of female participants reflected the ratio of male to female patients admitted to the study setting. I completed a demographic form for each patient (Appendix II). This gathered information about the patient's age; date of admission to hospital; date of interview; permission to contact GP; marital status; and details of the carer if they were willing to participate. Patients could choose whether or not they were willing to have a carer participate. In two cases, the patient did not nominate a carer but were still included to participate because I wanted to understand their experiences. I sent a letter (Appendix III) to each patient's GP explaining the purpose and nature of the patient's involvement in this research study.

3.9.2 Carer participants

The term 'carer' was applied to describe the individuals' partner, the individuals' children, the individuals' parents, the individuals' relatives, the individuals' friends or the individuals' professional carer (Department of Health, 2005). This was also in line with the research undertaken by Sampson, O'Cathain and Goodacre (2009; 2010). The intention of including this group was to explore the impact of the PPCI and hospital experience upon a person who was closely associated with the patient. It was anticipated their emotional involvement surrounding the PPCI would be different to the patient's but exploration of their experiences would build on the current but limited understanding. The carers had to be willing to be interviewed within 14 days of hospital discharge and able to converse in English. In total, eight carers were recruited with the sample consisting of six wives, one daughter and one husband.

3.9.3 Nurse participants

All the cardiac nurses were qualified nurses and were directly involved in care delivery surrounding the PPCI. They were all employed in the same heart attack centre. The rationale for recruiting nurses was to understand their experiences during caring encounters with patients and carers during the hospital phase. I recruited ten nurses; four nurses worked in the cardiac catheterisation laboratory and six nurses worked in the HDU and cardiac ward. All the nurses were female. The nurses who worked in the ward would have been involved in the recruitment for the patients. I completed a demographic form (Appendix IV) for each nurse participant regarding information about length of nursing career from qualification, length of time working in clinical area, length of time working and professional qualifications.

3.10 Recruitment procedures

Before recruitment commenced I gave a brief presentation to the nurses to explain the purpose of the research and recruitment strategies. A flyer was displayed in staff areas to indicate the inclusion criteria for the study. Patients were identified by the cardiac nurses working on the cardiac ward. By relying on the nurses it was possible that some patients may have been excluded because of nurses' concerns about patients' illness states or fears about causing anxiety and distress. Heavy workloads and clinical priorities may also have constrained recruitment. I regularly visited the ward and informed the nurses about progress with recruitment. The nurses appeared enthusiastic about the research study, pleased to be involved in a study which may enhance delivery of care.

On the day of the patient's discharge, the ward nurses checked the patient's medical records and if patients met the criteria they were informed about the study, given a research pack and invited to take part. Each information pack consisted of a covering letter inviting the patient into the study (Appendix V), a participant information sheet for the patient (Appendix VI) and carer (Appendix VII). A response sheet for interested participants requesting contact details and a stamped addressed envelope was also included. When I received a reply from the patient participant I arranged for an interview to happen within 14 days of their discharge from hospital. I spoke to all participants regarding the purpose of the study, expectations of participation, aspects regarding potential harm and benefits, confidentiality and anonymity. Access was gained to the carers through the patient who was asked whether they would like to nominate a carer who had been with them at the time of their hospital experience. If a carer did not wish to participate then the patient could still participate in the study. Agreement from the carer to participate was indicated on the returned response sheet.

I approached the nurse participants via the senior nurses responsible for staffing in the catheterisation laboratory, HDU and cardiac ward. These senior nurses handed out information research packs inviting nurses to volunteer for participation (Appendix VIII). The nurses working on the HDU and cardiac ward were already familiar with the research as they had been involved in the process of identifying patient participants. I attended a staff meeting for the nurses working in the cardiac catheterisation labs and explained the purpose of the research and their potential involvement. Familiarity gained through my role as a University Senior Lecturer facilitated relationships with some of the nurses working in the cardiac areas. Many of the nurses were keen to be involved in the research and share their experiences with me. Interested nurses were sent the participant information sheet (Appendix IX).

3.11 Risks and benefits to participants

I was responsible for designing a study in which efforts were made to minimise potential harm to participants, protect privacy and maintain confidentiality. Participant recruitment did not commence until ethical clearance was sought and granted by a Research Ethical Committee (REC) and NHS Research and Development Committee. It was articulated to all participants they were not obligated to participate but should they wish to do so, they could withdraw at any time without detriment. Participants were provided with a detailed explanation of the purpose of the study and the details of what would be involved if he/she agreed to participate. This information was articulated again before commencement of the interview to check their understanding. It was also explained and pointed out on the information sheet that extracts from their interviews (direct quotations) would be used when the nurses were interviewed but their identity would be protected. A consent form was signed by every patient (Appendix X), nominated carer (Appendix XI) and nurse (Appendix XII) who participated. It was not expected participants would directly benefit from participation but some expressed a desire to be in the study if only to help others who found themselves in similar situations. All participants who were recruited completed participation.

A potential risk of participation in this study was that participants could become upset when recounting emotional aspects of their narrative. I informed participants that if they became distressed when recalling memories of their experiences, the interview could be temporarily stopped. Alternatively the interview could be re-scheduled or they could withdraw. Should they become upset or if patient and carer participants had concerns about any aspect of care they were encouraged to inform their GP and or cardiac rehabilitation team. In addition if patient participants were in need of any medical advice there was an expectation either I would ring their physician or they would be encouraged to do so. If any of the nurses reported poor practice there would be an expectation I would report this to an appropriate person. I was acting as a doctoral student rather than as a health professional but I was still bound by the Nursing and Midwifery Council Code of Conduct.

Confidentiality was assured by substituting participants' names with identification numbers on research records, computer files and the digital recordings. All of the participant's digital recordings, consent forms and personal details were retained for the period of the research and then disposed of as in accordance with the requirements of the REC. Computers containing research data were restricted by

password entry. Notes relating to identifying data were kept separate from the de-identified study data and secured electronically via password protection. Privacy was also attended to where the interview was conducted. I arranged with each participant a convenient time for the interview. Interviews for the patient and carer participants were conducted in their home where they felt most comfortable. Nine of the nurses were interviewed in rooms away from the clinical setting in the Heart Attack Centre, with just one nurse choosing to be interviewed in her own home. All interviews with the nurses were conducted after the completion of their shift or on a day off. I was aware fatigue could have affected the quality of data collected from the nurses.

3.12 Data collection procedures

The research design had three distinct stages:

The first stage involved interviewing the patients and carers. This included a pilot interview to explore the interview guide. The pilot interview was not included in the final sample number. This stage consisted of interviews with 10 patients and 8 with carers within 14 days of the patients discharge from hospital.

The second stage involved the development and production of two vignettes representing an 'artificial story' of the patients' and carers' experiences.

The third stage involved interviews with the 10 nurses. The interview format entailed each nurse being asked a series of questions about their experiences of caring for patients receiving PPCI and the carers. When there were no further responses from the nurse, the vignettes were presented to the nurse. The nurse was informed the patient vignette was constructed from analysis of the interview data from the patients and the carer vignette constructed from analysis of interview data from the carers. The nurses were then given the patient vignette to read (Appendix XIII). They were then asked to describe their immediate reactions. The same process occurred for the carer vignette (Appendix XIV).

Reflective notes were made after each interview (Bolton, 2014). These were used to keep a record of my biases, assumptions, thoughts and emotional responses.

3.12.1 Interviews with patients and carers

In narrative inquiry, the process of interviewing is reflexive. Data collected is co-constructed. The narrative is the product of a unique point in time and interaction between the researcher and the participant (Riessman, 2008). Using interviews rather than written statements was an effective way to capture participants' feelings, attitudes, choices and evaluations. They would also capture the emotionality of their experiences. For each interview, I tried to ensure I created an atmosphere that would be comfortable for the participant to give detailed descriptions of their experiences. Each interview was digitally recorded and lasted 20-40 minutes.

Open-ended interview questions were planned in advance and focused around three time points; before, during and after the PPCI for the patients (Appendix XV), carers (Appendix XVI) and nurses (Appendix XVII). These questions acted as a guide rather than as a list. My intention was to be as flexible as possible so I could gather their stories to discover what was important to them and why. The interviews for the participants began with an opening question to provide context and facilitate the happening of a past experience or experiences. For the patient participants this was "Can you tell me about your experience of realising you were having a heart attack and needing to go to hospital to have treatment?" For the carer participants their opening question was "Can you tell me what it was like for you when --- was taken to the hospital to receive treatment for their heart attack?" This allowed issues and events they considered important to emerge in their own words and with their own emphases and structure.

The importance of allowing the story to emerge according to the events important to the person was a notable result from the pilot study. I adopted a conversational style in the interview to encourage the participants to tell me their story in their own words. On some occasions, questions were asked such as "what was that like", "how did you feel", "what happened next". Some questions emerged naturally whereas others were used to help participants explore the description of their experiences. My questions were asked to acquire smaller stories about particular experiences and events.

Initially I was uncertain about what I would hear from the questions I asked but on reflection the participants told me more than I anticipated. As Frank (1995) paraphrased, participants tend to say what they want to say rather than what the researcher wants to hear. Towards the end of the interview, I invited the participants to tell me if there was anything else that they wanted to share or that had made a difference to their experiences. This last question proved to be valuable because participants talked about particular values, beliefs and concerns; the 'gold nuggets'.

I conducted the interviews in two phases. The first phase consisted of interviewing the patients and carers. I had intended to interview the husband-wife, wife-husband and mother-daughter dyads separately but all expressed a desire to be interviewed in the same room together. At the time it did not seem appropriate to send the patient or carer to another room in their own home. Only two patient participants were interviewed individually. Questions were presented to the patient first and then once they had finished speaking, questions were presented to the carer participants. The person answering the question was the narrator but on some occasions the other person (patient or carer) provided a more detailed story about the chronology, individuals who were present, events that unfolded and the attitudes of other people. This immediacy in telling provided insights important for inclusion. It was recognised that having both participants present could have affected the data. Potentially, participants may not have wanted to say anything that might upset the other person. On one occasion, a male patient participant was overwhelmed as he talked about a situation in which he thought he had died. The presence of his wife meant he was immediately comforted; the fragility of their experiences evident.

The dyadic interviews provided a uniquely constructed reality of the experience between two people who had experienced a similar event but from differing perspectives. I recognised this type of interview produces a different account than one participant provides. Initially I was concerned that having both participants present in the room at the same time would affect what was being told. There was a risk of one person dominating the other (Seale, et al., 2008). Kendall et al. (2010) noted some couples may struggle to fully disclose their experiences in front of the other, highlighting the conflict that can occur when there are major differences between how participants view events. By conducting the interviews in this manner, I was capturing individual constructions and co-constructed accounts of their experiences.

The positives and challenges of interviewing participants together have been acknowledged widely (Morris, 2001; Seale, et al., 2008; Gysels, Shipman and Higginson, 2008; Kendall, et al., 2010; Pinnock, et al., 2011). White (2008) concluded that combining interviews often resulted in participants volunteering more information. Taylor (2009) used joint interviews to acquire perspectives from patients with Dementia, their carers and/or medical prescribers to understand treatment with medications. Combining interviews led to a deeper understanding of what it was like to cope with the illness (Seale, et al., 2008; Kendall, et al., 2010; Pinnock, et al., 2011).

3.12.2 Production of vignettes

Before the nurses were interviewed, I constructed two vignettes which provided an overview of the patients' (Appendix XIII) and carers' (Appendix XIV) core experiences. A thematic analysis was used to construct artificial stories which reflected the experiences of the patient and carer participants. The thematic analysis focused on the content of the narratives, the events that occurred, the experiences and the meanings of these as a set of themes. The intention was to gather a collective of the individual patient and carer participants' experiences. To simply have re-told all the participants' experiences would have resulted in an extensive text therefore I presented the themes by grouping together participants' quotations.

Different types of experiences were integrated to reflect differing experiences. Direct quotations were used to convey participant's voices and their evaluations of different events to represent two artificial stories. The patient vignette reflected the experience of arriving at the Heart Attack Centre to receive the PPCI, being treated in the High Dependency Unit and then being discharged from the ward. For the carers, the story focused on their arrival to the Heart Attack Centre, waiting in the visitors' room and visiting the patient after the PPCI. The patient and carer vignettes were presented to the nurses after the cardiac nurses had been interviewed.

Vignettes have been used in interviews and surveys to explore people's perceptions, beliefs and attitudes towards different care groups (Barter and Renold, 2000). Spalding and Phillips (2007) described how vignettes are commonly used to simulate real life events and to collect data about healthcare professionals' responses to these scenarios by inviting participants to comment upon what role they would have taken in that situation, how they have responded and what they would have done differently. Loveridge (2004) developed ten vignettes to provide descriptions of various cardiac disorders of patients regularly presenting in Accident & Emergency departments. Appropriate electrocardiograms (ECG) and a corresponding questionnaire were used alongside the vignettes to assess the nurses' knowledge surrounding management of the patients. Brown and Pritchard (2008) and Brown (2010) developed vignettes for training hospital staff to use complex medical devices to understand perceptions of risk. Soundy, et al. (2010) used vignettes to consider the responses of physiotherapy students' regarding three illness narratives which were developed from the experiences of rugby players who had suffered a spinal cord injury.

The advantages of using vignettes (Wright, Heathcote and Wibberley, 2014) are that they enable information to be gathered from reactions to situations that may be difficult to observe or rationalise. They are a valuable research tool but they also have their pitfalls. Hughes and Huby (2002) concluded vignettes can feel static compared to real life and so never truly reflect the reality and dynamism of people's lives. My intention for developing these vignettes was not to represent the truth but to stimulate reflection, discussion and potentially improve understanding. I wanted to give something back from the first phase of data collection to the nurses. I felt it was important to share preliminary findings from my study with the nurses. I realised this was an innovative way to use the vignettes. Constructing the vignettes made the research accessible to those providing care to patients and the carers to understand their representations of their experiences. The vignettes could potentially have an impact on the way they cared for patients and carers just from reading the quotations.

3.12.3 Interviews with the nurses

The final set of interviews was with the 10 cardiac nurses. The format of the interview was piloted with a senior cardiac ward sister before data collection commenced. This provided an opportunity to both rehearse the questions and pilot-test the vignettes to ensure feasibility, clarity, accuracy and comprehensiveness prior to their use. The initial interview began with a general greeting and introduction along with an explanation of the purpose of the research and the interview. Using an interview guide, the nurses were asked questions to find out about their experiences of what it was like caring for patients who had required a PPCI and the carers. When no further statements were offered, the two vignettes were presented to the nurse to read.

The vignettes served as a way to convey the area of interest. After reading each vignette, each nurse was encouraged to describe their reactions and comments about the experiences presented. Some nurses stated their agreement, surprise or dismay as they reflected on the patient and carer situations. The vignettes acted as a device for generating further discussion because further narrative accounts were generated as the nurses reflected on their own experiences of aspects that concerned, worried or helped them. After each interview, I made notes about how the interviews progressed, what had surprised me and occupied my attention. These notes helped my thinking and preparation for the next interview.

3.13 Choice of data analysis

I was careful in considering which narrative analytical approach would be most suitable for my research. On reading Frank (1995), I was reminded that it was important to think *with* the stories rather than just think about stories. To think about a story was to reduce it to its content and then analyse that content. I wanted to move beyond simply what was said and think with the experiences, the contexts that shaped the person, thinking about the moments that shaped their telling (past, present, future). Thinking with stories was not easy and it took a while to learn how to join with them. I had to allow my own thoughts to adopt the story flow and narrative tensions. It was not about the story becoming my own but instead feel the nuances, understand the plot and how it had led the narrative and narrator in different directions. Narrative analysis aims to interpret how people make sense of their experience in relation to their lives through the sharing of experiences of events (Riessman, 2008).

Initially I struggled with knowing which analytical approach to use in my research. The thematic analysis had served a purpose in the development of the vignettes, in that a common set of themes that resembled patients and carers experiences were evident but there was a risk of missing important differences and reasons. I wanted an approach to explain the meanings, evaluations and emotions for the narrators. In adopting the Labov structural analytical model (1972; 1997) I believed I could uncover the personal and emotional content of the participant's narratives. It offered a perspective from which to reflect on the types of voices, their meanings and for comparisons to be made between participants. I would be able to see how the PPCI meant different things to different people; looking both at individual experiences as well as contrasting different experiences. Each experience was unique. I wanted to capture these to reflect the different journeys taken by the patients, carers and nurses. My decision to use this approach was confirmed following a review of others who had used this approach with narratives.

Robichaux (2002) used a Labov approach to understand the practices of critical care nurses when they faced ethical challenges surrounding end-of-life care situations. She found there were recurrent themes across the incidents reported by the nurses but when she examined the structure of the stories particular sequences of action were repeated. The model helped Robichaux identify narrative components across the accounts. Narrative structure was also analysed in a study involving relatives telling their stories of sudden and unexpected death from stroke (Rejnö, Berg and Danielson, 2014). In attending to the structure the authors gained a deeper

understanding of how experiences were managed. It was noted how the narrators returned to the event, focused on different parts and identified particular turning points (events of importance) in their experiences. Riessman (1993) also used Labov's analytical model to interpret stories about divorced couples to find not just the reasons for breakdowns in the relationships but also how these reasons were sequenced in the stories to understand the range of meanings.

The structural framework of Labov (1972; 1997) has 6 common functional elements: abstract, orientation, complicating actions, evaluative, resolution and coda clauses. Each narrative contains a combination of, or all the functional elements. These clauses each have a specific function to serve as a series of answers to questions.

- The *abstract* (AB) acts to summarise the whole story and tells us what the story is about. The abstract precedes the orientation.
- The *orientation* (OR) provides the time and place, people and activity in the situation (who, what, where, when). This is the background information that the participant may indicate as necessary to understand the narrated events (the setting). The orientation is commonly found near to the beginning of the story but is optional. Its presence orientates the listener to the contextual information for the narrative (people, place and situation).
- The *complicating action* (CA) involves the recapitulation of past experiences in a sequential order that is referred by Labov as narrative sequencing. It is the part of a narrative which describes a series of events ending with a result.
- *Evaluation* (EV) is the narrator's interpretation and relates to how the narrator has chosen to interpret it (why it was told and what the narrator is getting at). It reveals the attitude of the narrator toward the narrative. It gives meaning to the narrative. Labov acknowledged that evaluation is taken from different perspectives: *external evaluation* which reflects the narrator standing metaphorically outside of the story as they tell the point of the story; *embedded evaluation* relates to how the narrator felt at the time of telling; and finally *evaluative action* relates to whether another person was used to evaluate the action at the time of the event.

- The *resolution* (RE) follows the evaluation and describes how the complicating action was resolved. It focuses on how and what finally happened.
- The *coda* (CO) presents the end of the narrative, returning the listener to the present moment. The coda is optional.

Labov (1972; 1997) states narratives should contain all of the functional clauses. The narratives collected in my study had variations of these clauses. Some of the clauses appeared several times in the same narrative, some narratives did not contain all elements and some varied in their sequencing. On some occasions the abstract and resolution were not clearly evident. The absence of the abstract may have been due to the questions I asked as the interviewer in that I may have inadvertently framed the subsequent narrated experience and as such given the abstract. The narrator may have felt it unnecessary to re-state what the experience was about. With regards to the resolution, it is possible that the understanding of particular events and experiences may not have yet reached a resolution. The functional elements of orientation, complicating action and evaluation were present. The coda tended to reveal itself at the end of the narrative when the whole experience was compared to what was currently happening.

These variations of the clauses did not mean narratives were less useful rather I needed to be aware of the different ways the clauses presented and were sequenced. I decided to use narratives which did not include all the clauses but as a minimum they had to have a complicating action and evaluation. It was necessary to have 'the point of the experience' and the significance of 'why' it was worth telling. Many but not all of the narratives were organised around a 'high point'. Events were described and built up (complicating action) to highlight what was important (evaluation) about particular experiences. Labov believed that when the participant re-lived their experience they were completely unaffected by the researchers presence. I was mindful that questions I asked may be influential of the way accounts were given.

Despite these limitations, I felt it was worthwhile using a Labovian approach because it allowed me to step back and observe how the narrator was using form and language to create effects and relations between different parts of the narrative. By being attentive to the narrative accounts (slowing them down), I could get a good grasp of the narrative and 'what' was going on within and 'why' to scrutinise what the story was about and how different parts contributed to the overall story. This approach enabled me to gather different evaluations (truths) about experiences and the nature of those

experiences. I found that the formal framework of structural analysis helped make meanings more explicit. Paying attention to the evaluative (EV) clause was particularly helpful because it attended to the values and meanings through which a person interpreted their experience. Riessman (1993) describes the evaluation clause as the ‘soul’ of the narrative.

3.14 Analytical process

The interview transcripts were transcribed to include all of the narrator’s words and features such as crying, laughter and pauses. This illuminated the personal reactions and emotional content. I transcribed all the interviews and added line numbers. Each narrative was read through separately, examining sentences and paragraphs for scenes that depicted a single event or portrayed a particular topic in the narratives. These were often identified as when the participant began a description of a particular patient experience. The data was then explored to discover:

- What was this about (what is the ‘told’ story about)
- Who, what, where and when
- How had they interpreted it
- What was the meaning for them – why was it told/attitude
- What finally happened

The 6 functional elements were noted on the right side of the transcript to identify plots (stories woven together). Table I provides an example of how the 6 functional elements were noted on the right side of the transcript.

Table I Transcript showing application of functional units

So we got there	AB
....and we went straight into the operating theatre	OR
he said right we are going to give you what is called a stent	CA
and told me very roughly you know just what was happening	CA
there was a conversation between the two of them	CA
whether it was going in the groin or my wrist	CA
they looked at my wrist and said oh kind of thing	CA
you are quite lucky because we are going to put it in your wrist	CA
he said your wrist is suitable for that	CA
afterwards I understood why I was lucky	EV
because it is quite uncomfortable if it goes in the groin	EV
they put a cold, froze it, a local anaesthetic	CA
I was just conscious	EV
there wasn't any pain	EV
I was conscious that something was happening here	EV

I had got the feeling that something was going through	EV
whether it was the thing being pushed up	EV
they did tell me what they were going to do	RE
They said they were going to put something called a stent up	CA
they didn't go into any detail	CA
but I had realised	EV
because I read afterwards	EV
he said it's a small balloon and told me what was going to happen	CA
I was just lying there	EV
I saw this, I was conscious of this big photographic machine	EV
I thought oh this isn't an x-ray surely	EV
obviously it is some kind of photography	EV
it came over and didn't bother me really	EV
it was only cold	EV
I was just aware something was happening inside, movement	EV
but it didn't hurt, there was just an awareness	CA
I remember thinking ooh as they are doing it	EV
it's got to my shoulder, they have got to my shoulder	EV
but I certainly didn't get any other problems at all	RE

The intention of the narrative was noted to reflect aspects that stood out as important to each individual. These included evaluations of different events and situations and the participants' emotions and behaviours to these events. An endeavour was made to identify contrasting experiences so as not to miss important differences. Notes about the different scenes and plots and their meanings were put in a table. These were used to identify emotions and types of characters and what these brought to the narratives. These detailed memo notes enhanced the processes for understanding the contextual influences on the narratives. I summarised the different events of each patients' narrative and the ways in which they spoke about those events. This enabled their story to emerge from the analysis. This was important because otherwise each narrated event may have just appeared separated, disconnected and meaningless. I then put all the accounts together and looked across for similarities and differences in which they described their experiences. I wanted to understand the point of the story and what it meant to the narrator. This was important for exploring the underlying mechanisms of the story.

Handling the data took a long time, mainly because of the large amount of data I had collected but also because I wanted to attend to the detailed structure of understanding the individual's stories. I decided to summarise the particular ways in which participants had understood their experiences. So I grouped together relevant cases under different headings. Some were parallel to one another, some merged together to illuminate the complexities of these events and for the participants

experiencing them. This provided an audit trail. Some seemed to start one way but over the course of their narrations it became evident that they became different characters according to the events happening to them and the meaning these experiences had for them. The structural analysis enabled the specifics of patients' experiences to be represented.

So that the reader is able to associate with the participants and where the information comes from, particular examples have been chosen to illustrate how meaning is created in people's accounts so that inferences can be drawn from the text. The integration of findings from within and across the patients, carers and nurses' accounts facilitated the development of narrative typologies organised around recurring and different 'journeys'. The final analysis consisted of formulating coherent explanations for the factors and reasons for these different experiences.

3.15 Trustworthiness

Narrative inquiry does not claim to generate objective representations of reality rather it focuses on the subjective meanings that participants assign to their experience. Trustworthiness is an important element in my study. The criteria of Lincoln and Guba (1985) were employed to evaluate the rigour. Firstly, credibility: was a true picture of the phenomenon presented. Transferability: does the researcher provide sufficient detail of the fieldwork so that a reader can decide whether the environment and situation is familiar to them so that they can determine whether the findings can be applied to another setting. Dependability: this can be difficult in qualitative research but could a researcher strive to repeat the study and finally confirmability: what steps have been taken to demonstrate that the findings emerge from the data and not from the researcher. In this study, the focus of trustworthiness was on the credibility and plausibility of the narratives collected through the semi-structured interviews. Therefore as a narrative researcher I needed to ask:

- How credible is the narrative approach I have used?
- How credible is the analysis of the data?
- How credible is the collection of the stories?
- Data collected is from participants' telling their 'storied experiences' - how do I know if they are being truthful?
- What if the telling has been embellished will the research be credible then?

It was important to articulate the methodology employed and the rationale for choosing narrative inquiry. Details surrounding the sampling methods, data collection and analysis are also described with the rationale. Within the interpretive paradigm it is acknowledged that other researchers may not produce the same result (Tobin and Begley, 2004). I was not seeking out for the facts but rather an interpretation of those facts (Riessman, 2008).

Narrative research provides an opportunity to hear participants own words. They provide insight, understanding and meanings about what it is like for that person in that particular situation. They personalise the experiences being described and place the individual at the centre of those experiences. I have strived to be transparent about the nature of the collected data and how these are re-represented to reflect the meanings of the participants' experiences. To keep the writing seeming 'real' and 'alive', 'transporting the reader directly' to their experiences. Clandinin and Connelly (2000) posit that if narrative studies are to have plausibility and believability the audience needs to understand the decisions, actions and emotions felt by participants. Loh (2013) suggests this can help readers to understand whether the findings have been reported and analysed from a neutral stance or from a particular theoretical perspective (Webster and Mertova, 2007).

The findings will be presented to reflect the voices of the participants. This enables the participants to speak to the reader from the 'self'. Details about the narrators are presented in chapters 4, 5 and 6. The stories collected in my research will not be an exact record of what happened and so will not be claimed as an absolute truth because as Crotty (1998) notes different people construct different meanings about the same area of interest (Squire et al., 2014). The narratives given were a version of their reality at the point of data collection. Lincoln and Guba (1985) also suggest member checking as a way to find out whether the interviews provide a 'true story'. Accuracy of the transcriptions was verified by reading the transcripts whilst simultaneously listening to the digital recordings. I made the decision not to return interpretations derived from the data to the participants. Each narrative was regarded as unique and co-constructed between the participant and myself at a particular time point. I was aware these may change as they were re-told meaning they may not reflect what was told at a later time or elicit the same feelings as they did at the point of narration.

Bryman (2012) claims that as narratives are represented they transcend from the original telling and can be misread by participants. Other experiences that had occurred since may have affected recall or potentially 'blurred or coloured' experiences. Problems such as potential participant morbidity, lack of access and alteration to the participant's situation and distress caused from recalling events were other reasons for not using member checking. My aim was to go beyond the participants' self-understanding of what they thought and felt about the topic. I was looking at this from a different perspective, as a narrative researcher, I was seeking the interpretation of their realities rather than concrete descriptions. I was interested in learning about their experiences and the effects of these realities on the individuals (Riessman and Quinney, 2005).

To demonstrate transparency I have presented the analytical method employed in a detailed manner so that the processes for interpretations and conclusions can be seen. My approach adopted the structural analytical framework of Labov (1972; 1997). I am aware this approach has its criticisms but it had a good fit for the aims of my research study. Details surrounding the sampling methods, data collection and analysis were described along with the rationale which informed these decisions. The difficulty for me working within the interpretive paradigm is another researcher may not produce the same result (Tobin and Begley, 2004) even so as Polkinghorne (2007) asserts it is important to be transparent about the nature of the collected evidence and how these are re-represented to reflect the meanings of the participants' experiences. I was mindful the goal of my research was to enhance clinical practice.

3.16 Reflexivity

Reflexivity was a necessary tool to enhance rigour. It was also a valuable strategy to explore my subjectivity and reflect on my assumptions, actions and expectations. It was inevitable prior experiences, background and my view of the world would influence the research study as a whole. I adopted a self-awareness to understand the rationale for the study, my role in data generation, relationships with participants and my involvement in how the data was analysed (Bolton, 2014). I used my supervisors as ways to debrief and clarify understanding of the data as a researcher rather than as a cardiac nurse lecturer.

The discussion that follows describes the potential lens that may have influenced the study.

I recognised that my background as coronary care nurse had the potential to block new understanding. I began nursing in 1986 and spent the majority of my clinical career working as a coronary care nurse managing people with a range of cardiac disorders. A large proportion of patients were diagnosed with AMI's and treated with Thrombolysis Therapy. Patients were often seriously unwell and spent 5-7 days in hospital.

In 2003, I took the decision to move from the acute care sector into education. My ongoing interest in cardiac care and the development of nurses' knowledge and skills related strongly to the position of Senior Lecturer I obtained. It was in this role whilst teaching cardiac care to post-registration nurses I became aware of the different conversations between coronary care nurses and nurses working in a Heart Attack Centre as to where and how patients with AMI would be treated.

A descriptive qualitative study undertaken as part of my MSc explored the experiences of cardiac nurses and managers to evaluate whether a post-registration cardiac module was meeting the needs of the service and students. The key findings revealed nurses valuing the knowledge and skills gained from the module. These gave nurses confidence and the belief they were able to enhance patient care. I began to wonder about the experiences of the nurses in the Heart Attack Centre. What was important to them? How did they feel about their caring encounters? Did they have any worries or concerns?

I deliberated upon whether being a cardiac nurse made a difference. After a great deal of thinking, reflecting and reading I decided, I occupied an outsider position. As a nurse, I had not experienced caring for patients who required PPCI. As such I was gathering data with my eyes and ears being open. As Asselin (2003) highlighted I may have known something about the culture but I did not understand the subculture. I had some familiarity with the nurses but I was not one of them. I was mindful the nurses could have assumed I already had an understanding of their experiences leading them to omit information from their stories (Blythe, et al., 2013).

Had I been an insider I may not have noticed the ordinary, routine things which were essential to understanding their experiences (Kanuha, 2000). Some participants asked questions during the interview about the PPCI, cardiac rehabilitation or particular drugs. I was able to answer their questions as I unconsciously slipped into my nurse role. My skills as a cardiac nurse and lecturer helped to establish a good

rapport with the nurses. In positioning myself as being on the outside, I have written up the findings about 'they' and 'them' rather than 'we' and 'us' to avoid the impression that I am speaking from the experience of having received a PPCI, being a carer and nurse. The stories of the participants are real to me; I can hear their individual voices. Their words speak about their experiences. It was this intimacy which has drawn me into my research study.

3.17 Summary

This chapter has been presented to legitimise the approach taken and to justify why particular decisions were made. Understanding the relationship between the ontology, epistemology, methodology and research methods has been fundamental and purposeful for developing this research study. This narrative study was designed to answer four research questions about patients, carers and nurses experiences surrounding PPCI. Narrative analysis was described as an appropriate method to explore what's and whys. Sample selection and data collection procedures were addressed. The chapter also included a discussion of methods to enhance trustworthiness of the study. The next chapter will focus on the presentation of the data collected from the patients and carers with analysis and interpretation of the findings.

Chapter 4

Being a tourist to illness

The presentation, analysis and interpretation of patients' experiences

4.1 Introduction

A structural analysis approach was used to identify the meanings across ten patients' narratives. The analysis yielded four types of travellers and their travelling experiences from the onset of the AMI, before the PPCI, during the PPCI and then recovering after the PPCI. Patients were interviewed within 14 days of hospital discharge so some of the narratives reflected the experiences of being at home. To illuminate the personal emotions and behavioural responses, exemplar narratives will allow the reader to enter into the situation. The data for the ten patients is presented in the following manner: the profiles of the patients; an explanation for how emotions and behavioural responses were identified within patients' narratives; the beginnings of the patients' journeys; the reasons for the types of travellers; and the narratives as related by the participants.

No one narrative was representative or was meant to reflect all experiences rather I wanted to present a range of experiences. Instead of using fragmented quotes from the transcripts which is congruent with some thematic analysis, the participants' narratives are deliberately presented using long chunks. Narratives are contextual and so are presented to reflect the layers of responses, reactions and behaviours that illustrated the journeys taken by the patients. Their words are not put in italics instead the intention was for the big narratives to speak for themselves enabling the voices to be visible and heard.

4.2 Presenting the patients

Participants' names and references to other people were replaced with pseudonyms to ensure anonymity. Ten patients were recruited including seven males and three females (Table II). The average age of the patient participants was 68 years and the majority were males. The PPCI service covered a large geographical region meaning that some participants had to travel quite far to reach the HAC. Six patients remained in hospital for an average stay of 2-3 days. Four patients needed to stay in hospital longer because they required further treatment for cardiac-related or non-related complications. The timing of the interviews ranged from the second day after discharge through to the thirteenth day.

Table II Demographics for patients and carers

Name	Age band years	Days in hospital	Interview day	Carer	Name
Jack	70 – 79	2 days	10 th day	Wife	Susan
Alan	60 – 69	9 days	13 th day	Wife	Teresa
James	60 – 69	2 days	2 nd day	Wife	Carol
Stephen	50 – 59	2 days	13 th day	Wife	Michelle
George	70 – 79	4 days	8 th day	Wife	Joyce
Andrew	60 – 69	2 days	6 th day	Wife	Maggie
Roy	70 – 79	2 days	7 th day	None	-----
Patricia	70 – 79	3 days	7 th day	None	-----
Linda	50 – 59	5 days	11 th day	Daughter	Donna
Helen	70 – 79	4 days	6 th day	Husband	Peter

4.3 The patients' journeys

Throughout this thesis I wanted to understand 'what' the participants were indicating as mattering and 'how' they and their emotions were managed within the narratives. This involved attending to stories about events that were important to the patient. This would enable a better understanding about how they managed and coped with various situations. To organise the large amount of data, I organised the narratives into scenes as suggested by Riessman (2008). I analysed these scenes using Labov's six functional clauses (3.14). The clauses enabled notes to be made about the meanings of participants' emotions, the people involved and their relationships with them, the environmental factors and the outcomes of different evaluations and actions within different scenes. The scenes related to three phases: before the PPCI, during the PPCI and after the PPCI.

Analysis and interpretation revealed different types of emotional and behavioural responses. These reflected patients' reactions as they encountered conflicts, tensions, other people and the hospital setting. The patients' behaviours seemed to start one way but changed depending upon what (conflict) happened to them. The patients either chose to separate from the situation or let others take control (accepting) or oppose/contest decisions taken by health care professionals (protesting). Some felt at risk (worrying) by the interactions of others or because their own needs were not met. However at the end of hospitalisation, they all felt well believing the interactions from others had enabled them to be rescued. They had

experienced different routes as they transitioned from a person who was firstly well, to a patient with a life threatening illness then back to a well person again.

The responses were influenced by the extent to which the person felt threatened and then recovered. Various emotions were demonstrated within and across the different phases. These closely related to the level of comfort associated with situations they encountered, the amount of personal control they believed they had, the nursing activities, the PPCI, physical factors (such as pain, restricted movement), relationships with others, previous experiences and environmental factors.

Positive feelings reflected comfort whereas negative feelings reflected discomfort and a state of tension. Looking at these aspects enabled me to explore how patients coped with their experiences and which aspects were important to them. Ascribing certain characteristics facilitated a deeper understanding about their responses to different situations. These responses are presented with the descriptors in Table III. Excerpts from the narratives were chosen to illustrate the patterns in the structure.

Table III Descriptors for patients' responses

Response	Descriptor	Excerpts from narrative
Accepting	The patient just accepted what happened to them. They allowed others to take responsibility and make decisions for them. They felt detached from the situation. There was no attempt to resist or challenge. There was a sense that what was being done was correct.	I just laid there watching it all happen up at the screen and literally after a few minutes they had started. (Andrew)
Protesting	The patient did not believe others understood their needs. They wanted to be independent but were not allowed. They felt restrained. They freely expressed their disapproval, objection or reluctance. They felt let down, disappointed, angry and irritated. They doubted others ability to manage the situation. They would challenge rather than negotiate. They were always pushing the boundaries.	I said well nobody else will take it off, you said two hours; nobody came so I took the bloody thing off myself. (Alan) They said I was not to get out of my bed...in fact they wouldn't let me even onto a commode that first day. (Helen)

Worrying	The patient felt anxious and troubled about actual or potential problems. This led to upset, fretting and panic. It was a state that felt uneasy and uncomfortable. They felt vulnerable and susceptible to risk. The involvement of others was important but could also unbalance well-being.	I thought the heart attack was serious and you start worrying don't you and you don't do yourself any good because you are worrying about what has happened. (Patricia)
Being Rescued	The patient felt as if they have been saved from harm or danger. They had been rescued from a difficult situation. Other people (who they trusted) had come to their aid. They had gained something that was hoped for but not expected. They were no longer ill and feeling sick; they felt well, positive and alive. They were in the right place with the right people. They felt safe.	They had made me very comfortable ...when I got back there I felt good. Whatever they have done they have obviously repaired it; the damage that was there. (James)

These emotions and behavioural responses led me to think about the types of experiences and the journeys of the patients at the beginning, during and after the PPCI: their experiences as travellers.

4.4 The beginnings of the journey

The patients are now introduced using the orientation clause (OR) of the structural analysis to understand the; who, what, where and when that the participants indicated as necessary to understand the narrated events. These introductory scenes contain the elements that indicated the orientation. They are depicted from the patients' perspective and use their own words.

Jack

"I had a pain in the morning which I thought was the usual kind, no, it was different actually, I could tell the difference because it started going down my arms, into my hands and I had read enough about it to realise that this could be something more than just kind of indigestion. My wife was at church, fortunately my daughter was here and I said to her "Look I think it's something a bit more serious. I want to go to A&E go, get mum and she can drive me up," which she did and I suppose we got there about quarter to nine and went into A&E. They said I think I have either had or are having a heart attack. They took my blood pressure and stuck things on and said right

we will get the ambulance. The paramedic started asking me questions and writing things down, when was it, this and the other. I suppose I must have been in there for about 10 minutes before we actually started off. I just happened to say, "I suppose I have had a heart attack," and she said, "Well you are having it now actually." So I said "Oh." "The blue lights were flashing and sirens going and I thought this was a bit different. My thoughts were actually doing the route. I knew exactly where I was. She must have thought I should be worrying about my heart."

Alan

"I didn't know I was having a heart attack, I had these pains back in January across my chest and we put it down to indigestion. On the day before the heart attack I had these pains across my chest again. I just walked to the bathroom and I threw everything up and that was it is, all the pain had gone. I got into bed had a lovely night sleep (laughs). When we walked into the town I said, "I've got those pains in my chest again and I can't breathe very well." I said, "Let's sit on the wall," and then the pain sort of went, I started walking again and then it came on again but I didn't tell Teresa this time. Finally I could not walk anymore; I had to sit down and I slumped inside the doorway. Teresa went to find help. The paramedic was there within five minutes; he put some things on me. My blood pressure was okay. He said he was not happy about something and said can you walk up to the ambulance. So we walked up there nice and slowly, I got into the ambulance and Teresa stayed outside. They laid me down. Started asking me my name, this that and the other, I was asking them all quite lucidly and then I sort of closed my eyes for a moment and then I said I am sorry I sort of dropped off. Then my heart stopped. I had thought I had nodded off but my heart actually stopped."

James

"I came home with pains in my chest and sweating profusely, I just couldn't stop sweating, I didn't know I was having a heart attack, I thought maybe but I wasn't sure. So I came and said, "I don't feel too good," and Carol put me on the bed and I lay on the bed and then the pain got worse. The ambulance people were here fairly quickly. We then had the journey with the lights flashing and all the rest of it and the pain was getting quite bad."

Stephen

"I had just started working for maybe 20 minutes and I got that pain in the chest and started sweating but I didn't think it was a heart attack so I thought I will just rest. A person came by and said, "What is happening to you?" I said, "Oh just pains." He told me he was calling the ambulance and I said, "There is no need to call them." I think he asked me five or six times but in the end he didn't listen to me, he called the ambulance. The first person who came was separate from the ambulance and he checked me and said according to the ECG, you are having a heart attack."

George

"I didn't realise I was having a heart attack, I just got in my car and felt funny, peculiar. I came home and lay on the bed, and I thought I had indigestion. I was sweating profusely with it and I had a slight metallic taste and a pain just in my chest and down my left arm slightly. Joyce rang the doctor and gave me the phone but then the receptionist said to ring 999 and I thought, "What the bloody hell is the receptionist telling me to ring 999 for, I had asked to speak to the doctor, not ring 999." So I rang that and it started the whole thing in motion. The ambulance was there within minutes."

Andrew

"I went over there to mow the bowling green. I had done about three quarters of it and I was getting indigestion like pain and it was gradually getting worse so I thought I would sit down for a bit and it eased off so I got up and did another couple of lengths and then it got quite bad so I turned the mower off, and sat down, it must have been about for half an hour, nobody else was there. A club member came round, I explained what happened and he said, "Shall I phone Maggie?" While he was standing there I said, "I think you had better phone for an ambulance."

Roy

"I had been getting heart burn quite a lot previously, the doctor said, "Keep off the spicy food and stuff like that," and then Saturday evening, it was fairly late I was getting this terrible heart burn. It crept up into my shoulder part and outer chest, into the arms and everywhere, so I phoned the on-call service. They told me to have a hot glass of water and walk up and down the room because that would relieve the heart burn but of course it didn't. So I rang them again and they said they would send someone around. As I say I lost track of time, it could have been early Sunday morning. Then nothing improved so I dialled 999."

Patricia

"On the Friday I got a pain, more of an ache and I had pain down my arm which I have never had before and I kept rubbing my arm and I thought I've got indigestion. I was talking to my daughter and she said, "You have been lying on your arm that's why it hurts," and so it went on Monday, Tuesday. I was awake half the night and it was getting bad. I keep emergency numbers on my phone but I daren't press the 999. I was sort of frightened because I thought it was a big step. Anyway I pressed it and they said, "Which do you want?" "I said Ambulance." By then I could hardly talk. The paramedic came and then the ambulance came and took me to the local hospital first. Then they put me in the ambulance and said, "Don't be worried but we will put the siren and lights on," and you think, "Yeah, yeah." He dashed over and put an oxygen mask on my face and we got to the hospital and there were people all out there and you know you are in pain because I had got an oxygen mask on and all that stuff and it was hurting."

Linda

"It had started about a week before and then sort of cleared. Every time I was eating it would come back. I went to the doctors and I told the nurse what was wrong and she said, "I will book you in with the doctor." She asked if I was going to wait and I thought, "Well that's a bit bad with somebody who has got chest pain" and then the doctor called me, by which time the pain had started to subside a bit. He decided he would book me for an ECG, he didn't listen to my chest or feel my chest, he gave me some tablets and sent me back to work and then of course the pain started to get bad again within just getting back to work which is about ten minutes away. So work called an ambulance. They were really good I thought, thinking back now it should have been scarier then what I felt it was and when I got there, everybody just appeared from everywhere and that was it so."

Helen

"When it started at about two o'clock after my light lunch I thought it was reflux so I sat and gradually realised that it wasn't going to go away and it started to affect my arms which I understood was something you should worry about so. I just knew that this wasn't normal and I needed to get some assistance. They told me I was having a heart attack and they needed to get me to hospital and that was it."

4.5 Types of travellers

I used the metaphor of a traveller because the patients travelled to different locations, some staying for a brief amount of time others having to revisit locations. Travelling involved passing through different transitions of illness to wellness. Patients were forced to go on a journey, a trip which they had not chosen but it was a journey on which they had to travel. For some, this meant the self-had to change as the body was engulfed by discomfort and suffering, for others little changes seemed to happen and yet for others there was an attempt to block changes instead taking a different route. As such, the short and often swift journey involved straightforward routes, detours, delays and some obstacles. Sometimes the route looped back, returning to an unwanted point (location). Their emotions reflected the challenging and difficult ways their bodies felt and coped. In all cases the destination of being rescued (survival) was believed to be reached.

The emotional and behavioural responses which emerged from interpretation of the patients' accounts were used to form types of travellers. The following describes the type of traveller with a descriptor of their characteristics and emotions:

- The **'long distance' traveller** was a person who separated themselves from the situation (denial, passivity, fear and worry). They often realised or knew something was not right and in doing so needed help from others to get through. They were relieved to not have to make decisions, wanting others to take responsibility for getting them through the situation (confident, secure, trusting others and feeling well).
- The **'frustrated' traveller** was a person who like the long distance traveller initially let others do things for them, not feeling anything, wanting others to deal with the situation. Then suddenly and unexpectedly they became ill again. They were forced again into a situation they had not asked for. Some travellers felt frustrated with themselves and some were frustrated with the actions of others (dissatisfied, anger and annoyance). Decisions made by others were questioned. Once the obstacle hindering their progress was managed they returned to feeling rescued and well.

- The **'reluctant' traveller** was a person who showed resistance to receiving help from others. They did not want to be dependent on others even when it benefitted the self. They did not feel ill and they did not want to be ill (impatience, annoyance, denial and self-protection).
- The **'disappointed' traveller** was a person who did not like what was happening to themselves. They objected to decisions and were critical of nursing activities (anger, irritation, disappointment, fear, worry and vulnerability) but they also wanted attention from others. They felt let down by others actions.

The experiences begin with accounts from James, Roy, Andrew and Jack to demonstrate how travelling during the journey was framed positively but in doing so was 'accepted' from a distance. They accepted what happened to them throughout the three phases; quickly reaching the point of 'being rescued'.

The experiences of Alan, Linda and George are considered next; from the outset Alan had a difficult journey; in the beginning he was reminded by his heart failing that there was a risk to travelling this journey. Alan was 'rescued' but then had an unexpected diversion caused by a further episode of illness. His story is compared to Linda and George's who also became ill after 'being rescued'. Each person dealt with their diversions in different ways.

Then the experiences of Stephen are presented. Not everyone just let things happen, some were reluctant to participate. In Stephen's case it was an uphill struggle, 'protesting' all the way until finally he realised he had reached his destination of 'being rescued'. Only then the reality of what had happened took effect. Andrews' story demonstrates another way of 'accepting' but also 'protesting' the situation. Andrew found solutions that enabled him find another way when he felt restricted and trapped.

Finally the situations of Patricia and Helen are examined. Their accounts are presented to understand that travelling experiences could be a disappointment when expectations were not met. In particular, this disappointment rose from their interactions with those doing the caring. Helen's narrative reveals the strategies used to improve her own needs. Table IV reflects the different emotional and behavioural responses in different journeys experienced.

Table IV Types of travellers and responses

Long distance travellers	Before PPCI	During and after PPCI
James	Accepting	Accepting → Being rescued
Roy	Accepting	Accepting → Being rescued
Jack	Accepting	Accepting → Being rescued
Andrew	Accepting	Accepting → Being rescued (Protesting)
Frustrated travellers	Before PPCI	During and after
Alan	Worrying	Accepting → Being rescued → (becomes ill again) → Protesting → Accepting → Being rescued
Linda	Accepting	Accepting → Being rescued → (becomes ill again) → Protesting → Accepting → Being rescued
George	Accepting	Accepting → Being rescued → (becomes ill again) → Accepting → Being rescued
Reluctant travellers	Before PPCI	During and after PPCI
Stephen	Protesting	Protesting → Protesting → Accepting → Being rescued
Disappointed travellers	Before PPCI	During and after PPCI
Helen	Accepting	Accepting → Protesting → Being rescued
Patricia	Worrying & Accepting	Worrying → Protesting → Being rescued → Protesting → Worrying

So that readers are able to associate with the patients and understand where this information has come from I have chosen particular examples to illustrate how meaning was created.

4.5.1 The 'long distance' traveller

- A person who separated themselves from the situation. They often realised or knew something was not right and in doing so needed help from others to get through. They were relieved to not have to make decisions, wanting others to take responsibility for getting them through the situation.

James was admitted straight to the HDU because the catheter lab was busy with two other patients. The following statements reflect the complicating actions and evaluative statements as James assesses his situation. The nurses had given him some morphine and this had "eased the pain, it didn't take it away fully, but he was comfortable." James was struck by how the nurses "seemed so matter of fact; they knew exactly." He observed how "the nurses were working together to get things done. One nurse made you feel really good. It was like what you were having done was an everyday thing. Which it wasn't really and that made you feel good you know. I couldn't fault it; I just felt comfortable; I couldn't believe that it was so easy."

During the PPCI, James was aware of having things done to him. There was a sense of caring but not caring. "I felt at ease all the time I was down there. I wasn't really taking it on board. I thought whatever they have got to do, they have to do it." Initially James had felt cold "maybe it was the trauma of it all but I started to shake as I was going down to the theatre. Soon after I warmed up, whether they upped the temperature in there I don't know." James was not really sure what they were doing to him. He could feel somebody playing with his leg. His first thought was 'they should be up here (laughs and points to his chest), I couldn't really understand that. I could feel a bit of heat down here. They told me they were going to put a dye in and that I would be down there for an hour but he didn't recall it being that long. It didn't seem that long." James presumed there "was a problem because of all the pain he was getting." The evaluative phrases set the tone for James. He was trying to work out what was happening; why he felt what he was feeling.

From what he understood they were able to 'scan all the arteries and see if there were any other problems there and then do what they had got to do'. He believed "it was necessary". He "felt confident" because of 'their confidence' and they were 'so matter of fact of what they were going to do' to him. So "I went along with it". It felt very comfortable and an hour later he was back (in the HDU) "I felt good". James brings the story to the present announcing "and here I am, it was amazing".

Jack also had no idea what was happening, what it meant and how it related to his heart attack. He knew something was happening because he could feel them inside him. "I was conscious that something was happening here (points to upper arm). I had got the feeling that something was going through. Whether it was the thing being pushed up, you could just, I was just aware something was happening inside. A movement, it didn't hurt, there was just awareness and I remember thinking as they are doing it, it's got to my shoulder. I certainly didn't get any other problems at all. I saw and was conscious of this big photographic machine. I thought this isn't an x-ray surely but obviously some kind of photography. It came over my head, it was a bit claustrophobic kind of thing but it didn't bother me really."

Andrew recounted his experience as if it had happened to someone else. It did not feel like him. The following complicating actions reflect the series of turning points that were used by Andrew to make sense of what others were doing to him. His evaluative statements reveal what these meant to him and for his body. He was taken through to where they did the procedure; "they explained what was going on and asked me to sign a document but the signature on it didn't bear any relationship to my usual signature. And then they just did it. I just laid there watching it all happen up at the screen and literally after a few minutes they had started there was no pain at all. It just disappeared. I wasn't too interested in what the surgeon was doing because when he first started I was struggling. I had a lot of discomfort but when he actually started I noticed the screens on the side and I could see the heart pumping away and I thought that's interesting and I was watching and I thought wow that's my heart and it's pumping." The only sensation he felt was "the surgeon's hand as he was actually feeding it in. Every time he pushed a length in it made contact with my hand." Andrew was then told it was all done. He thanked the doctor suddenly realising he felt better than he thought he would "I felt very well and I found I was just lying there wondering what to do next. The nurses said don't do anything, stay there." So Andrew just lay there waiting to be told what to do.

Roy's main objective was to be pain free; he wanted to be well again. His evaluative statements reflect his non-participation. Throughout his narrative, Roy frequently used the metaphor '*they*' when talking about what the health professionals had done. *They* were doing things to him rather than for him. It was about what *they* decided was good for him rather than what he chose. His choices of words were medically orientated, for example, he talks about an 'artery blockage', 'balloon', and 'femoral artery'. "*They* put that endoscope, it came up onto my right side and I never felt it but *they* felt an artery blockage so *they* put this balloon in it. I didn't feel anything at all, no pain but I

could still feel the indigestion. I had this scan thing come over me. I suppose that was an x-ray machine working to guide *them* to where it was. That was going backwards and forwards, up and down, it was very quick. I wasn't really worried about anything. I wanted to get rid of the pain. I think the pain went when *they* opened the femoral artery up. *They* didn't waste any time. I was straight on the table and they tore everything off me but I couldn't care. I just let *them* do it. *They* knew what *they* were doing."

When Roy reached the HDU he recalled being "plugged in." The nurses started doing all sorts of things to him "I had that cannula put in, *they* were taking blood samples, I had the monitor on and the ECG; I had about a dozen leads coming off everywhere. It didn't bother me, you have just to go along with it, and you don't have time to worry, you were just glad to get through it. "*They* checked that (the sheath site) quite a lot, it was bruised but you expect that."

Roy was keen for this illness experience to have a temporary status in his life. He had realised that without *their* help, his destination would have been completely different. "I wouldn't be here now, it was that painful, and I would hate to go through that again. It was really excruciating, if you haven't experienced it, it is terrible, it is horrible and you can't breathe". His statements reflect that he believed he was in the right place "it's fantastic really it's a very nice place" but he also evaluated it as "very boring, it got very boring. There was nothing to do because you can't use a mobile phone or anything. In the ward you had the day room but in the intensive care you had nothing, you were just staring at a ceiling all day." It was an aspect that had to be endured.

Whilst some aspects of hospitalisation were not stressful; activities normally undertaken by the 'well person' seemed more difficult. Patients were often reminded by nurses of the potential risk to their selves and the requirement to remain dependent. The importance of adhering to their rules and regulations was frequently emphasised. James laughs as he describes the tussle between the nurses and him as he forced to comply with their terms. "They made sure I kept my right leg still, they were stressing upon me I must not move my leg. I know I crossed my legs once and they told me I must not do that. I would keep lifting my head; I was trying to do this but they said no keep your head back. I was trying to be helpful. I felt so good after coming round. I felt as if I was ready for home, I didn't know what I was doing there. It was amazing when you think of what I had done. They looked after me well. I just felt very confident with the people there, they relaxed you. You felt confident, there was no panicking. They just went through the routine."

Jack recalled some difficult occasions during his experience. "I wanted to go to the toilet rather than use a commode by my bed. I was constipated, I couldn't go for two days, I don't know whether it was the medication; the toilet was just outside which was actually quite handy. So the nurse said, "I will watch you and if I think you are okay you can walk," but she said, "Whatever you do don't strain because the heart won't like it." I really wanted to go, so I didn't strain and then I was okay. Instead the most painful bit was when they removed the tube from my groin. They told me if they did it by machine it was going to take an hour or it would take fifteen minutes. They said the pain or discomfort would be the same either way so I thought we would go for the fifteen minutes. The discomfort was from them pressing on it. I think they have to press quite hard on it. They explained it was a main artery. They did say, "This is going to be the worst bit of it because we have got to press on your groin now otherwise it will just hit the ceiling." For fifteen minutes they were pressing on my groin but I knew exactly what the consequences would be if they didn't do that. That was the worst bit but now it is just a bit yellow."

Jack described the other patients in his bay "there was a patient in the bed opposite, he was elderly and in a very bad way, he seemed to have a lot wrong with him. Jack asked another man diagonal to him "what are you in for?" To Jack's dismay he replied "well the same as you but it has taken four days, I have been four days here waiting and then you came in and had it done straightaway, he wasn't nasty or anything" but it was evident Jack felt slightly hurt referring it to be 'like a joke'. Upon checking with the nurse, he was told "you were an emergency" and so Jack just had to accept it because "that was how it was."

All the patients were very surprised about how good they felt and being allowed to go home so quickly. Being allowed home was a further confirmation of their wellness. James was really pleased, "the doctor had said he would be going home on Thursday but then they let us all home Wednesday, all three of us. That was a pleasant surprise because when you are feeling good the time does drag very much in there, you know you are reading and having a cup of tea. There was good care, but you know, you are feeling well; if you were feeling ill then it would be a different thing but I was feeling so good, I thought I don't really need to be there and they obviously thought the same because they let me out. No I didn't have any worries really. It had all happened so quickly. They have literally scanned and said that everywhere else is healthy. Whatever they have done they have obviously repaired it; the damage that was there. Hopefully I can get on with my life again now unless they tell me different. But that's what they said everything was healthy apart from this."

Jack also thought he would be in there for a week but when they said “you will be out on Saturday” he was slightly taken back “I didn’t realise actually it would be as quick as it was.” It was earlier than he had expected and in some ways earlier than he wanted. Much to his relief the doctors decided that “instead of coming out on the Friday night I came out on the Saturday to give me the full forty eight hours. In fact I probably had about fifty two or fifty three hours but you know that was pure and simply timing and I was very pleased that they went, perhaps over did it, rather than under did it.”

The narratives depict a sense of resolution and coda when the men describe how lucky they have been with all the timings; it could have been much worse. James was more fearful and uncertain at home. “I find it quite pleasing really that I had it when I did because this was something that was going to happen sometime. We go off to Spain for two months and it could have so easily happened over there. I am really glad I had this problem when I did.” James was going to see his daughter in America. He felt well but was then fearful when the insurance company told him he needed some further tests. “I have been waiting for six weeks. It will get dangerously near. If the check was a bad one I wouldn’t really have any time to do anything about the holiday. I am a little bit concerned whether I really should be doing a fourteen hour flight.”

Roy compared the heart attack to a stroke in which the impact on quality of life was considered to be far worse. The “disappointing thing is I can’t eat grapefruit anymore. It’s the enzymes and the Simvastatin gives you headaches.” Whereas, Jack talked about feeling better but needing to take care “I’m aware I have to take things easy so I am being careful. Not to stretch up and bend down, I walk about slowly. I was told I have got three arteries and one of them is blocked but I don’t feel at all worried because I have got two left kind of thing. So, no, I wasn’t worried, I am not fatalistic; you know when the time comes that is it.” Andrew had received a phone call saying ‘the district nurse and the doctor would get in touch with him but he was still waiting.’

These four men were described as ‘long distance travellers’. Throughout their experiences they distanced themselves from taking any responsibility; instead choosing to ‘accept’ the situations that faced them. They felt very little, disconnected at times from the reality of the situation, letting it happen; letting others do things to and for them. The immediate disruption of the heart attack changed them from independent adults (well people) to passive dependents (ill patients). Their whole beings became isolated from any familiarity whilst they were ill. They seemed to ‘accept’ a reduced level of personal comfort even when the outcome was unclear and

ambiguous. The heart attack was unexpected but once realised or confirmed they wanted treatment and decisions to be made quickly. They each appeared quiet, pleasant and co-operative (passive) as they felt ill and others viewed them as ill. They chose to 'accept' interactions and interventions from nurses. Even activities considered as normal which were restricted were 'accepted' in a positive manner. The aim was to travel safely.

Developing adequate relationships and co-operating with the nurses was important for reaching the desired destination (feeling well, 'rescued'). As soon the men reached a stage where they thought something would happen or they would need to do something they were manoeuvred to the next point. This quick progression may have affected their ability to appraise and then cope with the experience. Subsequently, the men were neither overtly optimistic nor were they pessimistic; rather they slowly transitioned through this 'smooth ride'. It was only when they were at home, that the reality of the situation and significance of the illness had taken its effect. Actions to respond and adapt were then being considered to minimise the seriousness of the heart attack and promote their well-being.

4.5.2 The 'frustrated' traveller

- A person who like the long distance traveller initially let others do things for them, not feeling anything, wanting others to deal with the situation. Then suddenly and unexpectedly they became ill again. They were forced again into a situation they had not asked for. Some travellers felt frustrated with themselves and some were frustrated with the actions of others. Decisions made by others were questioned. Once the obstacle hindering their progress was managed they returned to feeling rescued and well.

The narratives in this section reflect a series of crises and evaluative statements. The tone of the narratives identified how each participant dealt with their diversions in different ways. Alan, George and Linda were all 'accepting' of what had happened and for the actions taken by others when they first found themselves ill. They then graduated towards a stage where they felt well. However shortly after 'being rescued', there was an expected diversion in that they all became unwell again. The following accounts compare the ways in which they managed the situation, themselves and how they reached the feeling of 'being rescued' again.

Following a dramatic start to Alan's journey it all became a 'smoother ride' during his PPCI and care in the HDU. "I did the stairs on the Wednesday and all felt fine. Then that evening when it was lights out I started coughing. Cough, cough, cough, cough, cough and I started fetching up blood and this went on for quite a while. I went out to the nurse out on the desk during the night and I said, "I am coughing up blood," and she said, "It's probably quite normal." But I knew it was not normal to cough up blood. She told me, "You have been coughing hard and may have just burst a little vessel or something like that." The nurse had provided a reason which Alan felt he had to accept. Their actions had helped him before so there should be no cause for worry but Alan felt slightly reproached by her. He went back to his bed again but the coughing just carried on. Alan became conscious of his coughing "there were only two of us in the ward but I was worried about waking and keeping the other chap awake. I returned to the nurses' station again." Alan wanted a different kind of response. He was more suspicious, questioning her judgement "I said look this can't be right I am coughing up blood". He was both relieved and dismayed when the nurse told him "not to worry, we are getting the doctor to come round and see you."

The doctor did eventually come round and saw Alan at about five o'clock in the morning. Alan was told "they were going to do this that." Initially he was given some oxygen and a young nurse came in and sat by him. Alan felt very unwell. He told the nurse "I feel that bad I reckon this is the end of me. Never mind about the heart attack, this is going to do for me now." I felt awful. To cut a long story short they whipped me straight back into the HDU. That's when they put that CPAP on me. I have never felt so (pauses), when they first put it on. I felt as if I had put my head inside a dark hole and I couldn't see anything, smell anything (pauses) and then there was just this noise, it was just my breathing (takes a deep breath in and makes a loud expiratory noise twice). I immediately ripped it off. They said, "Are you claustrophobic?" I said "No" and they said, "You have to keep it on". I said, "I can't its awful, its torture." They said, "No you will be alright." I said, "How long do I have to have it on for?" Not too long. Six hours. Six hours I had it on that time. My lungs were filling up." In this section of the narrative, complicating actions are followed by evaluative statements drawing attention to how frightened Alan felt. His life was in danger. This intervention was different to the PPCI; it was distressing, uncomfortable and unfamiliar.

The following night Alan describes how he was told by a nurse "You are going to have to have that CPAP again." I said, "I am not" but she said, "You are going to have that CPAP." In an act of defiance Alan tells the nurse, "I would sign myself out before I had that darn thing on again, its torture" but the nurse simply ignored him. She told me, I

“would just have to have it again.” Alan tried to bargain with the nurse about exactly how long he would have the CPAP. “I said an hour but she said no, two hours.” He challenged her response offering an alternative, “an hour.” Still the nurse did not budge from her two hours. Alan was getting nowhere, he felt frustrated because the nurse was not co-operating with him; she ignored his negotiations. In the end Alan backed down “so I said okay two hours.” The complicating actions reflect a series of events that were employed to try and manage the situation. An agreement of sorts had been set.

“It was half past nine at night when they came to put it on. I think they gave me an injection as well, to try and get me to relax.” From the moment the CPAP was placed on Alan, clock watched. It was a way of distracting himself. The CPAP went on and on and then the two hours arrived. The “chap in charge that night of the machine didn’t come and it was two hours, then two hours and five minutes went by. I just ripped it all off. A nurse came to see me, she was a ‘nice woman’ but she told me I was not supposed to take off the mask.” Alan remarked on her ‘sounding very severe with him’. Alan was indignant; as far as he was concerned they had reached an agreement and they had broken the terms set. “I said well nobody else will take it off, you said two hours; nobody came so I took the bloody thing off myself.” Alan felt frustrated and angry; they had let him down. “The nurse just put on a mask and that was okay. Then for the next forty eight hours I went from the mask to the two little ones up your nose.”

Afterwards Alan surmised his experience had “been perfect.” However his experience was still at the forefront of his memory. He felt frustrated with others when he was vulnerable and needed help. Alan also felt frustrated with himself. “It annoyed me I had got this other blinking thing when I see the other chaps coming in and going out after two or three days I have to go and get a lung infection or whatever it was. I was thinking oh God I don’t do things by half. The good thing was I had to have a catheter for a few days but I didn’t have an infection.” Alan felt he had been saved from another difficult situation.

George distinctly remembered the point when his journey was temporarily diverted. Frustratingly, his heart was still causing him problems. “I got up and upset the water; it was as someone had switched the light off and on quickly. They x-rayed me and found the blood not getting to my brain quick enough through the valve. It was the valve that caused the heart attack, not the artery which *they* had opened at the back. It was definitely the valve which done it I think. They got me on this bed and the chap put this probe on my rib. He was so tall he was laying on me and he said you can hear it squelching about. He then turned round and said, “I am going to call my boss, I am

not getting a very good reading” and as soon as they say that you know it is something not right. He wouldn’t be in that job without finding anything. About ten minutes quarter of an hour later his boss came in. The next minute I was back on the ward and the doctor came back in the evening to tell me what he had found.”

Whilst it was not a situation George had welcomed he liked the way the doctor was straightforward with him. Not trying to cover anything up. “He told me, “either you hold your breath, drop dead or have a new valve”. I liked that approach you know. I would rather have him say it, otherwise people start to panic. I was glad they had found it.” His evaluative clauses reflect the gratefulness to the staff. “I am one of those sort of people if it wants doing have it done. A lot of people panic and worry and all of that, no I believe that if anything wants doing, do it as quick as possible. If they phone me up tomorrow and say come in. If you die on the table you don’t know anything about it. Well that’s how I look at it anyhow. If they are going to cut me open I want to know which bit they are going to cut out and chuck out. It doesn’t worry me, if it has got to go.”

To deal with the frustration, George employed a sense of humour to counterbalance his encounters with others. “We were having a dam good laugh and I said when I get my sonic valve I am going to come and chase you about and she said, “I can just see you with your skin pulled on your face tight and your hair back through the wind.” We had a big laugh in there really. It makes an awful lot of difference if you are grumpy. There are too many miserable chaps about and I do like to be around happy people, not miserable people because that makes an awful lot of difference.”

Linda compared this experience to previous hospital experiences it was better “all the staff whether they were a cleaner, doctor or a nurse were all brilliant. The hospital had that old style where you get a cup of tea when you wake up in the morning. It all added to the patient comfort and if you asked somebody something they knew it. The place was clean and really nice and that made a lot of difference.” It was all going well until the doctors thought she had a chest infection “they didn’t know what it was or whether it was a chest infection or something. So they gave me an antibiotic which gave me diarrhoea which I knew it would because it is vile.” Linda knew the antibiotic would help but after feeling so well she was frustrated; it felt like a step in the wrong direction. “I don’t really want to take it until I had spoken to the doctor.” The doctor agreed to do microbiology tests. Linda’s frustration was not altered when the results were “neither positive nor negative. He thought I might have C Diff so they put me into isolation and gave me another antibiotic. That’s how I ended up staying in.”

Having regained their personal comfort and control after the PPCI; Alan, George and Linda then became 'frustrated travellers' when another episode of illness threatened their well-beings. They were frustrated by the actions of others who previously had given them confidence versus the frustration of their own bodies letting them down. It had all happened unexpectedly; they were not prepared for it, and they felt powerless to prevent it. They each responded in a different way to get back to feeling well and 'being rescued' again.

After a difficult start to his journey, Alan's experience remained settled until he was greeted with another diversion. He seemed emotionally vulnerable compared to the other two participants. He wanted help from the nurses and doctors and had tried to be receptive but their help and responses made him feel frustrated because they had not met his needs. It altered his relationships with others and manifested into a person who did not want to co-operate with the wishes of others. Tearing off the CPAP mask and making threats to discharge reflected reactions concerned with the loss of personal control. Bargaining was briefly helpful but also led to frustration and despondency. He was reminded of his own mortality. He had to relinquish control to others to get through the situation.

Despite the frustration of becoming ill again, George was certain the problem could be navigated so that he could resume his journey again. The valve problem had presented itself at the right time. He was in the hospital; the signs had been recognised and necessary tests taken. George was more positive than the other two patients interpreting this newly diagnosed problem as 'being rescued' again. Laughter was used to demonstrate the positive impact on the therapeutic relationships he'd experienced. Potentially it was a coping strategy. This patient-initiated humour enabled George to successfully interact and communicate with the nurses and doctors. It allowed George to recognise how he felt.

In contrast, Linda had been consistently passive throughout the first two phases of her travels. However faced with a choice she was unhappy about having antibiotic treatment which she knew would make her ill again. Her frustration put her at odds with the biomedical view taken. All three had different agendas reflecting their own unique experiences.

4.5.3 The 'reluctant' traveller

- This person showed resistance to receiving help from others. They did not want to be dependent on others even when it benefitted the self. They did not feel ill. There was impatience about having to be ill.

It did not occur to Stephen he might be having a heart attack. His first response had been to try and rest and remain in control but that decision had been taken away from him. The situation was not helped by not knowing what was happening “*They* even didn’t tell me where *they* were taking me, I didn’t know anything. When I arrived *they* were waiting for me, there was five, six people working on me and after a few minutes *they* took me directly to theatre. *They* told me to sign a consent form, I felt I did not have any other choice, what were my other choices.” If *they* were going to cut him *they* would need to give him an anaesthetic but “*they* didn’t give me any anaesthetic.”

During the PPCI, Stephen watched them “but then I got bored. I did not feel anything, you feel nothing. I didn’t want to watch how he was going into my vein. I did not know how long it would take. Then I started to watch again. When I watched; it looked like a hook cleaning the walls. The only pain I felt was the normal pain that happens when *they* insert the stent. I could feel that. It was almost at the end and *they* said what you are supposed to feel. Suddenly you feel something like burning and concentrated. The pain went off quite quickly it probably lasted about 10, 15 seconds. During the whole procedure you don’t feel anything; there is no pain, nothing. The pain disappeared and after that I felt immediately better.” These evaluative statements reveal how Stephen had not known what to expect initially but afterwards realised it was not intrusive and everything was done quicker than he had expected. His description of the pain reflected the explanation given to him by the nurses. “Really it looks so simple but it is deceiving. The fact *they* didn’t have to cut me, was huge and that you don’t have scars.” Resolution was reached when he realised he had survived.

After the PPCI, Stephen “asked if he could go home but they said no so that was that.” He was told he had to wear an oxygen mask but “it didn’t fit, I wanted to remove it, *they* allowed it because *they* said my pressure was okay so I could take it off. I wanted to stand up but because it’s main artery you are not supposed to, you can’t move and you have to lie down and you don’t want to. You are told not cough, sneeze or laugh so you don’t bleed but I said who is going to laugh but as it happened I laughed a lot.” Then it was just waiting, I could walk around but *they* said do not put too much pressure on it and things like that.”

The waiting was made easier when a doctor 'gave me a hint' that I could probably go home the next day after a minimum of 48 hours. Then *they* brought another two people like me, the same afternoon. *They* came, almost a difference of half an hour and there was another old gentleman who was waiting, he liked to talk and so we laughed. He entertained us. We wanted to go home. Effectively you are bored. I asked my wife to bring me in book but it is not really the place to read".

Andrew also found some aspects of the ward routine restraining. "It was about as good as it could be. They were very attentive and got on with their job, when I rung for them for different reasons they came quite quickly. I only got told off once for unplugging from it and trotting off for a pee but then about an hour later they said you can take it all off." These complicating actions and the evaluative statements reflect the events and behavioural responses employed to manage the situation.

Back at home the realisation of the seriousness of the heart attack was more evident. Stephen was completely shocked he had "high cholesterol and this had appeared four months or five months ago." Stephen's narrative reaches the coda when he states "on Fridays I had my blue cheeses which I really liked. I thought it was just once a week and I could afford it but obviously, not now."

Whilst the heart attack was not always verbalised in the men's narrations it did feature in the background. Stephen was reluctant to admit he was unwell; doing so made him feel vulnerable. Keeping and maintaining control was important. He did not want to be ill or admit that he was ill or be seen by others as being sick. There was an expectation of harm or unpleasantness and a strong fear of becoming dependent on others and having less control. These aspects were unwanted and 'protested' about throughout their experiences. The hospital routine was unpredictable; at times uncomfortable and restrained. The short time made it easier but also difficult to understand decisions imposed by others. Both men were keen to leave the hospital and consequently a problem-solving approach was sought. For Stephen, a temporary but valued relationship was developed with fellow patients partly as a distraction from the boredom. Andrew was governed by a strong desire to improve his comfort needs. The cardiac monitor was an obstacle to his independence. Having got his wellness back he was prepared to take risks where he believed the benefits outweighed the risks. Disobeying the rules made him feel alive. It was not until afterwards the men could see how the actions of others had helped to ease the unexpected transitions in their travels as they reached a state of 'feeling rescued'.

4.5.4 The 'disappointed' traveller

- This is was a person who did not like what was happening to themselves. They objected to decisions and were critical of nursing activities but they also wanted attention from others. They felt let down by others actions.

Patricia and Helen were both grateful for the treatment they had received but there was a constant dissatisfaction (protesting) about the way in which they had felt they were treated. There was a sense the journey taken had not been enjoyed because of the lack of attention from the nurses: their travelling needs unmet.

Patricia remained in a fearful state throughout her travels. It is possible that her anxiety made it difficult for her to process information because at times it is evident she was unclear about what happened and why. "Well I wasn't really aware of what they were doing because they don't sort of tell you and they just sort of started. They told me, "We are going to give you a local anaesthetic," and then they started pressing on my arm. It was almost like living out an experience as somebody else. You are in there and you are sort of whipped along. It's all taken out of you and you just go along with everybody. You don't question anybody because after all they know better than me what they are doing. I didn't know what was happening because you've got a screen in front of you. They had got the monitors going backwards and forwards like a picture thing and the screen was facing them, because it had got to be facing them but I wouldn't have wanted to know that anyway. That would have been frightening to see it. I didn't know what had happened but it seemed to go on for an awful long time, like sort of a hurting. They said, "Keep still, keep still, you must not move." The main discomfort was laying still and not moving for a lot of the time. You get a bit sort of fed up. It was just uncomfortable lying there, I couldn't move. It is all being done for your good so you can't complain can you because where would I be now? Then at the end they said, "That's done." I came here tearing along in an emergency and now I am done, finished'. It was hard to believe. It just was not registering, I think after what you have been through. I mean one minute you are at home and then the next minute you are in hospital and you feel alright. I know I feel alright but I am worried."

Patricia conveyed reasons for her actions by comparing her vulnerability against others having the same experience. "When I was downstairs I kept hearing the siren and you are sort of lying there and thinking people keep coming all the time and you realise you are not the only one. There are all those people in there and you look at them and so instead of sort of feeling sorry for yourself, you think well they are all in here for the same thing. That was a bit of a shock to me. You know the hospital is

there but there's just one or two trailing along. It seems they were coming in all day, it makes you think."

The ability and quality of the nurses to meet and manage her comfort needs was both important and an expectation. "There was one nurse and she was very comforting, she made you feel comfortable. I mean not everybody does, do they? But she would sort of walk up and down a lot and look at you and smile across at you. A lot of the time that does a lot more than medicine. If you know there is someone there to comfort you; it's not always a tablet is it? She was there all the time. She didn't disappear, she was a very nice girl, and she gave you confidence. I haven't got a name but she was a very nice girl, she was on all day and by being there she made you feel better because you would think if you have a funny turn or anything then she is going to be there straightaway."

Her observations revealed the variations in attention she received from different nurses. "The nurses were very good but they change every day don't they; you have the night shift on and then the day shift and then the night shift and then another lot so you don't get to know them. They were very nice but they did seem very busy. I know it's hard but if they could have spent a little bit of time talking to you and reassuring you because you're there. You try not to show it but you are frightened. It would be nice if somebody could spare the time, could sort of sit there and reassure you about what had gone on, and that would calm you down a bit." Patricia talked about the times she had worked as a volunteer at her local hospital reading to people and doing their nails "really they just wanted to talk to you and have somebody with them."

Patricia sensed the nurses valued the personal approach less important than other aspects; "I thought the heart attack was serious and you start worrying don't you. You don't do yourself any good because you are worrying about what has happened. I know they are very busy, they are going backwards and forwards all the time. The doctor come round once but you know if they had a person or something like that they could spend the time because you want a bit of reassurance yourself. I am not a person who can tell everybody about it. It frightened me." These evaluative statements emphasised her vulnerability. Throughout her journey, the importance of her psychological and comfort needs remained vivid.

Patricia viewed the nurses as being monotone and de-humanised in their approach “they all seemed like they were used to it all but my mother and father did not die of a heart attack and nor did my husband nor did my brothers and sisters. I thought what have I done to deserve this? When you are in pain and you are frightened you are not in the mood to sort of have a conversation with them. They are busy and they are not inclined to sit and talk to you. The attitude is they haven’t got to nurse you. I mean they take your blood pressure all the time and they come round giving your pills. The things which did worry me, if you’re going to be an emergency and they have not got time to sit and talk to you and to reassure you and tell you what it is all about. That would probably frighten you more. Better sometimes what you don’t know as far as I am concerned. I mean they haven’t got time to sit and hold your hand and talk to you. I understand that, but I think it wouldn’t have hurt for a little bit more information. I should be able to go to my doctors and get that shouldn’t I?”

Helen was also disappointed by the nurses’ responses towards her. During the PPCI; “I was laying, I absolutely hate lying flat which I think I kept telling them. I was whinging about it but I know I had to at that point. Then, I had to be monitored every half hour for the first two hours. I had got this blood pressure thing on and it is automatic but they didn’t think to take it off. So the first night I was woken every half hour assuming I had managed to go to sleep. I was in the high dependency bit. The chap next to me, his would go first and that would wake me up and then mine would go and you just lay there and you think every half hour this thing will go off. When they came in the next morning they said why have you still got that on? But I don’t know, perhaps they had changed their mind perhaps somebody thought I should have it on. So you don’t complain you just think oh well, silly things like that.”

Helen felt disappointed by how she felt, it was different from how she had been told by the nurses she would feel. She felt down when she thought she would be happy “I suppose I was a bit disappointed because I had thought from what they had said I would have just recovered and off we go sort of thing. That first day, I thought all I need is this gloomy, gloomy outlook. This isn’t what I had hoped for at all. I am a relatively optimistic person and as I started to feel a bit better well I thought come on don’t be so stupid, you are still here sort of thing”.

Helens criticisms continued as she described how essential needs were not met. "That was another thing they said I was not to get out of my bed. In fact they wouldn't let me to even onto a commode that first day and that is a horrendous experience because the stupid cardboard bedpan things are absolutely useless. You cannot as a woman who has had a hysterectomy, lie flat on her back, trying to go to the loo on this thing. I thought, I shall give myself another heart attack. The effort of wanting to go and trying to go and twice the bed got wet and had to be changed and I thought this is such a stupid arrangement. So the next day, on the Tuesday, I was in the ward with a loo just here, could I go? I am still hooked up to the monitors. "No, you are only bed to chair," I was told.

"When the doctor came round, I said to them, "Could I please get out of my bed and go to this loo." He said, "That's alright, why have you not?" But you see the nursing staff unless they have been specifically told that it is okay they won't do it, they will stick to what it says from bed to chair. You can understand it but that again was a silly thing and as I say in my book twice they had to change that bed. You get very nice young nurse come a long and wipe you down and change your sheets, tip you up and whatever. You lose all your dignity it is like having your children all over again. I thought you've made yourself all this work because I could have easily have been sat on a commode and all would have gone well but there you go. It wasn't for long. When I could go to the toilet it was, "Hallelujah!" It means such a thing and of course then every time you get up you have to unhook yourself and the monitor goes off and at the nurse's station, the thing rings. I was exceedingly wicked. I noticed they came in and pressed the silent button. So every time I got up, I pressed the silent button because there was nothing wrong. It was just going to the loo and when I came back I just hooked myself up and got back into bed."

"That's the other thing you end up in there as an emergency with nothing. They strip you off. Put all your clothes in a bag. They have to strip you completely, they took everything off. So then you have got absolutely nothing there what so ever. They produce this little toothbrush, toothpaste, comb, bar of soap and they provide a towel and pack of face cloths. So that was nice because you do want to comb your hair as soon as you can sit up and the rest of it so I thought that was a nice touch." Helen described what she was made to wear, "A gown, one of those things with a split down the back. The ladies who had gone in for elective surgery in our ward, who had a pacemaker fitted, had been given disposable pants and when one of them went on the Tuesday she had a pair still left. She gave them to me. So you can at least feel that if you flap at the back you have at least a little protection on your rear. I mean to

start with you don't care but as soon as you feel a bit better. There was a lady there who had been in for some time and she just managed to get someone to come and help her have a shower and she had come out with wet hair. I had offered to give her. They had got a hairdryer there. So I was giving her a blow dry because I know what it feels like. You just want to have your hair washed don't you?"

Helen viewed her experiences with a critical eye. "I was still hooked up to the screen at the thing and some of those go a bit dodgy. Every now and then somebody's has a funny spell and bells start ringing. You know technology is a wonderful thing isn't it? The danger is that they cry wolf so you don't pay much attention when you actually get a red light flashing that should be flashing. It's like the dayroom, it isn't really a dayroom, it's where they park people who are waiting to go out and waiting for someone to come and pick them up because they have no television or radio in there. It is quite a small room and it's got lots of upright chairs. But when people are discharged there is often quite a long wait. People arrive to take them home and they are told they can't go either because they haven't got the paperwork or usually because the dispensary hasn't done their drugs. So when the doctor said to me I could go I thought, "Well I won't summon Peter straightaway. I'll let him come at the normal time because the chances are the drugs won't be ready." I had seen other people I had said goodbye to at about 11 o'clock in the morning and 2.15 they are still sitting in the day room having not had their lunch because they thought they were going. I had been forewarned, so I thought I will eat my lunch. In fact the dispenser came up at lunch time. So when Peter did come we were ready. The thing is not to assume when they say you can go home, that you can go home then. They are ever so good on the essential stuff but slightly not quite so good on what they would call the non-essential."

Both women talked about previous illness experiences before the heart attack. Helen had "been in hospital for a foot operation and hysterectomy." Whereas Patricia talked about the comparisons between a surgical procedure and the heart attack; "After my gall bladder I was signed off work for 3 months on full pay because I couldn't work and then you have a heart attack and you come out of hospital within 3 days, that's what seems amazing to me. I didn't think a gall bladder was nothing but he said, "Well it's serious, but how serious is a heart attack if you can have 3 months off work with a gall bladder but maybe that's progress may be you can have your gall bladder out and be back at work the next day nowadays. I have a big scar here, well it was quite a serious operation, I can tell you. But if someone were to say which do you think is the worse, gall bladder or heart, you would say heart."

These two female participants fought to control their experiences in order to maintain and enhance their dignity. There was a sense of 'worrying' because they wanted to feel more secure and most importantly increase their comfort needs. They wanted to get away from the uncertainty and anxiety to become 'themselves' again. Whilst the technological abilities of the nurses were recognised, deficiencies in caring skills were noted. The nurses' actions provided constant reminders of their ill status; not being allowed to sleep because of the blood pressure cuff; not being allowed to use the toilet; not talking to them.

Patricia and Helen longed to be seen as a person (protesting) rather than as an ill person. Both women felt 'rescued' but the nurse's decision-making had caused dissatisfaction. Both felt they had experienced more discomfort than expected. For Helen, decisive action (protesting) was taken by asking doctors to bypass nurses' decisions whereas Patricia 'worried' and lacked confidence in the nurses. Both women believed opportunities to relieve their suffering had been disappointing.

4.6 Summary

The narratives from the patients reflected that although they had all started their journey with the same illness event, the actual travelling experience changed depending upon their evaluations of the subsequent events. Four types of travellers presented in the data. Patients either chose to separate themselves from the situation and let others take control (long distance traveller). Others were frustrated travellers because of other people or their own actions. Some did not want to be ill or dependent on others (reluctant travellers). Finally, the disappointed traveller felt let down by others because expected needs were not met putting them at risk. The next chapter will focus on the presentation of the data collected from the carers.

Chapter 5

Destination unknown

The presentation, analysis and interpretation of the carers' experiences

5.1 Introduction

In this chapter the experiences of the carers are presented in the same format as in the previous chapter. The same analytical process (3.14) was undertaken with the patients' data and is presented. The analysis yielded five types of passengers. In total, eight carers were recruited and were interviewed within 14 days of the patients discharge from hospital. The carer was a person closely associated to the patient treated with a PPCI and had visited the patient in the hospital setting. Six wives, one husband and one daughter represented the carers (Table II). The analysis and interpretation of the data are presented in the following manner: the emotions and behavioural responses identified within carers' narratives; the beginnings of the carers' journeys; the reasons for the types of passengers; and the narratives as related by the participants. The chapter concludes with a discussion looking across the patients and carers' narratives to discuss the similarities and differences of the emotional and behavioural responses surrounding their experiences.

5.2 The carers' journeys

The carers recounted various stories surrounding their experience from the moment the patient became ill, arrival to the hospital, waiting in the day room and visiting the patient. Different emotional responses and behaviours were reflected in the carers' accounts (Table V). The start of the experience began with the carers immediately worrying for the patient and feeling little choice but to accept what was happening (feeling helpless). As they made their way to the hospital there was uncertainty about where they were going and what they would find (searching). There was a period of 'waiting' to be endured which included waiting for the patient to have the PPCI and waiting to see the patient. Various strategies were put in place to manage the 'self' during their experiences. It was a case of having to look after the self (feeling brave). In some circumstances, carers had to rely on others (feeling helpless) or endure or experience a degree of discomfort (worrying or protesting). Similar to the patients, they all reached a point (feeling rescued) in which the outcome was better than expected.

Table V Descriptors for carers' responses

Response	Descriptor	Excerpts from narrative
Feeling helpless	The situation felt beyond the capability of the carer. They felt stunned; swept along by the events; resistance was futile. They had to rely on others.	I was beside myself; I was in shock, like I was watching a film, something happening to someone else, not to us. I didn't know what to expect. (Michelle)
Searching	The carer followed the trail of the patient. At times it was difficult to navigate the terrain; to fathom the direction amidst the chaos; to know where they were going or what they would find.	It was like the scariness of not being able to find her at first but as I walked in, the severity of it started hitting me. (Donna)
Worrying	The carer realised the seriousness of the situation for the patient but also for the self. They battled internally with the turmoil of fear, uncertainty and susceptibility.	That next half an hour was very worrying, you don't know what is going on but you understand they have got to get on with the job. (Carol)
Dissatisfied	The carer felt a dislike towards certain situations. They felt frustrated, disappointed and excluded.	It's that sort of time when you really do with, just a little bit more. I saw no one at all. (Peter)
Feeling brave	The carer found themselves managing circumstances initially perceived to be beyond their abilities. Slowly they discovered they could fend for themselves.	I must admit I have settled down a bit, I have surprised myself I think really that I am sort of well not coping, but getting on with it, I have done more than I thought. (Joyce)
Feeling rescued	The carer felt saved from a situation that could lead to harm. They felt relieved and positive; they had gained something wanted but not expected.	The best bit was seeing how well he looked really. I wasn't expecting him to look, I thought he would be. He was sitting up in bed looking as though he was on holiday. (Maggie)

5.3 Beginnings of the journey

As with the patients, the carer participants are now introduced using the orientation clause (OR) of the structural analysis to understand the; who, what, where and when that the participants indicated as necessary to understand the narrated events. This allows the reader to understand the carer's interpretation at the beginnings of their journey from their perspective.

Susan

"When I went with Jack I didn't realise they were actually going to transfer him. I had the car at our hospital so I came back. They had said he would have an angiogram and probably have a stent put in but there was no need to hurry because he would be a good hour having the procedure done. So I came home and arranged for my daughter to come and we went up in her car."

Teresa

"I suppose when it happened, I think deep down, I think I knew that it was something fairly serious that was going on. You sort of switch into automatic really and you are just sort of concentrating. I have got to keep calm and sort this out and be calm for him. So I just went in to that I think. It seemed to be an age I was standing outside the ambulance and I was thinking what on earth is going on, I could hear sort of movement and it was sort of rocking about a bit and I thought ooh what's going on? If we had gone up with the trip I don't think he would have been here now; I think that would have been it."

Carol

"When James came in and said he was not feeling very well I got him onto the bed and I thought, "Ooh he's missed his high blood pressure tablets again," because that happened once before. When he said about the pains across his chest felt like a band, I immediately thought, "Heart attack," (becomes upset). I dialled the ambulance and they were brilliant."

Michelle

“I could not get hold of Stephen at his work so I decided to telephone his secretary but then she called me and said I am really sorry to tell you because nobody expected it to happen to him”. A taxi was organised to collect Michelle “because I really couldn’t have even thought of driving there. You know I was worrying. I was going through the house and getting ready and breathing really heavy; I had no idea why, I thought it might help.”

Joyce

“George didn’t want to phone the doctors but I did and that was sort of how it all sort of started. It was bloody frightening to be truthful”. Her two daughters came straightaway. Her youngest daughter went with George in the ambulance and her eldest took her to the hospital.

Maggie

“It was quite a shock at the beginning because I was cooking Sunday dinner. The worst bit was it happened to my parents and my father died on the golf course and mum was cooking his dinner so it sort of brought that back a bit, it’s fourteen years ago now. Although they had said he was alright; in my heart I thought he’s okay but still in the back of my mind was that other feeling. When I saw the car come in and I realised someone else was driving it. It was horrid. I went to the front door and I said what’s happened.”

Donna

“Mum’s work told me they had called an ambulance and said someone would go with Mum in the ambulance to the hospital so I went straight to the local hospital”. It was not until Donna got to the hospital she realised she was in the wrong hospital.

Peter

“It was a complete bolt out of the blue. I had no idea that Helen needed any treatment but clearly if she had a heart attack then treatment had to be given”.

5.4 Types of passengers

The results for the carers are presented on the basis of the emotional and behavioural responses which emerged from the interpretation of the carers' accounts. The descriptions of these responses were used to shape and form types of passenger experiences. I called them 'passengers' because they were swept along, caught up in the experience. In being a person closely associated to the person they were the travelling companion; cast into situations where they had no control. The five types of passengers were:

- The '**lost then found**' passenger was a person trying to locate the patient's whereabouts. They often did not know where they were going or what they would find or where they would end up. Even when they felt lost (anxious, fearful and vulnerable) they still carried on searching for the patient. Eventually they found the patient.
- The '**helpless**' passenger was a person that found it difficult to grasp what was happening to the patient and to their self. They felt caught up in the chaos unable to help themselves. They were forced to rely heavily on the presence of others to manage the situation.
- The '**disappointed**' passenger was a person that believed they were let down by the actions of others. This person felt personal needs were not taken into account.
- The '**worried**' passenger was a person that knew this was serious and feared the worst; the patient may die. They tried to keep calm, trying not to worry but instead all sorts of thoughts came into their heads. They wanted and needed to talk to others; to be reassured.
- The '**accepting**' passenger was a person that was content to let others take control. As far as they were concerned the patient was in the right place. They were satisfied with what was happening. In knowing this, they could separate the self from situation to manage and protect the self.

The experiences begin with accounts from Susan and Donna to reflect how a certain amount of 'searching' had to be undertaken to find the right route for reaching the destination (feeling rescued).

Teresa's narrative demonstrates that 'feeling rescued' could incorporate a seemingly straightforward but then twisting route. Reflecting the journey taken by Alan, Teresa finds herself 'feeling helpless' as she was forced to be stationary at certain points not because she could not deal with it but because factors made it beyond her control. Teresa did not like this but she had to cope with it. When Alan became ill again, her 'feeling helpless' was exacerbated. Only when Alan became well again did she finally return to 'being rescued'.

In the case of Peter, disagreement between the manner in which the nurses handled his journey and destination led to 'disappointment'. There was nothing he could do about this apart from finding ways to fend for himself (feeling brave).

The experiences of Carol and Michelle are then explored. Each 'worried' about the patient and their self but gradually as they 'felt brave' they were able to find ways to cope with their unexpected journeys (being rescued). Finally the account of Maggie and Joyce are presented. Their experiences show how an acceptance that being in the right place and receiving the right treatment meant the destination (feeling rescued) could be reached smoothly (feeling brave). As noted in Table VI all carer participants eventually felt rescued.

Table VI Types of passengers and responses

The lost then found passenger	Before PPCI	During and after PPCI
Susan	Searching	Feeling brave → Feeling rescued
Donna	Searching	Feeling brave → Feeling rescued
The helpless passenger	Before PPCI	During and after PPCI
Teresa	Feeling helpless → Worrying	Feeling brave → Feeling rescued → Worrying → Feeling helpless → Dissatisfied → Feeling brave → Feeling rescued
The disappointed passenger	Before PPCI	During and after PPCI
Peter	Feeling brave	Dissatisfied → Feeling helpless → Feeling brave → Dissatisfied → Feeling brave → Feeling rescued

The worried passenger	Before PPCI	During and after PPCI
Carol	Searching → Worrying	Feeling helpless → Worrying → Feeling Rescued → Feeling brave & worrying
Michelle	Feeling helpless → Searching	Worrying → Searching → Feeling brave → Worrying → Feeling rescued
The accepting passenger	Before PPCI	During and after PPCI
Maggie	Feeling brave	Feeling brave → Feeling rescued
Joyce	Feeling rescued	Feeling rescued → Feeling brave

5.4.1 The 'lost then found' passenger

- A person trying to locate the patient's whereabouts. They often did not know where they were going or what they would find or where they would end up. Even when they felt lost and vulnerable they still carried on searching for the patient.

When Susan arrived with her daughter, Jack was already at the hospital receiving his PPCI. By the time she arrived it was about midnight: "the only problem is when we got there we couldn't find where to get in". We were standing outside trying all the doors wondering where to go when my daughter in America rang and said, "What's happening?" Well, "We can't get in." She gave me the telephone number from the internet and I rang and got put through to the reception. I said he had been admitted but I don't know where he is, do you know how I get in? She told me where to go. I think they should have a notice on their main entrance as to either the telephone number or where to go to find a doorbell. You know you are anxious and you can't find out how to get in. I found that was very frustrating. I did not have the stress of driving up there in the dark but we didn't know where the car parks were. You are looking for the building. You are not looking for car parks. The next day we said, "Oh there's a car park there! We did not see that last night."

Even when Susan and her daughter found their way to the ward they were still no closer to seeing Jack. "We were put into a waiting room until he came back from the lab and they said that they would settle him in the high dependency unit and then they would call us. When Jack returned the nurses told us once they had got him all wired up we could go in and see him." The 'lost' feeling crept back when Jack was back at home "everything seems to have been tackled and dealt with apart from his diet and his chocolate eating. I was surprised they didn't give him one of those charts about the 'should not's and should eats' but they didn't. He got all the other little booklets but they didn't give him one of those. I was quite surprised about that."

Donna experienced a different journey. Right from the start her complicating actions and evaluations represent how she felt lost and separated; unable to locate her mum. She struggled to deal with what had happened. "At first it didn't sort of kick in. Then it was just the shock really because I didn't know where she was. I went straight to the (local) hospital but when I got there she had gone. I was running around the hospital for an hour trying to find her. So I think it was that initial scariness of not being able to find her at first. Obviously the severity of it started hitting me as we were on our way. I was like thinking, "Why all this way?" It seems such a long way, a long journey, when you do not know what is happening. But as soon as I walked in to that hospital I was so glad they had brought her there. It was the right place to be especially being her heart as well. I just followed the signs around. We went right the way around and then I just went in and found somebody and said, "Can you tell me where so and so ward is."

"When I went in she had only just come back from the procedure so they put me into like the waiting room and I just sort of sat there for about fifteen minutes. I was dreading it. My aunt said on the way down she didn't want me going on my own. I just kept saying, "I will be alright" and so then something sorted of started clicking, hang on a minute you know she is not going to look good when I walk in. But when I walked in, she lay there and said she'd had it. It was really scary hearing those words 'high dependency' but when I got there it was a totally different feel and to walk out of there. I felt quite happy to go home and leave her, to sort of know she was safe and she was going to be okay there. They explained everything that they were doing, any questions you asked, they would answer. You could see they were constantly there monitoring. Even if they didn't touch her every ten minutes they kept looking at the screen. So you knew she was well monitored and that was reassuring. If you phoned they would actually take the phone to mum."

Donna had heard of a PPCI but even after the doctor had explained what they had done to her mum she “didn’t really understand, I couldn’t really take it in. Like every time I rang up. It was the honesty, I would ring every morning and every night and when I rang they would tell me exactly what was happening, what they was doing. Like when they put her into isolation. The nurse actually rang to tell me she was going into isolation and why and when the results would be back. There was a personal feel that they were actually interested and really cared.”

Susan and Donnas’ narratives both reflect the emotional triggers that happen when a close member of the family is threatened by an unexpected frightening illness. Both women described how being lost and feeling lost meant a sense of reduced personal comfort and control. Physically and psychologically they had to make that journey even though the whereabouts of the patient and the outcome from the illness were both unknown (searching). There was a need to be near and close even though it was very stressful. Both Susan and Donna were stunned, dazed, uncertain fearful and worried; reflecting the initial stages of an emotional rollercoaster. They felt they had no control over the situation; feeling powerless. The risk of death and losing their husband or mum seemed a strong possibility. Then almost as soon as it has happened the patient was well. There was a strong sense of feeling more positive and hopeful (feeling brave), the worst had happened, life could return to normal (being rescued). The danger had passed. They had all survived. Being able to survive had also been strongly influenced by the presence of the nursing staff. Susan and Donna felt safe; they were in the right place with the experts. Afterwards the normal ward routine of visiting made the situation feel surreal. In particular for Donna there was a mismatch between what she had expected and the reality. Both Donna and her mum were able to do normal things. Donna felt accepted by the nurses; she felt the nurses liked her because they let her visit at different times. Whilst Donna felt her needs were met, Susan was more sceptical. These feelings were suppressed when she saw how well Jack looked but returned again when she felt less satisfied about the information given by the nurses when they had returned home.

5.4.2 The 'helpless' passenger

- A person that found it difficult to grasp what was happening to the patient and their self. They felt caught up in the chaos unable to help themselves. They were forced to rely heavily on the presence of others to manage the situation.

Similar to Alan, Teresa's journey was difficult. They both arrived together in the ambulance but "when we got to the hospital, there was a doctor and an anaesthetist waiting, Alan went with them and the nurse took me off up onto the ward. They said Alan had been taken straight in and they were going to do an angiogram. I had to wait in the day room and they would come and tell me a bit later what was going on." In the day room, Teresa recalls two other couples in there; two sisters and their husbands, their mum had been brought in that morning with a similar sort of thing. "They were lovely, they were very supportive. They had brought a big bag of food with them and drinks have some of this they said so that was very nice and it sort of took my mind off it. Then the nurse came back and told me, "They are still sorting your husband out in theatre but it shouldn't be too long now before they bring him back, so I will get you then." It seemed to go on for ages. I kept looking up you know. The other people were in and out of the day room, taking it in turns to sit with one another and then wandering back. They asked, "Have you not heard anything?" But I had not. They said they didn't think it would be too long. In the end I went to the desk and said, "Could you just tell me; fill me in on what's happening?" She was told, "He is back but they are settling him down and getting him all sorted." Finally, Teresa was able to see Alan.

Despite the long wait she found herself thinking "I won't stay too long. I think its best if he just rests," my daughter was going to be coming the next day but she was actually on her way. So I waited for her to pick me up from the hospital and we did just pop in. Then that was it. It was sorting me out really that was bit of a problem. I had to get a bed and breakfast." Teresa decided to stay in a nearby village. "It was just down the road, just past that fantastic police station. She was brilliant you just went into her home. I said "well I can get the bus in but because I had worked out the buses." I would have had to come back early but no she wouldn't let me do that, she would take me and pick me up. "You can go back in the evening if you want to, I will take you back at night. So I just used to stay until six on the Monday and Tuesday night" and then went back and had a meal with her. She made it much better, because if I had been in a hotel, they are a bit well cold and soul less, where she was just lovely. So there was something going on a bit, you didn't feel quite so isolated."

From then onwards everything seemed to go really well, better than expected. "He was fine on the Wednesday and did the stairs when we were there. It was absolutely fine. Then when my daughter phoned on the Thursday morning just to see if Dad was okay because they would take the phone to him, he wasn't there, he was in HDU. I thought he can't be in the HDU. The nurse gave him the phone and he had got this CPAP thing on and my daughter said, "I don't think it was even Dad, it wasn't Dad, I think they have got another Alan," and so we were thinking, "Well if he's there, what's he doing there?" So we thought we will just go to the hospital and the really nice nurse took us in to an office and explained everything that had happened. So that was the only down bit that, I felt very down and I was thinking, "Oh dear, this is something else happening." When she explained it to us, she said this had all happened in the early hours, well about four or five o'clock". Teresa could not understand why the nurses had not called her. The nurse explained it was Alan that had told them not to phone and they felt they couldn't go against that. "So we had a little chunter to Alan and said if there is anything you must let them let us know. My only concern was like with him telling them what they had to. He had got to do what they said. If you have got to have it, you have got to have it. That was quite unlike him. He does get a bit stroppy sometimes but normally under those circumstances he would do exactly what they told him so it must have been pretty horrific."

Teresa expressed a sense of gratitude. The journey had not been simple but overall "it all went just really very smoothly, it was a shock. The only thing was I was very tired when I got home I felt exhausted. I think when you get home you are a bit worried your confidence goes a little bit. I came home for the one night without Alan. I thought I wouldn't sleep but I slept like a log. One morning Alan phoned and I thought something had gone wrong and I woke up with a jump. I thought, "Oh my God what's happened?" I raced down and you had phoned for something." The story then returns to the present and ends as Teresa recalled worrying she "would not be able to sleep on his first night home instead having to lay awake listening for every sound."

In the early stages Teresa accepted there was very little she could do. The situation was beyond her control. She had to let others take charge. At times she felt frozen by the fear of what was happening and what could happen. She felt unprepared for these events (feeling helpless). Even activities that she normally could have managed seemed difficult. It was a relief to have other people around her. It was a way of keeping herself distracted. It was also a way to cope with what was happening to and around her.

Teresa wanted to know but did not want to know what was happening. It did not feel real, yet it was happening (searching). Finally she felt brave enough to find out. It was better than anticipated. There was no need to remain fearful. Alan was well, all was well. Then she had to think about herself, she needed to look after herself (feeling brave). Staying in a local B&B meant she remained close to Alan but it also reduced her personal control. She was no longer an independent person instead a passive dependent (feeling helpless); under the jurisdiction of others, the day was scheduled to fit in certain activities.

Teresa was able to balance her negative emotions with sufficient positive ones once Alan became better. He was travelling in the right direction. But then Alan became ill again. Becoming ill again was unexpected after he had recovered so well following the PPCI. There was no longer a sense that the heart attack had been mastered (feeling helpless and worrying. Preparation for an uncertain future had arisen again. Teresa confronted the situation with two different responses. She was emotionally upset with the nurses and Alan; venting feelings of anger and despair (dissatisfied) because she was not contacted about the situation at the time.

There was a resigned acceptance in that decisions had been taken by others to protect her from a stressful situation. In coming to terms with the inevitable there was a realisation that the whole situation had been horrible for Alan and her. The second response was to confront the problem and make it manageable and less stressful for her (feeling brave). Teresa did this by telling Alan off for his behaviour and seeking information from the nurses. The reward was that Alan became better again (feeling rescued). However the fear of that threat remained with Teresa (worrying).

5.4.3 The 'disappointed' passenger

- A person that believed they were let down by the actions of others. This person felt personal needs were not taken into account.

Peter travelled in the ambulance with Helen but when Helen was "taken into the theatre for the angiogram, he was taken up to the dayroom. That was the one point which I would say a better mark was needed for the hospital. I was taken in to this dayroom which was a bit bleak and there was virtually very little reading material. Apart from some journal which was an in-house magazine and one or two novels. It is not very sensible to start a novel in those circumstances and the chat magazines are not quite my thing. I was put on my own in there. There was a jug for water, but it

was empty. There were some beakers. When I had been there for just over an hour I started getting hungry. First of all I said to the nurse, "Is there any chance of some water?" "Yes, fine," and she went off and got it. "Is there anywhere I can just get anything to eat?" I said, "I am getting a bit wobbly and hungry." I was told there was a vending machine in the ward opposite so I had to go and find that. The dayroom on the other ward was larger and that was where the vending machine was; full of healthy snacks like crisps and chocolate bars."

"They were looking after Helen brilliantly and of course that's the highest priority, it has got to be but I think perhaps they could have somewhere just a little a bit more available. You know if you need something to eat there and so on. That would have been helpful when you are left on your own in this situation you imagine all sorts of dire things happening. It's that sort of time when you really can do with just a little bit more. I saw no one at all until somebody came in and said Helen was back in the ward and I could go through. By which time I had just been able to find the vending machine and so I went in with half a Twix bar in my mouth and a beaker of water. Obviously I was of secondary importance, I am bound to be, but just that little bit of extra, is it creature comfort or whatever you like to think about, a consideration would have come in useful and in other respects they were fantastic. They were all very nice, pleasant and the way they spoke to you, involving you but if I have been told for starters if you need something to eat it's over there. If the water had actually been there rather than just an empty jug and you know if you want anything, we are over there sort of thing. They are busy people and I accept that but it's just that. There were other times when I came into see Helen, the dayroom was full of people; consequently I was just sort of tucked in a corner over there."

When Peter saw Helen she looked well but he realised she was not quite the same "well she was a bit woozy, she was able to speak but it was clear she wasn't fully herself. I knew she had medication of various sorts and that didn't surprise me. You took it as that's the way it is. I stayed with her for some while. I'd arranged to meet with my daughter at 8 o'clock at the entrance. That was the end of visiting time anyway. They are quite good there. They did say don't be there at mealtimes or whatever. I went in on the Monday and Tuesday in the afternoon because there is quite a long session then. I arrived pretty much at the beginning of it and stayed through. Then by the time I went on the Monday all of the sedatives and the medicines had got out of Helen's system. She was actually able to converse in a very normal fashion, well for her anyway. I came in with my notebook and pen and everyone was very impressed. You could see I had been well trained for the last 45 years."

As Peter told his story he appeared composed and unshaken by the onset of Helen's heart attack. However, his narrative reflected disappointment. The inability of the physical environment to meet his comfort needs was a dominant feature in his narration. Finding ways to distract his self may have been a way of dealing with what was happening to Helen. He knew his wife was being looked after but he felt disappointed with the nurses.

He needed to be there because being there when it mattered was important (feeling brave). There was very little he could do but being allowed to stay meant he could be of some help to Helen. It was only towards the end of the narrative that Peter begins to feel he has been 'rescued'. His wife was becoming well, she was able to talk with him but she still was not normal (worrying). Bringing in his 'notebook' allowed him to have some involvement. He had a role to play (feeling brave). Slowly he could regain some sort of control.

5.4.4 The 'worried' passenger

- A person that knew this was serious and feared the worst; the patient may die. They tried to keep calm, trying not to worry but instead all sorts of thoughts came into their heads. They wanted and needed to talk to others; to be reassured.

When Carol arrived with James in the ambulance, "they whipped him into the HDU and this man who met the ambulance took me through to the waiting room and said, "A nurse will come and see you," and disappeared. Then of course that next half an hour was very worrying because you don't know what is going on but you understand they have got to get on with the job. Then my daughter arrived so she was with me the whole time. They told me he would be about half an hour down there. If they did not find anything but if they found something, they would put the stent in and it would be about an hour. So I thought they've obviously found something because it was coming up for the hour."

"I'll tell you what did surprise me, after he had it done and come back, the colour in his cheeks, he looked so well. I didn't realise how grey he looked because he has got quite a tan. I could then see how ill he had looked underneath that tan beforehand. That made me realise you know that it had been coming on for a while. That it didn't just happen did it. Then they monitored you all that day and the rest of the day and through the night. I was back again on the Tuesday when they moved you into the

bay. They gave me the mobile number for the actual HDU unit. So instead of ringing the desk I could ring straight through. I actually spoke to James while he was in there after I came home that night which was nice.”

“It was definitely quite traumatic. I think if you haven’t got any support and some people haven’t. Having my daughter there made a lot of difference. Otherwise I would have been sitting there on my own. They said to me if you are worried about anything or if you have got any questions just ask and I did. I said you know he had this scan on his heart does that show up at anywhere else? And they explained no, the rest of it was all clear which was very reassuring. Everything was explained whatever they did and they would have a little joke with you which made you feel very relaxed. They explained what he can do and gave us booklets. We are very lucky to have somewhere like that so near or in the area.”

Michelle arrived at the hospital before Stephen went in for the PPCI; she describes how it felt not being able to see him. “They said it shouldn’t be something really over complicated or serious and at the end even if it is nowadays so many things and procedures we can help people. If you sit down, we will send somebody to tell you all of that. And so it happened, somebody came and everything about the procedure was explained and immediately it was better”.

Michelle remained very worried “when Stephen went in. I really didn’t know what to expect. I was beside myself. I was in shock, really in shock, like I was watching a film. Something was happening to someone else, not to us. I didn’t know what to expect and I have a few friends who have had serious heart operations. I was ready for all sorts of stuff you know. I thought Stephen might be like that. I was waiting there and then the nurse came into the visiting room and told me not to worry. She said, “I can’t say it’s nothing because it’s really always something important when the heart is concerned.” I had noticed two old people were waiting. They were both over eighty, her husband had gone through this procedure and I thought if this man can survive, then it is good. It is not being cruel it is human, comparing Stephen to someone who is eighty.”

Michelle was too afraid to expect anything. “I decided there was no point fretting around and saying, “Oh my goodness, what will happen, this and that,” just go with the flow, whatever happens deal with it because I really couldn’t cope with myself being like that and to be honest I don’t like that sort of behaviour anyway it doesn’t help anybody really. When there are really sick people around, I can’t cope. So when I saw Stephen a huge relief came over me. I was thinking he’s had an operation but

he was so well. It was easy to think nothing had happened. You really do have to remind yourself because it is so un-intrusive. He felt immediately better and you know everything looked normal really. I really couldn't believe it at the beginning and I kept asking, "Are you feeling better? Is everything alright?" I was so grateful. When I met him after the operation he told me he was feeling better than he had for a long time. You have to really remind yourself, it's not something you can just brush off. It is serious stuff and you have to really look after everything that needs to be looked after; to help yourself. The procedure is so un-intrusive and so friendly that the patient feels really immediately relieved. I was amazed definitely, absolutely."

These two women were described as 'worried' passengers; from the beginning they realised the seriousness of the situation for their husbands but also the impact for the self. They each battled internally with the turmoil of fear, uncertainty and susceptibility and risk of the heart attack (searching and worrying). They could not think or were unable to cope with the possibility of a bad outcome. In the early stages, Carol felt 'helpless'; she had no choice but to accept what had happened; it was beyond her capability. All she could was rely on others who could manage the situation and help her out of this horrid experience. There was no telling what they would find but they would know how to deal with it and tell her afterwards; she did not have to make any decisions, she was happy for others to be in charge and to do what was necessary. It was not until afterwards Carol realised it could have been a lot worse. On reflection she could see how ill her husband had been and now how well he looked in comparison (feeling rescued). She could not comprehend how she had not seen this before. How had they missed the development of something so significant? How had she not seen it coming? She knew her husband and what he looked like normally. Her unknowing caused a sense of personal discomfort. Carol did not want to be alone. She needed comfort for herself. She gained this from the support and involvement of her daughters (feeling brave). Being able to speak to James by telephone allowed her to participate and be part of this ordeal and be closer to James. It provided Carol with a sense of personal comfort. But the 'worry' was always there; always present.

In contrast, Michelle was more expressive and visual about her emotional state. Firstly, she simply had not realised Stephen was susceptible to a heart attack. Being ill was something she expected to happen to older people but not her husband. She felt 'helpless'. Michelle was constantly 'searching' for hope and reassurance from others, particularly those who had already been through the experience. Michelle instantly realised the seriousness and prominent risk of death. In her mind if it was possible for an 80 year old person to survive then there was definite hope for Stephen

(searching). It was evident that Michelle felt uncomfortable in the presence of illness. She did not like being around sick people. It reminded her of her own fragility and vulnerability. She was also at risk (worrying). She was forced to accept what was happening. Her individual efficacy and personal control was reduced. She did not like having to rely on others, she felt vulnerable and powerless to alter the direction this journey was taking them (searching). It was only when Stephen looked so well that she knew they had taken care of her and Stephen. They had steered her to a better outcome than she had initially anticipated. In realising her husband had survived and was well and no longer ill Michelle felt she could regain some control and comfort (feeling brave). Michelle could cope and be 'rescued'.

5.4.5 The 'accepting' passenger

- A person that was content to let others take control. As far as they were concerned the patient was in the right place. They were satisfied with what was happening. In knowing this, they could separate the self from situation to manage and protect the self.

Following the initial shock of Andrew's car returning without him driving it, Maggie found everything else ran smoothly. "I was quite impressed with the hospital, it was nice. I thought he would be lying down, I thought there would be lots of machines and things. There was a machine but it was not as bad as I thought. It was a lot better than I thought. I think the best bit was seeing how well he looked really. I was surprised, I wasn't expecting him to look I thought he would be, you know I watch Casualty and they are all sort of flat out with their wires all over the place. He was sitting up in bed looking as though he was on holiday, everything was fine."

"I phoned up on the Monday morning and they said, "Oh he's fine he has been moved to the ward." So I thought I don't need to go this morning. I will go this afternoon and we picked the other son up and my daughter-in-law came and we all went. I thought he is fine. I think it gave me a bit of comfort that he had that because one of my friends' husbands had it and my brother-in-law. I know how well they were afterwards and I felt sort of confident in it. That really helped knowing that someone I knew had gone through it. Since then he has been alright, a bit tired but nothing."

Joyce knew George was in the right place. "You couldn't have wished for anything better for the treatment. The doctors were nice, the nurses were nice; everyone was nice in there. There is no good dressing it up. I think you know whether people are not telling you the truth. It is a shock but it is easier to accept. I have not had

nightmares but you do sort of wake up in the night, especially when he was still in hospital. I have an over active mind anyway and I whittle about anything. You sort of try to visualise the valves in the heart and silly things like that. It all goes through your mind all the while.”

“I must admit I have settled down a bit, I have surprised myself. I think I am sort of not coping, but getting on with it. I have done more than I thought but it didn’t sort of bother me to be on my own. It didn’t bother me that much somehow, I don’t know, normally it would have, I would have panicked because I am on my own but with the very good neighbours we have around here, they were all very helpful. So I had got plenty of back up. I knew he was in the best place and they knew what they were doing. You just accept that has got to be done and let them get on with it. I don’t think I was really worried as such about what was going on because I knew as I say he was in the right place and they were going to do what needed to be done. I did think when they said about him coming home, “Oh I wish they would keep him in and do it because he is there and if anything happens, he is there and they can sort it out.” But then I thought, “Oh well while the girls are away if he is still in hospital, if he is home I have not got to bother anyone to take me.” I do drive but I would not attempt that on my own that amount of distance.”

The entire experience had been better once Maggie reached the hospital. Andrew had looked well; not sick as she had expected (feeling brave). She was somewhat muddled by the HDU setting thinking it was less serious than anticipated for someone who had just experienced a heart attack. Her situation was in complete contrast to that of her mother. This was completely different. The crisis was over; the threat had been managed, there was nothing to fear anymore (feeling brave). Andrews’ pain had gone and the hospital had given him the correct medical treatment. Her evaluation clauses suggest she felt safe and secure. Emotions that had been unbalanced had reached equilibrium (feeling brave). Appraisal was further stabilised by the experiences of friends and family. Maggie felt safer and secure; she felt reassured and pleased (feeling rescued).

For Joyce, in knowing and enabling others to help her, Joyce felt she had been ‘rescued’. An alternative route had been located to face the threat and find ways to cope. Joyce discovered an inner strength she had not previously known. She relied on others for support as required (feeling brave). Her narrations provide a peek to the vulnerability of how carers strive to manage the ordeal for themselves. Joyce’s narrative depicts the need to ensure the carer also feels cared for and looked after.

5.5 Understanding the journeys of patients and carers

The aim of this study was to engage in a narrative inquiry approach to explore the experiences of 10 patients receiving PPCI as treatment for an AMI in a heart attack centre and the 8 carers closely associated to the patient. Structural analysis revealed the emotional states and types of behavioural responses of the patients and carers as they coped with their experiences. The participant's voices open up new ways of understanding the world of the hospitalised patient and carer. These voices depict the reasons for their emotions and behaviours as they experienced a sudden change in illness and wellness, the hospital environment, procedures which affected physical and psychological well-being and relationships with other people. Despite the differences in their experiences, all patients and carers at some point in their journey felt they had either been 'rescued' or 'felt rescued'; finding themselves in the right place, feeling safe and trusting others. However, each participant had also experienced a sense of vulnerability which in some way was related to loss of control, a perceived risk of harm and reduced comfort.

5.6 Encountering illness

At the onset of the heart attack, patients and carers responded to the types of bodily changes experienced. In all but one case there was a realisation that something serious had happened. They were having a heart attack or someone close to them was having a heart attack. In Stephen's case the failure to recognise the symptoms may have been a protective strategy against a threat to his safety as he tried to carry on with his usual activities. For all, the outcome of the journey was unknown. They had to allow others who could manage the situation to take charge.

At the height of the illness experience patients had to believe what was being done for them was correct. They cared, but they were not in control and when emergency health professionals arrived, they were content to be free of responsibility. They enabled others to take responsibility and make decisions for them. It was possibly a way of finding some personal space to deal with the difficult, unfamiliar and frightening aspects of the experience. It was often a non-confrontational state in which the patient or carer found themselves within a harmonious relationship with others. It was a state that meant active participation was not required. To the outward 'eye', they may have appeared passive, simply accepting what the nurses and doctors were doing to them but there was also a realisation they had no choice; the alternative was far worse, they could die. The suddenness of the illness episode redirected attention away from the emotional aspects and as a result emotions were concealed.

During the procedural aspects of the PPCI, many patients experienced some form of discomfort. Generally this discomfort was perceived to be an integral part of their treatment in that the painful and uncomfortable sensations would lead to a valued personal gain (survival). There was a strong belief that what was happening was correct because they felt safe with the doctors and nurses. Not everyone accepted the discomfort; Helen and Patricia viewed lack of comfort and being unable to move as an obstacle to their integrity. Detaching and distancing one's self from the situation was again noted at this stage of the journey. Patients described how their bodies were behaving "I was doing nothing just lying there" (Patricia). Jack recalls "I was aware something was happening inside, movement, but it didn't hurt, there was just an awareness and I remember thinking ooh as they are doing it it's got to my shoulder but I certainly didn't get any other problems at all." Alan noted how "they did something there." George turned his head and "saw my heart sorting of going like this (moves fist) and the wee wire going around like a little alien inside you know. But I felt no sensations whatsoever." Andrew described how he just laid there "I wasn't too interested in what the surgeon was doing because when he first started I was struggling, a lot of discomfort but when he actually started I could see the heart pumping away and I thought wow that's my heart and it's pumping." They had become malfunctioning parts which they believed and hoped could be repaired by others. This made the PPCI and heart attack feel more real afterwards.

The perception of their illness and wellness states seemed to influence the patient's sense of control and comfort. Experiencing a sense of comfort or no discomfort made the patients and carers feel stronger and less vulnerable; in feeling well and normal again they felt more in control of the situations they encountered. Interpreting experiences in a positive manner equated to emotions that reflected a positive nature such as feeling well, safe/secure, happy, and confident and satisfaction. However experiences interpreted in a negative manner, decreased feelings of personal control and emotional comfort. They felt unwell, dissatisfied, disappointed, as if they had no choice, restricted, not knowing, vulnerable and reluctant to trust others all leading to a belief that they had suffered unnecessary discomfort.

For the carer participants, the acute hospitalisation of a family member with a heart attack often caused distress and uncertainty. They were faced with the possible loss of their wife, husband or mother. The heart attack centre was not their local hospital and the need to receive specialist intervention meant an unfamiliar geographical journey. Whether travelling in the ambulance or following on with other family members there were varying states of uncertainty, unknowing, alertness and

anticipation of what would await them. They were facing their own crisis. On some occasions they either arrived at the heart attack centre before the patient had arrived or whilst the patient was in the catheter lab or after the patient had returned to the HDU. In all cases they had to wait in the waiting room; not knowing what was actually happening and not knowing what would happen next.

5.7 Impact of the environment

The environment was viewed as both positive and negative by the patients and carers; evaluations were related to perceived needs surrounding comfort and control. The hospital was a place where they all needed to be, for a good outcome. Patients and carers were forced to surrender to this because they had no choice. The hospital was not a dangerous place but on different points of the travelling experience it was viewed as a hindrance. Symptoms, side effects from medications and the PPCI all contributed towards levels of reduced comfort and control. Monitoring equipment initially seen as protective became intrusive and an obstacle to participating in activities such as walking and going to the toilet. They were forced to be dependent on others because they were immobile. The space around them was non-negotiable and caused feelings of frustration and annoyance. It confined them; making them into patients instead of being a person. The environment meant they had no control over their bodies.

The patients knew they had to be in hospital, so they spent their time doing what was expected of them but there was an intense desire to get out, to escape and go back to being a well person (their self). Wanting and having the company of others helped greatly and facilitated a positive atmosphere in the ward (Helen, Stephen, James, George). It allowed a connection with others, to make comparisons but also measure progress and freedom. Camaraderie amongst patients was important and appeared to boost feelings of confidence and well-being. However as Jack found these connections could also make you feel vulnerable if quizzed by another patient.

The day room was seen as a place to be 'in waiting'. It was safe but was a physical space that could also be uncomfortable and facilitate a feeling of anxiety (fear of the unknown). Teresa was left 'waiting' finally feeling bold enough to venture out and find reassurance from the nurses. Peter felt the nurses should have been able to reduce his discomfort caused by the lack of drink, food and reading materials. The environment affected his ability to function normally; it made him feel insecure and created a sense of uncertainty and danger for his own well-being. Interactions with other carers made the environment comforting or uncomfortable. The dayroom also helped to reduce factors such loneliness because support was frequently sought from

other patients' relatives who had survived their experiences. Accompanying family members also provided a sense of support for the carers

5.8 The impact of nurses' actions

The competency of the nurses was expressed in terms of nurses' caring behaviours. This was determined by the extent to which they perceived the nurse had cared for them, answered questions, allowed them to do normal activities after the PPCI and checked them. Other characteristics such as knowledge, skills, trust, relationships, interactions and presence were also attributed to competency. Nurses were positively praised for their actions. Feeling safe was important because none of these patients had experienced a heart attack and PPCI previously. Their lives were in effect 'at risk', a health crisis was being experienced and in being a recipient of care they had to be dependent on others. Trust was placed in the hands of the nurses.

Patients felt more secure when the nurses were at a close proximity particularly when they felt most ill and vulnerable. When able to relax they found an inner confidence or sometimes meaning they could have a laugh and joke with the nurses. However, when expected behaviours and actions did not occur, some patients (Stephen, Patricia, Helen, Linda, Alan) and carers (Teresa, Peter) began to distrust the nurses.

The expected direction of their travels had been halted by the actions of others. They doubted nurses' knowledge and felt 'unsafe'. Rather than alleviating their suffering, they felt they had no choice but to agree and comply with the nurses' terms. Patients felt disappointed, angry and annoyed and tried to question these rules. Some nurses were seen as focusing more on physical aspects, gravitating towards the medical needs of their bodies; concentrating on technological tasks. These characteristics enhanced the vulnerable states of patients and carers further reducing their ability to retain personal control; making them feel less secure. In accordance with illness/wellness states, patients and carers wanted the following qualities from the nurses.

- To provide reassurance during difficult times
- To provide necessary help to enhance comfort and alleviate discomfort
- To help patients reach and achieve their needs
- To notice the person behind the diagnosis
- To provide information for managing current, ongoing and new (unexpected) situations

5.9 Summary

Overall, the patients and carers were satisfied with their care and treatment through the different stages of their journey. This satisfaction led to feelings of confidence, strength and capability. It gave them the belief they had regained control and levels of comfort. For the patient this meant they were ready to go home (they had gained freedom) and for the carers this enabled them to start looking after themselves again and believe that everything could return to normal. These findings provide negative and positive views, giving a better picture of reality to understand how the caring acts and behaviours of nurses have a profound effect on the experiences of hospitalised patients. The next chapter will focus on the presentation of the data collected from the nurses with analysis and interpretation of the findings.

Chapter 6

Guiding illness to wellness

The presentation, analysis and interpretation of the nurses' experiences

6.1 Introduction

This chapter focuses on the narratives of the nurses working in one Heart Attack Centre. As with the previous two findings chapters (4 and 5), a structural analytical approach was applied. Data analysis for the nurses occurred after analysis of the patients and carers' narratives. The analysis yielded five types of routes taken by the nurses. Different to chapters 4 and 5, these experiences were not focused upon the types of nurses but were about their care experiences and particular episodes of care. These accounts contain specific nurses' experiences to demonstrate how the nurses made sense of the care they provided so to discover what it meant to them and what aspects mattered.

The first part presents details about the nurses. The analysis and interpretation of the data are then presented as: the emotions and behavioural responses identified within nurses' narratives; the reasons for the types of routes taken by the nurses; and the narratives as related by the participants. The chapter concludes with a discussion looking across the patients', carers' and nurses' narratives.

6.2 Presenting the nurses

Ten nurses were recruited and interviewed. Four nurses worked within the Cardiac Catheter labs and six nurses worked with the High Dependency Unit (HDU) and Cardiac Ward (Table VII). The cardiac services included three catheterisation laboratories, a 4-bedded high dependency unit (HDU) and a 25-bedded cardiac ward. All the participants were female which reflected staffing during the recruitment of the nurses.

The majority of the nurses had undertaken continuing professional development (mentorship modules and cardiac modules). Five had completed a BSc in Nursing. The table reflects the amount of time worked in the Heart Attack Centre.

There was a wide range of experiences reflected in the nurses in terms of years of being qualified and time spent working in the Heart Attack Centre.

Table VII Demographics of nurses

Name	Years qualified	Time in HAC	Place of work
Anne	30-40 years	6-10 years	HDU & Ward
Sarah	0-5 years	0-5 years	HDU & Ward
Emily	0-5 years	0-5 years	HDU & Ward
Rachel	6-10 years	6-10 years	HDU & Ward
Jenny	6-10 years	0-5 years	HDU & Ward
Claire	13-20 years	0-5 years	Catheter labs
Alison	30-40 years	10-15 years	Catheter labs
Jane	0-5 years	0-5 years	Catheter labs
Louise	0-5 years	0-5 years	HDU & Ward
Sally	20-30 years	10-15 years	Catheter labs

6.3 The nurses' journeys

I wanted to understand 'what' was important to and for the nurse participants as they cared for patients and carers and 'how' they managed their experiences. Using Labov's functional clauses, the meanings of different evaluations and actions within different scenes were unwrapped. The orientation depicted the background in terms of who was present and what they did. The complicating actions represent the turning points or crises (Riessman, 2008) and the evaluation clauses represent the nurses' interpretations of those situations and what it meant to them. Resolution indicated what finally happened and the coda returned the nurse back to the present. The different events and situations related to three phases: before the PPCI, during the PPCI and after the PPCI.

Structural analysis and interpretation revealed different types of emotional and behavioural responses for the nurses (Table VIII). The journeys taken were known to the nurses; they were familiar with the landscape because this is 'what they did'. They knew what events may happen during the journey, the places to 'guide' the patient and carer towards and the places that needed to be visited and how to 'respond' and 'adapt' to the terrain. The responses reflected the activities needed to get patients and carers through their experiences. Their job was to 'guide' the travellers to reach the nurses' desired destination (receiving the PPCI, being kept safe and keeping well). The nurses constantly watched patients and carers to 'protect' them from difficult situations.

Table VIII Descriptors for nurses' responses

Response	Descriptor	Nursing activity
Protecting	The nurse is constantly watching over someone or something. They are attentive; wanting to protect others or themselves from harm and complications. They want the 'best outcome' from the journey. They believe and care about what they are doing.	Monitoring and checking Providing cardiac rehabilitation Limiting mobility Checking blood tests Providing emotional support and reassurance Concerned with well-being Safety for others
Guiding	The nurse 'knows' the route needed to be taken and followed. They know what is best. They lead, steer, direct, take or have control. They use these to influence the behaviours of others.	Procedural checks before, during and PPCI Detecting complications Managing visitors
Adapting	The nurse is able to 'adapt' to different situations. They are skilled, able to prioritise, can problem-solve and cope with challenges.	Receiving new patients Managing ill events Medical emergencies Taking on different roles
Responding	The nurse 'responds' to situations in a positive or negative manner. Their emotions influence their evaluations of how the situation was handled.	Sheath care Caring for ill patients

Throughout the narratives, the tone, language described situations that mattered to the nurses. These were the situations that demonstrated what was important to them as they performed their various nursing activities. They cared about what they did, and why they did what they did. The nurses' stories revealed certain 'routes' were taken to navigate the patients and carers along to the nurses' destinations. These routes were influenced according to the perceived illness state of the patients as positive or negative experiences for the nurses. Positive experiences meant that the goal, activity or outcome was easily reached. Negative reactions signalled that for some reason a caring activity had not followed the expected 'route' or that an action had meant this was more difficult to achieve.

The narratives revealed the nurses' reactions about the extent which they believed they could 'protect' patients but also occasions when they felt they needed to 'protect' themselves. Both led to different types of tensions. Whilst the nurses were often the ones in control, there were occasions when the nurses did not feel in control. Particular activities or caring situations made some nurses 'respond' to situations where they felt insecure or at risk from their own activities or from others. There was a strong indication that nurses saw the PPCI as 'rescuing' the patient; their nursing activities continued the success caused by the PPCI.

6.4 Types of routes

Analysis of the nurses' experiences revealed five routes were experienced:

- **Getting the job 'done'** – this reflected the responsibilities and roles for getting the PPCI completed in a timely manner. This involved preparing for the procedure and the new arrivals (travellers). Being ready meant everything was packed on the trolley before the patient arrived. Not knowing the illness state of the travellers meant nurses experienced emotions such as uncertainty, stress, excitement and fear. There was a knowing that complications could happen at any point. Some of the nurses liked not knowing whereas less experienced nurses found they anticipated problems. Knowing other nurses were available and present made a big difference. The nurses in the catheter lab had one key aim: getting the job 'done' (protecting). There was an acceptance that at times caring was at a distance; the priority was to complete the PPCI (guiding). There was a knowing the PPCI would keep the patient safe. Different strategies were employed to respond and adapt.
- **Taking a 'familiar' route** – this involved following a well-trodden pathway in which the nurses 'guided' travellers through their journey. Familiarity with post procedural care meant the nurses performed tasks known to them. They used skills, knowledge and technical competence already mastered. The same steps were taken whether patients were ill or well. There was a pre-determined order of doing activities. Knowing what to do and when to do it generated the feeling of being in control, feeling comfort and confident. There was a knowing that checking and looking at the technological equipment surrounding the patient would enable the patient to reach a point of wellness (protecting). Protocols put in place made it easy to care; to know what to do, to be guided what to do.

- **Handling the passengers** – this was a route in which the nurses had some control but this was limited. They could control when carers visited the patient and for how long and what information was given. The nurses recognised relieving carer's anxiety was difficult. There was nothing much they could say until the PPCI was completed. Not knowing what was actually happening in the catheter lab meant a reduced sense of control for the nurses. They had to be careful with what they said; just in case they said the wrong thing. They had to protect themselves.
- **Managing 'difficult' situations** – this route reflected how diversions framed negatively still had to be 'responded' and 'adapted' to manage the patient and situation. This route reflected nurses' evaluations of dealing with situations that were not particularly enjoyed but managed. Managing pre-determined nursing activities alone induced a sense of vulnerability, discomfort and less control. Receiving patients who had not received the PPCI were viewed as being 'unsorted' and 'unfixed'. The nurses felt less in control. There was a perceived high level of risk and fear that complications may not be managed by the nurses. There was urgency to get these 'ill and sick' patients treated. Not all patients benefited from PPCI; some patients would die. In difficult circumstances, different emotions were experienced. Finally, this route highlighted personal difficulties with certain aspects of care in which the nurses felt at risk. Negatively viewed experiences indicated discomfort for the self.
- **Keeping patients on the 'right' track-** this route related to the nurses' destination of getting patients well again (protecting). They were confident that in giving the necessary information patients would recover. The ultimate goal was to prevent patients returning for another admission. This meant avoiding further complications and risks that could put patients in harm's way. Strategies such as restricting patients' activities and making patients understand they (the nurse) knew best were instigated to protect the effects of the PPCI. The voice of authority was often utilised to make patients see they were actually unwell. The narratives reveal the disappointment and frustration when patients do not follow their instructions.

The experiences begin with Claire, Alison and Jane who worked in the catheter lab. They were responsible for preparing the environment and equipment; everything needed to be ready for the new arrivals. Their experiences convey the difficulties with not knowing how much time they had to prepare, not knowing who was available to help and finally not knowing the patient's illness state. Caring actions revolved around asking for information to ensure the right treatment was happening, manoeuvring in different positions and assisting the doctors whilst also caring for the patient from a distance. There were occasions when it was difficult to get close to the travellers but this was accepted as part of getting the job 'done'. Sally describes how both patient and technical aspects are managed. Insights into the value of the PPCI service are provided by Rachel, Louise and Sally.

The experiences of Jane, Sarah and Jenny describe caring encounters when taking a 'familiar' route. Their experiences coincide with identified tasks and problems in which the nurses appeared calm and certain about the needs of the travellers. Their experiences reflect the ways the nurses 'guided' the travellers, how they believed they were acting to 'protect' and promote the well-being of these travellers. The experiences of Anne, Rachel and Jenny reveal the nurses involvement with 'handling the passengers'. The nurses describe factors influencing the amount of information given to the carers.

The intended route was not always easy and straightforward: 'managing difficult situations' illustrates three challenging situations encountered. The experiences from Sarah, Jenny and Louise demonstrate how diversions in the route whilst framed negatively still had to be 'responded' and 'adapted' to manage the situation. Alison and Louise provide a thoughtful reflection on 'guiding' themselves through care episodes in which the traveller does not complete the journey. Emily and Rachel reveal how challenging issues such as bleeding and sheath removal are managed to 'protect' the traveller and themselves.

Throughout all routes, the nurses were concerned with 'keeping the patients on the 'right' track. This represented what mattered to the nurses as they did their best to return patients back to a state of wellness. The key aim was to keep patients safe, well even after they left hospital. The nurses wanted to 'protect' travellers from further harm. Rachel, Emily and Sarah reflect upon how they feel forced to impose a set of rules upon the travellers in terms of mobility and education in order to promote the best outcome from the PPCI.

To illustrate how meaning was created from the nurses' turning points, conflicts (complicating actions) and evaluations, transcript quotes from their narratives have been selected to show the reader how the nurses experienced and participated in these routes.

6.5 Getting the job 'done'

6.5.1 Preparing for the PPCI

The following narratives reveal the overriding need for the nurses to be ready in terms of equipment but also with regards to who could and would be present during the PPCI. It was important for the nurse to be organised, methodical and prepared. If not there was the risk that something could go wrong. The focus was upon the technical tasks and items needed for this vital part of the journey. The priority was the PPCI and in order for that to occur, certain things had to happen first. From the outset there was an imbalance between timings and time. This reflected the difficulties and challenges for the nurses working in the catheter labs.

From Jane's perspective "it is usually very rushed, if we get a nice call time of about an hour we are very lucky. I had one the other night which was five minutes so the pressure is on from the start. You never know what you are going to get through the door. You never know whether they are going to be sitting up smiling or whether they are going to be in the throes of compressions with the ambulance crew. It can be quite daunting as to what is coming through."

Alison also describes her experiences of knowing patients are coming but not knowing what will happen, "I have known a couple of occasions where the paramedics have got to the patient and there has been no time for them to alert us and they just arrived. You have got to be prepared for the unexpected as well. We are sometimes alerted if there is a problem. If there are arrests on route sometimes the paramedics have to divert to a hospital to get immediate help and then come on. Sometimes we are told what is happening, sometimes we don't know. So you learn to be organised. I think we have all have got our sort of way of working. You have to be quite quick and to the point really. It all depends on how much time you have because if you have three-quarters of an hour then you can do it in a relaxed way, other times you have got ten minutes or your patient is arriving through the door and you are still getting your bits and pieces together."

Jane described what happened when patients arrive “the first thing is they are trying to get access, get the ECG and some defibrillation pads on to assess the rhythm. If there are two nurses in the room we will check the patient in and get as much information as possible. All their personal details, height, weight, medications, diabetes all get written up. It’s a little bit of listening in all directions and picking up what the ambulance crew are saying. They do give us a handover sheet about any medications like Morphine and a next of kin telephone number or address. It is so much easier with two nurses. It is slightly less pressure because you know they can get on with their job without having to try and do some of your job as well. If there are two of us in the room, one will be scrubbed already with the trolley ready to go. We will be shaving the groin area and getting them uncovered, trying to explain to them as much as we can what we are going to do. I am sure a lot of it just goes straight over their heads because they are in that state of, “Oh God what is happening?” But we still do try and explain everything. So then it is a case of getting on with the procedure. If we are that quick we don’t even get a chance to put a blood pressure cuff on most of the time it’s within five or ten minutes. Time is of the essence.”

Claire’s statements show the need to be ready: “you have got to prepare everything that you might need for a primary. We basically prepare a generic trolley with all the things we might need plus extra syringes, drapes, a long line and some fluids. Should we need to give any medication we can easily do it from the bed end without interrupting. Most come in with a cannula but if they don’t, the doctor has to do it because there is only one nurse and we have to try to be everywhere. So unfortunately your contact with the patient is very minimal. Once the patient is nearly ready we get them changed into a gown, shave the groin and connect the fluids. You have got to be there to assist the doctors with the trolley and make sure they have got everything they need but at the same time you have got to be there for the patient for like pain control, extra medication. If they are sick or if they need the toilet or whatever. So we tend to ‘adapt’ to what we need to do.”

Getting prepared had different connotations; it was about getting ready for patients, preparing the trolley and preparing the traveller to be ready to receive the PPCI. The orientation reflects the context about who was there and the effect this had on the nurses compared to when they were working alone. The evaluative clauses indicate how the nurses prepared the self to be ready. When others were present, there was a sense of confidence, belief and a knowing they could make the PPCI happen in a timely manner. The narratives also reflect the impact of feeling uncertain and vulnerable when familiar aspects are being performed.

6.5.2 During the PPCI

The success of the PPCI was also dependent upon 'who' was unpacking these items. There was an understanding that to enable the best outcome from the PPCI, the right team members needed to be present with the necessary skills, knowledge and experience to 'respond'. However not everyone who attended possessed those elements; there were limitations in some team member's abilities. In the narratives below, the nurses reveal how they have had to 'adapt'. Taking on co-workers roles could be frustrating but there was an attitude that this was just the way it was. As nurses they had the attributes to deal with these situations. The nurse was there for everyone; other nurses, doctors, handling the equipment and 'responding' to the patient. They were the key players, 'guiding' forward the route that needed to be taken; steering the team. This responsibility exposed vulnerability; the nurses did not want overall control. They believed their skills could 'rescue' the consultant when others were unable to help.

In the following scene, the complicating action centres Alison's difficulties in being able to do her role when skill mix is poor. "Some of our registrars are very experienced and some are quite junior. That's the difficult thing; if you have got a junior registrar they can't adequately assist the consultant. They tend not to be very useful in the room because they are unfamiliar with the drugs and we need to prepare things. It is not something you just go ahead and do if you have never done it before. It's mixing vials and drawing up and following algorithms, the doses, giving boluses, drawing up the infusions. That is the hard part because you feel sometimes you are assisting your doctor with the procedure and keeping half an eye on the registrar and making sure things are going okay there. You know it would be nice to be able to do just the role of the nurse to be there to assess and support that patient but we have just got to get on and do what we do. The more experienced you get, the more you start to do your own sort of assessments on patients. They look very sick, so this is going to be very tense. I have got to get in as quickly as I can. You become familiar and confident about how things are going to go, what you are actually going to do and what your priorities are. It is one of the parts of the job I enjoy the most really but it's quite an individual thing. I know some people don't particularly enjoy being on call, they find it quite stressful. I find it rewarding. I feel I made a difference. I feel part of something which is quite good. I have done something worthwhile. I quite like the acuteness and it's nice to work around an unexpected incident to get away from the routine things and use all the skills you've been prepared to use."

Claire was less experienced in terms of working in the Heart Attack Centre. She evaluated her role as being stressful “during the day we have two nurses, but on call, you are on your own. When you rely on the rest of the team you seem to work really nicely together because they know there is not another nurse who is going to do it. You tend to be helped that way but sometimes it is difficult to try and do everything. Even when the PPCI was well rehearsed and known, it was possible to feel helpless and not in control.” Claire knew that without the PPCI patients would not survive, the certainty of this outcome was confirmed by the knowing they had done the right thing. Knowing made a huge difference. “You see that patient struggling and then after the case you see them with a bit of colour, chatting and happy. It is just like you have made something right for a patient and at that moment you don’t really think whether you’ve one doctor or one nurse because you have achieved what you are there for; my role as a nurse.”

Overall the nurses believed they were making a difference, they valued the outcomes from the PPCI and were proud of their achievements. Rachel stated “The way we run the PPCI service runs very smoothly for us and for the patients. It needs to be quick and everyone needs to know what is going on. I think we have kind of figured it out. I know that they are scared. I think that the fact we can do something for them straightaway and make them feel better for the majority of cases is something nice to be part of. I haven’t actually put the stent in myself but we are all part of that. I feel very proud to be able to provide that for people.” Louise indicated the thrill on a personal level, “It is the closest thing I could do to getting a bit of excitement without working in A&E, I love meeting new people and when they are absolutely terrified, I find that is when you really know you can make a difference for somebody. I honestly couldn’t do anything else.”

It was the not knowing Sally liked, “you don’t know what you are going to be dealing with so it keeps you on your toes, you get that little bit of adrenaline rush which nurses either like or they don’t but it is seeing the result afterwards, you can see the ECG tomb stoning and the elevation come down and it is just brilliant. It might not always go back to normal by the end but when you see that dramatic effect you see that patient in pain, sweaty, pallor and you have intervened. You can see the clot you have pulled out and the patient’s symptoms are getting better. I really enjoy it. You are here to do the job. We are very lucky that a lot of our patients go out better than when they came in. It is not often you get a job where it is so instant.”

It was not the same for all of the nurses, Emily's account sheds a different light: "in the beginning when I was a bit more junior I absolutely loved it but nowadays I find it can be a little bit monotonous, one after another. A lot of the time they are very similar. We don't get really that many that are really unwell because the service now is so good. Often they are really stable when they get up. I kind of like the excitement of running around with IV's and you know CPAP but we don't really get to do that as much now. I still enjoy it otherwise I wouldn't work there anymore but it's getting a little bit samey doing the ICP multiple times every day. I don't have to look now. I just know it all off by heart and I think I need a bit more excitement."

Caring was made more difficult because of the procedural aspects relating to the PPCI. The PPCI had to be completed on time. Caring aspects had to be 'adapted' to what was happening but as Sally's narrative demonstrated ways were found to manage the patient. It was a matter of switching between personal and clinical personas using both technical and human contact. "When we first start off, we generally assess how the patient is but then we try and do a distraction technique. So when the doctors are putting the anaesthetic in and it stings we will try and talk with the patient, where are you from, have you got family coming to see you later. You try to get them talking to distract them but during the primary situation that is a little bit more difficult because you are all trying to concentrate on the emergency side of it. I can imagine its bit of a whirlwind but a lot of patients do go with the flow because basically they have not got much option. As long as we explain what we are doing as we go along, most patients are fine. We sometimes find that patients totally withdraw into themselves and that's difficult because then they don't necessarily say what's wrong. You can see them, something's wrong but you don't know whether it is physical or they have more pain or whether they are trying to process what is happening or if they are worried about their dog at home, you don't know. We keep an eye on the ECG and we talk."

"The thing the patient has to worry about is when it is quiet. More often than not people talk about general things and patients seem to really appreciate it. It takes the really seriousness out of it as oppose to you know. I think they want to know that somebody is listening to them and that someone is paying them attention. When they are very anxious they want someone to hold their hand all the way through. We have to explain that if the doctor is working one side using the monitors on the other side we can't stand next to you. We would be in the way and also too close to the x-rays." Due to her extensive experience Sally was able to convey how specific actions were used to

meet particular care needs and their effect on the patients' well-being. Talking was seen as a caring behaviour; letting the ill patient know someone was there 'protecting' them.

Again managing the situation was heavily influenced by who was around to help and the skills they possessed or with the skills the nurses believed they possessed. Everyone had a part to play but sometimes several parts had to be played by one person; namely the nurse. It was generally accepted that with the right skills and right people, events could be 'adapted' and managed. It could be handled alone but having the support of others was preferred. As such the ability to 'respond' was influenced by a feeling of having some control over this known situation. In feeling they were organised, they knew where items necessary for the experience could be located. They knew the extent of their problem-solving skills. They knew and understood their roles in making it possible for the arrivals to be ready for the main attraction. Not knowing the illness state of their patients induced both anxiety and excitement; emotional stressors which guided the nurses to ensure certain activities were completed on time. They had a job to do, a job that they liked doing, a job that meant they could be part of the 'rescuing'. They were aware of the risks and the unpredictability but they also had a knowing that there was much to be achieved by 'responding' and 'protecting'.

6.6 Taking a familiar route

6.6.1 After the PPCI

Following completion of the PPCI, a familiar route was then followed. Activities were described like a list; items were ticked off as they were done. At this stage there was an automated mechanistic approach as familiar set of steps known to all were taken. It was all about getting the patients to a point of safety. Safety could be created by the monitoring equipment in which patients were attached to and then re-attached as they moved through the different settings. The nurses felt safe when attaching patients to the monitors. The monitors raised the alarm of potential danger and variations in the patient's illness status. The nurses seemed certain, secure and safe in the actions they performed. There were times when the nurses felt it was all too simple. These emergency patients should have been more ill. The nurses had to remind themselves these patients had suffered a heart attack because they looked too well to be that ill.

Using a series of orientating, complicating actions and evaluation clauses, Sarah provides a picture of common nursing activities undertaken when the patient returns to the HDU after a PPCI. "We hook them up to the blood pressure machine and explain we are just going to be fiddling around for a few minutes. I usually say, "Do you know what has happened to you while you have been in the lab, did they explain sort of thing?" Then we go and get the family and explain to them again in front of the patient what happened. Then we do all the paperwork stand by the bed and ask questions and write all their observations down. We check if anything was missed or any drugs that need to be given and then pretty much for half an hour we look at the patient. We leave them with the family for a little while. We don't sort of pounce on them too quickly because it is all of a bit of a shock for them. It gives them a chance to talk about what has happened but we are still around. Then I go back and say, "Here is your jug of water," and they have usually got a few questions by that point. I give them the visiting times and telephone number and say we are always in here."

"It is not too bad, it is actually better than looking after somebody that is an unstable transfer because at least these ones have been fixed as such and their artery is unblocked. There is always the risk of arrhythmias within the first hour which is why we usually leave the pads on. So it is actually quite nice when they have had their stent fitted because they are sorted. You think because they have had a big heart attack they are going to die or have some fatal arrhythmia while you are there but they are usually fine when they come back. It kind of gets a bit like 'a conveyor belt' sometimes. You know you are doing it because this has got to be done. You have a little tick list in your mind because it is just so routine. In your mind, access site, make sure it is not bleeding. You are just checking look okay, things like that."

Sarah believed her actions were justified because it was accepted that this is what nurses did; these were her responsibilities. Suggesting the PPCI had fixed the patients, indicated a sense of gratitude that any imminent danger had been controlled by the PPCI. It also mirrored the feeling fixed voice identified in 2.4. This may account for patients who do not fully understand the nature of the PPCI. In the preceding narrative there was a tendency to not question but presume an automatic performance for the PPCI on a routine basis. In Jenny's account, actions reflect pre-prescribed ways of 'guiding', 'responding' and 'protecting' when particular signs and symptoms occurred. These physical and technical caring behaviours were used to manage the situation. They promoted a sense of security and comfort and contained the nurses' anxiety.

“They are connected up to the monitor so we are looking at heart rate, blood pressure, respirations and oxygen saturations. Some of them come back in pulmonary oedema so we try and get those sat up and give them Frusemide. Depending on how severe it is we might catheterise them. Some patients come back without oxygen on but if their saturations are a bit low we put some oxygen on. They send all the bloods off in the lab but if they haven’t, we would take the bloods. So we make sure all of that is done. Most patients now have radial approach so that’s a lot better. They can sit up a lot sooner. That is a big thing for ladies because they have to be on bed rest for twelve hours so sometimes that’s a concern for when they use the toilet. A lot of people want to get up before that time. Some don’t understand why they have to be on bed rest. It is to do with anticoagulation so they can’t get up. They all have fluids unless they are in severe heart failure but even if they are we tend to just trickle it through. Mainly because of the radio opaque dye effect on the kidneys, we also encourage them to drink quite a lot when they come back. We have the care plan which has got a bit of a checklist for when the patient comes back. It doesn’t remind you to do that, we all just know. I like to get them all tidied up and all comfy when they come back and make sure they are stable. We don’t really do much with them. We just let them rest, answer any questions they might have.”

Time was a precious element throughout the nurses’ narratives; they were driven by the need and desire to complete certain tasks at certain time points in particular sequences. Knowing that delaying these tasks would lead to consequences making rescuing more difficult. Many of the nurses in this study seemed to value the presence of monitoring equipment. It appeared to heighten their sense of patients’ dependency and vulnerability making the sickness status more recognisable. Although the terrain was familiar there were times when the environment made it difficult to carry out effective caring encounters.

Jane’s account highlights how aspects such as creating a dialogue and gestures such as holding their hand were important to the nurse but had to be balanced against the need to get the PPCI completed in a timely manner. Eye contact was used to make that first encounter relaxing and caring for the traveller. This also provided security for the nurse. Experience and intuition from previous encounters enabled them to ‘read’ what was going on and then ‘respond’ to manage the situation.

Sarah and Jenny's experiences reflect the security and comfort that could be sought from familiarity. The aim was to 'guide' the travellers to a certain point (wellness). Developing and applying routines enabled all the care aspects to be undertaken in a pre-defined period of time to meet particular care needs. Although it had its limitations the terrain was used to watch and look for complications; comfort was taken in events being 'managed'. The nurses felt in control.

6.7 Handling the passengers

As soon as the carers arrived at the hospital they were steered to the day room. For Anne there were several difficulties when handling the carers "they come to our day room on the ward which from our point of view is probably not ideal because they mix with all other relatives or any other patients who are in there because our day room is not very big. It is also a worrying time for them because they are told that their relative is being treated but they don't really know what is going on, how the patient is or what the procedure is going to be. So it is a time of apprehension. From our point and the patient's point we know what is going on, but from their point they are stuck in there until we can say we will take you round to see them."

Rachel shared her concern of the situation and demonstrated an empathic projection about the carer's experience as evidenced in the phrase "I can only imagine as a relative". She seemed to be identifying with the carer and in doing so revealed an inner understanding, compassion and vulnerability. There was a realisation it was difficult for the carers but at the same time it was also difficult for the nurses. Not saying anything protected the carers and the self in case something did go wrong.

"They are often left for a very long time without any information and it is difficult to get around. We do go in and they are offered cups of tea but they don't get an explanation because we don't know. We actually don't have any information, we know the patient has come in but not when they arrived. They literally go straight through the door into the catheter labs and we have their arrival time and so we kind of estimate the time they will be up to us. We don't get any other information so we can't pass it on until they get up to us and once they have it probably takes us about ten minutes to get them settled and then we can go and get their relatives and we do that pretty quickly and then we do all of our explanations. But I can only imagine as a relative sitting in that room, waiting, knowing, they have had a heart attack, that must be very hard but I feel uncomfortable going in and speaking to someone having no information at all. We just say, "They are still in the labs but as soon as they get back we will come and

get you.” They seem quite happy with that but deep down I don’t know how happy they actually can be with because it is pretty much no information. When we do we pick them up and bring them straightaway in and we are walking round to the HDU, we will say, “He is fine and he will be lying flat or you know he is sitting up and he is having a drink or whatever the situation because I think when you first walk into HDU it looks like a normal bay. Having an explanation as you walk round that he or she is fine is quite comforting.” This part depicted the resolution; the evaluation of the experience in terms of the how and what finally happened.

In the next scene, Jenny used several strategies to help the carers reframe their sense of not knowing and the strong potential for recovery. “Some people react very differently, they get extremely anxious, very upset, some people get angry. So I just try and calm them down and explain that they are fine, just give me ten minutes, I promise you can come and see them and then when they come in to the bedside there are different states that they are in. Some people might be very calm, some people are really hysterical. They may have lots of questions when I am taking them around are they okay, are they going to be okay? I just try to explain before we go in there what has happened. Some people come in with expectations and they think they are having a heart bypass. Once they have seen their loved one there is a whole different reaction there, relief, upset they might not have had any tears until they see that person and then the patient cries. It is quite emotional.”

The nurses’ narratives reflected the need to ‘guide’ passengers but this was a pathway that adopted a ‘stop and start’ approach. Passengers (carers) were taken, left in the day room and then collected when the nurse was ready. A standard statement was given to them about ‘the what’ but not the detail because this avoided (protected) any unnecessary discomfort for the nurse. In knowing their routes and being orientated (guided) too particular ways of doing activities behaviours were subconsciously done. The nurses describe their actions in an entirely natural manner with the ultimate aim of ‘protecting’ patients and carers from subsequent harm.

6.8 Managing 'difficult' situations

A 'difficult' situation was defined as event that caused inner turmoil or conflict within the nurses. These types of caring encounters led nurses to question their abilities and motivate others to do the 'right' thing so that the nurse's sense of control and comfort could be enhanced. Doing so enabled them to 'respond', 'adapt', 'protect' and 'guide' the patients to a place of safety. Three different challenging situations were identified: dealing with sick patients; dealing with death; and disliking care activities.

6.8.1 Dealing with sick patients

Sarah, Jenny and Louise shared their experiences of dealing with 'sick' patients (travellers) who were unable to follow the familiar known route. Their evaluations revealed less certainty and confidence compared to previous narratives. When Sarah talked about patients on the usual pathway she was calm and confident about her experiences. However, her tone and language completely changed when she conveyed her interpretations of patients who had not yet received the PPCI. In some cases, when the catheter labs were already full, patients with the heart attack had to be transferred directly to the HDU to wait their turn, "it's if they are pre-procedure because you know in your mind well they have had Anti-platelet drugs in the ambulance and that is it, that is just buying them time, until they have their stent done. Effectively they are still having their heart attack when they come to you. So you are like, "Let's get them to the lab quickly." Sarah felt stressed and her emotions directly related to her belief she was unable to do more for the travellers; she felt powerless and helpless. Until the PPCI was done patients could not be 'rescued'.

Jenny's story takes a similar tone, "You feel quite anxious for them because you know what they need and you just want to get them down there. You don't feel like out of your depth because you know you can handle the situation. You know what is wrong with them and what they need. So it is just a case of are they ready yet, are they ready yet? You keep phoning up. They look very different, like a typical MI patient, very grey and sweaty, nauseous. I have had people come up and they just vomit all over you. They come in all sorts of states, people come from work, I had a lady who had a MI in a stable; she was in her jodhpurs and boots. If we know it is only going to be five minutes they stay on the ambulance trolley and we will give drugs but if it is going to be more than five minutes we get them on to our bed, take their clothes off, pop them into a gown, take their jewellery off and give it to the family if they are there. It is quite exciting when you get them straight up."

As Louise's narrative reveals the nurses tried to find ways to deal with the situation. There was a sense of expected danger and discomfort. They were not in control instead captive to potential threats facing them. They were not ready for this ill and untreated patient. One method was to bargain with others; negotiating a transfer to the catheter lab. They had to rely on their assessment skills of looking and watching the patient; they were bystanders unable to stop the heart attack. Visual clues were all they had to confirm this person was ill. Louise noted their 'different' appearance "They are quite sick, grey like and clammy and you know that's the sickest we have seen most of them when they are just coming in. You feel really bad because they are so unwell. That is when they are really ill. Nothing is really going in at that point and there are you, the consultant and the ambulance crews and it's really quite intimidating for them. You just have to be, "It's alright you know we will get you down there as soon as we can." It's scary because they could go off at any minute. We don't really get a lot of arrests but they are really sick. If it does completely occlude they could just go. It's more scary because you are thinking, "Come on let's get a lab space." You also get your balloon pumps that come in. They are not well and it's a bit uncomfortable for them because they have to lie flat on their backs for a long time."

In the above and preceding narratives there was a strong sense of the nurses striving to do what was good or best for their patients but in doing so they sometimes had to endure difficult situations for themselves. When care encounters felt unfamiliar, the nurses felt unconfident and less able to 'respond' to traveller's needs. The sequence of activities became more daunting. There was notable discomfort and concern in the accounts of Sarah, Jenny and Louise. The level of sickness and severity of risk was often determined by visual clues such as appearance and the equipment required before, during and after the PPCI.

6.8.2 Dealing with death

In an environment most associated with survival and 'being rescued' the following narratives describe the experiences of Claire and Louise when dealing with patients who have died. The narratives conveyed the nurses' responsibilities in protecting the patients and the carers but also doing what they thought was right for the situation and the self. This meant they could continue to care for other patients.

Claire had "only had one death and it was at the beginning of the primary PCI's. It was daytime so there was quite a lot of people but it was not pleasant at all because you have just got to carry on knowing you have just lost the patient and you might get

another one who needs your help. You just lift up, in your mind and carry on. I had a 54 year old lady who came at six o'clock in the morning. I took over at eight and then the case finished at ten. They did everything they possibly could. She didn't die with us, she died in HDU but you have got that in your mind, all day long. It could be your mum. We are here for a reason. Nobody has forced me to work. I am here because I like it. I guess we have to be tough and put that feeling aside and carry on but it is never easy is it?"

Louise talked about her experiences of caring for patients who had died, "Sometimes they will come back up to us because they can't stay in the labs. If we have a side room they will go straight in there. The family have got all the time in the world but sometimes if they die in the labs they come straight to HDU. We just pull the curtains for the other patients or they might die the minute they get up there and it's like, "Oh." If they have arrested and you have tried to do something they might have the ET tube in. It's horrible and difficult because they might not have said everything they wanted to say. It makes me feel so upset thinking about it. It is just like the worst part of the job you know and you think, "Oh God." You can't help but cry with them because you just think it is the worst news and so when that happens they go to Sister's office. The consultant always comes up. You don't say anything until they go in and they talk to them. Then the consultant leaves and you stay."

In the preceding scenes, the nurses provide the complicating action, evaluation, resolution and coda. Both nurses are faced with a situation in which it is accepted that patients either live or die; no in-between. Initially their language was medical and distant as they described the processes that happened when it was known a patient may die or had died. Neither used words that confronted the issue of death but instead de-personalised their encounters. Then there was a sudden shift in the nurses' language as they identified how they would feel if it was them personally. Their evaluations revealed their attitudes from the perspectives of the patient, carer and nurse. The resolution describes how the events surrounding death are managed. Claire and Louise provide insightful evaluations about how nurses 'respond' and 'adapt' when outcomes are not good but still require close attention. Their accounts reflect the difficult parts of the job and the manner in which nurses disconnect and connect. Their own fragility and vulnerability is transiently visible.

6.8.3 Dealing with disliked activities

Difficult situations did not just relate to managing the travellers; Emily and Rachel narrated about situations they found personally challenging. There were some caring tasks which these nurses, given a choice, would have preferred not to have to do. This was because of the perceived level of risk for the patient and nurse. However, these challenges had to be internally managed because of their desire to help patients and because of how they wanted to be seen by other nurses.

For Emily, her nemesis was removing the sheath “whenever they come up with the sheath left in we go, “Oh no,” because for the patient it means they have to stay flat for an extended period. The bad side will be for us, we are going to have to take the thing out and it is really hard work taking a sheath out. I am not very strong so to physically put all of your weight onto someone’s groin to pull out the sheath is really hard. I tend to use the Femo Stop device these days just because I am not very good at doing it. I haven’t got the strength so I try and put it on which isn’t very nice for the patient but I feel safer doing it that way. I don’t like sheaths at all. They are scary because I had a couple that I couldn’t keep control of the bleed. I had to get someone else to help me and for myself, someone who is coming up to being more senior now and being on shift with juniors I feel a certain responsibility to be able to do it. I need to make sure I feel confident to do it because if I can’t hold it and there is no one else on more senior then we have got problems. So I don’t particularly like them. It’s not my favourite thing to do at all.”

Rachel also disliked this activity, “it is not something most of us like to do. There are two ways of removing the sheath. The first way is manual pressure. You remove the sheath and you have to press on the groin quite hard for ten to fifteen minutes. If you can imagine that’s quite taxing on us and it is quite a long time. You also have got to think about things like a vasovagal because they do happen quite a lot. When you are pressing hard and their heart rate drops you realise you are pressing a little too hard.

A lot of us don’t use them because there is a lot less control over it. You still have to stay with the patient because they have got an open femoral artery. You can’t leave them anyway. It just seems to me that it’s a lot of money because they are quite expensive bits of kit to use when we could just apply pressure. I just prefer to press, that way you have got total control of how much you are pressing. You can also feel around for haematomas rather than kind of leaving it and every so often going back. You just have to make sure the other nurses around know that is what you are doing because you are there for fifteen minutes. You can’t leave, there is nothing you can

do and if you need someone you know rather than pulling the emergency buzzer you can shout and someone knows where you are and what you are doing. They can grab whatever they need straightaway. It is also a nice time to have a chat. It's a really good time you've got fifteen minutes of just pure one to one although it's very uncomfortable for both of us. For them it is uncomfortable having someone for fifteen minutes press quite firmly on your groin."

The fear of causing harm was evident in Rachel and Emily's experiences; both knew what they had to do and why it was important to get it right. Overcoming fears or dislike for an aspect of care placed them in a position of discomfort and reduced personal control. Emily felt constantly on her guard, Rachel controlled by the equipment there to help her. When everything went well, it was a lot more enjoyable. Activities which were viewed negatively were perceived as extra work and effort for the nurses. They wanted to get it right but they were also fearful of doing it wrong. Their fears reminded them of the ongoing dangers from the PPCI rather than from the heart attack.

6.9 Keeping patients on the 'right' track

Nursing activities were aimed at guiding patients to becoming well and keeping them well. Certain priorities had to be managed if this goal was to be successful. Strategies were put in place to keep patients who had received the PPCI on the 'right' track. These patients were deemed to be ill because they still required close attention from the nurses. There was still a level of risk to the patients that needed to be managed. This involved restricting patient's activities and ensuring patients followed the instructions of the nurses. The nurses felt empathy for their patients knowing they felt well but they felt governed by a need to enforce control. Patients had to act in a certain way if they were to get better. They were disappointed when patients did not follow their instructions or doubted their knowledge. They knew the risks and they knew what was best for their patients. Their actions and desires were to 'protect' others from harm. Once patients reached a particular point in the route they were deemed as being safe and well. A different type of attention was given to 'protect' patients from further hidden harm. As far as the nurses were concerned, the travellers still needed 'guiding' even when travellers felt they had been rescued. The following narratives reveal the difficulties that could occur when patients no longer viewed themselves as being ill.

6.9.1 Well but ill patients

Rachel described reasons for why some patients found it hard feeling so well. “I had a gentleman last week who said as soon as they put it in, he was fine and felt better than he had for three months. A lot of them do feel this as soon as they have that stent in, it is clear. They feel ten times better but then to be told actually you can’t still get up for twelve hours and you are going to stay in hospital for three days by that third day. They are itching to go home because they feel so well.”

Emily shares a story in which she had to explain to a patient why they can’t do certain things. “Often they want a shower the first day after a heart attack. We have to go ‘sorry you probably shouldn’t’ and they don’t understand why they can’t do that because most people have showers. They want to do that because they feel great after their heart attack. Well most of the time they feel great and we have to go, “I am sorry but your heart isn’t quite ready for a shower on day one.” It’s the period of time they come off the monitor as well because the first forty eight hours are the most dangerous. Within the first twenty four we like to keep them on the monitor. To let them have a shower actually takes more energy out of them than they think it does. Sometimes they get angry or upset that they can’t have a shower. For me, I kind of sometimes go “Oh sure,” and then I go, “Oh wait,” because they look so good and everything looks brilliant so you kind of want to but then you are, “Oh no should I?” I think it is protocol that you are supposed to wait twenty four hours. I can never remember. I just try and be as safe as possible really. I have never had anyone collapse on me but other people have, so you kind of have to be safe really. It is like the lying flat is quite difficult, sometimes they can go to sleep and it is fine but they want to turn on their side. They can bend one leg up but there is not really much we can do to help. Sometimes you can put rolled up towels in certain places and sometimes sit them up very slowly. We can give them a time when it can come out. I am reluctant to do that because obviously we get busy doing other things. They are staring at the clock and thinking like, “Four o’clock this can come out” and then it is half four because we had another primary come in or something. It’s hard, sometimes it would depend upon how uncomfortable they are and if they are really that uncomfortable maybe I would check the clotting earlier and see if we could take it out a bit earlier. Yes it is hard. I don’t think you can ever really win.”

The nurses' frustrations appeared to be fuelled by travellers not acknowledging the full extent of their travels. Information was provided using language which the nurses felt could be understood by patients and carers however only the 'right' chunks of information were given when the nurse felt it was the 'right' time. This incremental provision of information was not uncommon. Their words reflect their need to make sure they were doing the 'right' thing for their patients.

Emily posits her rationale, "I just explain the best I can and then say it's up to you. I can only advise you. If you don't want to take my advice then that is really up to you but if I was you, I would take my advice seriously. Most people are fine but there is always a couple that think we don't know anything. Sometimes it is hard because they just won't listen to you. I will say well I will ask the doctor and they will say exactly the same thing to what you have just said. The patients say okay and they listen. So that's tough sometimes but now I just let it go over my head and I don't worry too much". For Anne, it was a case of just having to accept this was the way some people were "by the time they get to the ward they are relatively independent, other than being on a monitor they can care for themselves. We look at anything that could improve their lifestyle that can help them. Some people are keen to start and change their life style, others just completely ignore it. "It's happened I feel alright so I am okay now." Some people just blot out the fact they have had a heart attack and the pain they went through the day before."

Sarah's approach to providing cardiac rehabilitation reflected a similar controlled manner. She believed the way she did it helped patients to retain important information. "We do their phase one rehab ideally before they go out to the ward. That just involves giving them the booklet. You have got their cholesterol level, blood pressure and estimated weight and you just sit and go through that with them but not straightaway. If they come in the morning you can do it later that day. If they come in the afternoon sometimes patients aren't ready for it but usually it will be the next day. Hello, my name is... I am your nurse today, this is what has happened to you, and that is it. Then if they start asking questions we will show them the stents and say they have stretched the artery and this is how the heart attack has happened. A lot of patients think a clot has just travelled there and got stuck. They do not understand the process of it and then we say, "Right that is it I am not going to tell you anymore because it is too confusing. You won't remember and you kind of build on it. I try to sort of drip feed through that the tablets are important but not necessarily to talk about that straightaway. Then they are mobilising. They are up and about and the next day

they go home. That is the ideal world but I think our job is to say, "Look these tablets you must keep taking these, this is what has happened, you have had a heart attack although you are only in 48, 72 hours, but this is hard because you can't lecture people about what has happened, that is not what we are there for. We are there just to give them the information. They have to choose what they do with it."

Trying to make patients see they were well but still unwell was challenging and often frustrating for the nurses. Many of the nurses were perplexed by the patient's reactions. They cared but they were also troubled. Talking about the heart attack made it feel more real but it was harder when patients felt well. There was an assumption that the well person did not see the importance of information, they were not listening; they still needed attention and care. Sarah believed she was doing the right thing for her patients "When they come straight to us they are like 'oh we are fixed now, we are alright' and I am like well not really because you have still got a heart attack. You feel kind of bad for telling them that actually you are not okay but you want them to appreciate they are not okay in the sense they have had a heart attack but yet they are okay because they have recovered well. But if you tell them that they are absolutely fine then they will be like that's alright then I will carry on as normal and you really won't be able to because you will be too tired. We see this day in and day out, we are experienced, we know what we are talking about sort of thing."

The possibility to help the travellers become well again and keep them well was a driving force in how the nurses described their experiences surrounding the different phases of the PPCI. It was exciting but there was also an understanding of the opportunities and limitations arising from the technology. The nurses expressed feelings of powerlessness, frustration and disappointment when travellers asked 'if they could move', 'sit up' or 'go for a shower'. Caring for the outcomes meant the nurses had to make decisions for the travellers that would enable the effects of the PPCI to remain in transition. These decisions were not difficult for the nurses but could mean stressful encounters with the travellers. The nurses' focus was on the traveller's needs but this was made more difficult by travellers looking and feeling well soon after the heart attack. Consequently there remained the need to exert control and authority; they knew best. The over-riding desire was to 'protect' and rescue the travellers from harm and as such the nurses took on the overall responsibility with a genuine concern that if given the right amount of information at certain points a difference would be made and would 'guide' the travellers down the right route.

6.10 Understanding the nurses' journeys

This chapter has uncovered the experiences of ten nurses working in one Heart Attack Centre in the East of England. Five 'routes' were taken: Getting the job 'done', taking a 'familiar' route, handling the passengers, managing 'difficult' situations and keeping patients on the 'right' track. The narratives demonstrated a preoccupation with saving lives and navigating a route from a life-threatening illness back to being well again. There was a knowing that the PPCI would 'rescue' the patients. This reinforced ideas about the heroic nature of this medical intervention. The nurses knew that once this had happened patients would be 'protected' from harm and wellness could be attained.

Each of the three settings (Catheter laboratory, High Dependency Unit and ward) represented a zone of protection, acting as a defence against the AMI. Being able to manage equated to a sense of pride, satisfaction and heroism in that they believed they were doing the best for the patients (travellers). Rescuing was assumed but complications were always anticipated. The level of sickness (illness/instability) or wellness (stability) was indicated by the stage of the journey and the related nursing priorities required. There was constant stress, tension and urgency for travellers to be transported to the zone of protection they required at particular transition points in the journey.

Emotional reactions were often heightened when difficulties with rescuing were encountered by the nurses. New travellers who were untreated were labelled as sick because of their colour and being 'unprotected'. Travellers experiencing complications during or after PPCI were also viewed as 'sick' because they required additional support such as a balloon pump or intravenous giving sets. This particular view of sickness made some nurses feel helpless and uncomfortable because it was less certain whether they could rescue these travellers. Travellers unable to progress on their journey also meant nurses had to bear witness to a suffering. Not having the right skill mix or the right information meant a risk of harm to both the travellers and the nurses.

The nurses had to do certain jobs within a specified time period (hours rather than days). The practical aspects of the nurses' work were dominated by various tasks: 'putting them on a monitor', 'doing blood tests', 'checking results', 'monitoring the puncture site', 'talking to the carers' and escorting carers to the patient'. These activities were not viewed separately but as part of the care they provided. They were their ways of working. They were the responsibilities and rituals that had to be

travelled through. If they were not done, there was a risk of blame but more so, there was risk to the traveller, carer and the nurse.

All the nurses felt engaged, involved and attached. When the caring encounter was going well, they felt in control and comfortable. There was a sense of security from the sequences that served as co-ordinates for mapping the traveller's journey. This was a familiar and comfortable route to take. There was a structure to their work which acted as a guide towards an expected and wanted outcome. Yet this rational approach to tasks could also create a space between them and the traveller. The nurses had to focus on particular care aspects at certain time points in order to monitor illness status and prevent any complications. Actions were performed unconsciously perhaps as a way of coping with the situation or to protect themselves. As such these routines were deemed normal and appropriate by themselves and other nurses.

6.11 Reviewing the different journeys

The narratives gathered in this study reflect the different agendas of the patients, carers and nurses. During familiar or predictable or non-provoking encounters there was a tendency for the participants to be mostly objective, detached and distant but they remained positive. However, in unfamiliar and stressful situations or where danger was perceived or anticipated the participants mostly became subjective, involved and negative. These turning points related the extent to which the individual believed they could control what was happening and the degree of personal comfort attached to the experience. Reaching the destination had a bearing on the individual's ability to cope. The destination for the patients was initially survival followed by being well. They wanted to return to their previous lives with no accompanying symptoms. For the carers, it was coping with the patients' illness state, a situation they faced alone or with family members but ultimately they were alone. Their destination was feeling safe when the patient was in hospital and when they were back at home. For the nurses it was providing timely and effective care (PPCI) to make patients stable again.

Sickness for the patient and carer meant a sudden and unexpected hospitalisation. This was a situation where they were reminded of their own mortality. There was no sense of control or comfort. It was a case of willingly or reluctantly dealing with what was happening to them. The onset of the heart attack created a tension between their normal self and their now current ill self. They needed help to survive and this came from the nurses who had the knowledge and skills to deal with the crisis and could

make them feel better. The patients and the carers did not have the 'know how' for what was required, they mostly went along with what was happening. They became encapsulated within a state of being passive and accepting. There were times when the restrictions and control imposed upon them was legitimised and so was the state of being ill. They complied because they did not know what they should be doing but later they also realised it was good for them to do so.

After the PPCI had taken effect, personal comfort and control again became important in the patients and carers' experiences. When the patients felt well, they believed they had 'been rescued'. Feeling safe was an emotional state in which the person believed there was no imminent danger or harm; there was a sense of feeling secure and protected. They had been freed from a difficult situation. They had gained something that was hoped for but not expected. The emotion of feeling safe was subjective and as such their feelings changed frequently during the short period of their hospitalisation. Patients no longer felt ill. They felt well, positive and alive and in doing so became defiant and less compliant with the wishes of the nurses. Interestingly even when patients did become ill again they seemed to be interned with a different approach to their illness. There was a defiance that this should not be happening. It was a negative event but it was one that could be dealt with (again). To regain control, help was needed from others to improve the situation and outcome for their self.

In contrast, the sickness level of the patient seemed to give the nurses a sense of power, control, authority and dominance. The nurses were in charge of the situation. They had the control, the necessary knowledge and skills to make patients well again. They could prolong the status of patients 'being unwell' or 'acting unwell' for as long as it was deemed suitable or necessary to protect patients from harm. Even though the rationale for doing so was not always first and foremost in their minds the nurses 'knew' certain actions were needed. These had to be done to keep the patient on the right route (to reach the right destination). These patients were sick but stable and still at the point of illness. To further enforce this phase of illness, patients were encouraged to rely on the nurses for their needs, being told 'not to move' or 'not to have a shower'. It was the same with providing education and information to patients and carers. The nurses decided what was given, at what point, how much and the format of delivery. This may have been a protective stance from the nurses' perspective but it meant some patients and carers felt uncertain when they returned home.

The narratives appear to suggest that when patients were ill, the nurses had a clearly defined role. However when the patients became well there seemed to be a shift in the patient-nurse relationship. Despite nurses' arguing the positives for their requests, patients no longer appeared to adhere or listen to their instructions. For the nurses this meant undue risk and the potential to 'undo' the good that had already been achieved. For some patients, the need to argue, protest, fight or resist enabled a route to some type of control and comfort. This was exacerbated when nurses were deemed responsible for discomfort.

The three different phases of the PPCI (before, during and after) presented different needs and achievements for the three groups. Interactions focused on specific issues or time points. From the patients' perspective, time was occupied with being ill unexpectedly (almost dying) but then surviving and unexpectedly feeling well. Then they were forced to act ill until others decided they were well and then could go home. It was only then they finally reached the point of having been *rescued*. For most of the patients and carers the hospital environment offered a sense of protection (as it did for the nurses). If they left it early, they may become unwell again. Whereas others no longer wanted to be sick or be reminded that they had been sick. They did not realise the ongoing risk of harm but nor did they want to re-visit illness. For the carers, time was spent negotiating their travelling and visiting at the hospital. It was a matter of finding ways to manage the situation either by themselves or with the help of family members or strangers. Finally they prepared themselves and their home to receive a well person (even though doubt about the risk remained); they had been *rescued*.

For the nurses addressing certain needs and problems enabled the nurses to feel safe in their environments. They could achieve meaningful and successful patient outcomes. It was about getting their tasks performed and completed according to the patients' journey point with a view of reducing the risk of harm or further harm for others and themselves; they were the *rescuers*. They were determined to restore health and minimise any complications. Their ultimate aim was to protect the patients from further harm. Rescuing patients from an adverse event was achievable because the nurses knew the 'course of events'. The depth and distance of the nurse-patient and carer relationship related to activities surrounding the PPCI. Time spent with patients and carers was recognised by the nurses as a commodity in short supply and as such the different phases may have made it difficult to establish a sustained relationship. This may have influenced satisfaction of whether care needs or caring needs had been successfully met.

6.12 Summary

Throughout the findings chapters the metaphor of a 'journey' has been used to represent the patients, carers and nurses' experiences. At the start of this journey, a crisis unknown to patients and carers but known to the nurses was experienced. Initially, patients and carers were uncertain whether survival was achievable. The unfamiliarity of the landscape made it difficult as to whether it could be travelled. Travelling experiences were influenced by the patients and carers' physical and psychological coping mechanisms. For the nurses, routes were navigated through a familiar landscape to achieve the desired goal of reaching a successful outcome. The overarching narratives revealed happy and sad experiences reflecting individual's fears of death, resistance towards illness, fighting and negotiating with others to improve well-being and avoid danger. These types of narrative were linked to evaluations in which others were praised or blamed. These narratives provide a different view of reality and present the ways in which the narrators were cast into different roles: the rescuers, the strugglers and the saved (being rescued). The next chapter discusses the findings to provide reasons for different types of voices.

Chapter 7

Understanding the reasons for the voices

7.1 Introduction

The purpose of this chapter was to summarise the study and present conclusions from the narrative accounts generated from patients, carers and nurses experiences surrounding PPCI. The stories collected for this thesis reflect how individuals negotiated and managed feelings of insecurity, vulnerability, dependency, expertise and caring. Together they revealed the asymmetry in patient-carer-nurse relationships. The emotionality of their experiences and reasons for their behavioural responses will be instrumental in informing knowledge about these experiences.

This study began because of a change in the treatment pathway for patients having an Acute Myocardial Infarction (AMI). Following an announcement by the Department of Health (2008) a decision was made in the East of England that patients diagnosed with AMI would be transferred directly to a Heart Attack Centre bypassing the patients' local hospital. This required a significant service reorganisation for patients and changes in nurses' responsibilities. Skills that had taken nurses working in coronary care units years to develop were now required by nurses who had mainly dealt with elective patients but who would now manage patients who necessitated an emergency admission. As a coronary care nurse and now as a cardiac senior lecturer, I was fully aware of the benefits of patients receiving PPCI as first line treatment. PPCI has greatly reduced mortality rates and hospital stays as well as lowering the risk of having another heart attack (Department of Health, 2008; Hall, et al. 2016).

Thinking about the conversations I had with nurses prior to this thesis and listening to my inner voice, I wanted to find out what mattered to the patients, carers and nurses before, during and after the PPCI. In light of the pathway changes and growing numbers of patients receiving this intervention (Hall, et al., 2016) it was important to know more about how patients and carers managed and the ways in which nurses interacted and responded to them. Uncovering the reasons beneath these processes would reveal how these three essential groups managed their selves.

In this narrative-based study 10 patients, 8 carers and 10 nurses in one Heart Attack Centre in the UK were interviewed about their experiences of PPCI. The interviews generated narrative responses and the data was analysed using a Labovian approach (Labov, 1997) as suggested by Riessman (2008). I wanted to have a good grasp of 'what' was going on within the narratives for the patients, carers and nurses and the

'why'. This enabled me to scrutinise what the story was about and how different parts contributed to the overall story. The data analysis revealed the participants evaluations and interpretations so that I could make sense of the influence of emotions upon behaviours and possible reasons for actions taken or desired.

The discussion that follows in this chapter presents the voices that were heard in my narrative analysis of the participants' stories. In light of these findings, literature and theoretical influences are identified to explore the processes and interplay between different mechanisms that produced these voices.

7.2 The voices in my findings

Structural analysis enabled the gathering of different 'truths' and revealed types of travellers, passengers and routes. These were used to recognise journeys that reflected how individuals managed themselves at different points and junctions and how they coped with various diversions and obstacles. The voices being heard in the journeys depict the emotionality of the journey taken for the participants. Most journeys incorporated more than one type of voice. The voices are now presented:

- The **'quiet' voice** was represented by the 'long distance' traveller, 'helpless' passenger and 'accepting' passenger. This voice was heard during journeys that ran smoothly; there were no bumps or diversions.
- The **'feeling pleased' voice** signalled the turning point at which patients and carers participants felt they had been rescued. This was evident at different points depending upon preceding events in their journey. This voice also featured strongly in the nurses' experiences: 'getting the job done' and 'taking a familiar route'. The nurses were immensely proud of their actions. To be involved in a treatment which they believed made a difference to patients.
- The **'insecure' voice** was represented by the experiences of the 'frustrated' traveller, 'disappointed' traveller, 'lost then found' passengers, the 'worried' passenger, 'helpless' passengers and 'disappointed' passenger. For the nurses this voice was heard when preparing for the PPCI, 'handling the passengers' and 'managing difficult situations'. This voice reflected a sense of being on your guard in that something bad could happen. This voice reflected the degree to which participants felt insecure, vulnerable and unsafe.

- The **'annoyed' voice** was not previously heard in the literature. This voice was commonly represented by the 'frustrated' traveller, the 'reluctant' traveller, the 'disappointed' traveller, the 'disappointed' passenger and in 'keeping patients on the right track'. Overwhelmingly, this voice was heard when individuals felt their needs were not met or when they felt ignored by others. For patients and carers this voice was induced by a lack or limited choice or unnecessary discomfort. Equipment initially viewed as protective when feeling ill became obtrusive, a hindrance and an enforced way to be dependent on others (nurses). Choices were made by others making it difficult to determine the pathway through. Information was given but was often limited to specific issues. This left patients and carers feeling insecure and vulnerable, suspicious and critical of nursing activities, questioning nurses about decisions; not understanding why certain actions had to be taken. There was also a personal annoyance of becoming ill again; having to return to a state of being dependent on others. For the nurses, the 'annoyed' voice reflected patients not acknowledging their authority. They wanted to exercise their expertise and desire to care. On occasions, patients and carer's requests and actions were viewed as incompatible with nursing activities.
- The **'protecting' voice** was similar to the 'knowing' voice in section 2.9. This voice was represented by 'getting the job done', 'taking a familiar route', 'managing difficult situations' and 'keeping patients on the right track'. Throughout the nurses' accounts there was a powerful desire to ensure the PPCI was completed in a timely manner to ensure the best outcome for patients was reached. This involved being prepared and being ready and undertaking nursing activities to aid recovery.

7.3 Findings in relation to the literature

The different types of voices found in my findings are now compared to current understanding in the literature relating to research papers on PPCI. This will provide a contextualised understanding of the patients, carers and nurses' experiences and other relevant studies.

7.3.1 Literature for the 'quiet' voice

The 'quiet' voice strongly resonated with the findings of Astin, et al. (2009) and Sampson, O'Cathain and Goodacre (2009) in that patients and carers were initially stunned by the onset of the heart attack. As a result, a passive-like state was frequently adopted (Astin, et al., 2009; Radcliffe, et al., 2009; Sampson, O'Cathain and Goodacre, 2009; Dullaghan, et al., 2014). However this was not always the case, as demonstrated in my findings with the 'frustrated, reluctant and disappointed travellers'.

Similar to Astin, et al. (2009) and Sampson, O'Cathain and Goodacre (2009), the 'realness' of the situation was confirmed by the presence of the machinery in the catheter laboratory and seeing their hearts move on the monitors. This reflection of themselves was often difficult to grasp (Blaxter, 2009). Astin, et al. (2009) described this perspective as "looking from the outside in" (pp.78). Similar to other studies, most of my patients were not frightened by the machinery rather they were aware of it, feeling initially safe and secure in its presence (Doering, McGuire and Rourke, 2002; Gardner, et al., 2005; Lapum, et al., 2010). When patients felt ill, it was easier to cope with what was happening to them; functioning at a 'safe' distance (Almerud, et al., 2007). Different to the qualitative study of Radcliffe, et al. (2009) my patient participants recalled their experiences before and during the PPCI. This may have been helped by the shorter time period (within 14 days of discharge) compared to the wide time range of 13 to 91 days in the Radcliffe, et al. (2009) study.

The carers' response was not hugely reported in the PPCI literature. Sampson, O'Cathain and Goodacre (2009) focused upon identifying positive and negative views. Their follow-up paper compared satisfaction with carers' experiences of care at hospital providing PPCI against hospitals providing thrombolysis therapy (Sampson, O'Cathain and Goodacre, 2010). Overall satisfaction was constant but less was said about negative experiences. My findings provide more detailed understanding of the different ways carers quietly managed themselves whilst the main attention was upon the patient.

7.3.2 Literature for the 'feeling pleased' voice

Patients were grateful they had been treated quickly by doctors who had the necessary knowledge (Astin, et al., 2009; Radcliffe, et al., 2009; Sampson, O'Cathain and Goodacre, 2009; Dullaghan, et al., 2014). My findings reveal that smoother journeys were associated with high levels of satisfaction throughout the entire experience.

The 'feeling pleased' voice strongly matched the 'feeling fixed' voice reported in section 2.3 (Astin, et al., 2009; Radcliffe, et al., 2009; Sampson, O'Cathain and Goodacre, 2009; Dullaghan, et al., 2014). These studies were consistent with my findings and confirmed patients who felt well and safe became more optimistic. Similar to Dullaghan, et al. (2014) patients in my study were constantly aware the heart attack could return. They were keen to know their risk factors and take steps to change them to avoid risk of further harm. According to Mackey (2009), wellness is a subjective experience of health, a felt state or a state of well-being which emphasises the actual rather than a future dimension. The patients in my study viewed wellness as an absence of illness (Stein, 2008). The sudden relief from symptoms informed patients that whatever had gone 'wrong' was no longer a problem. It was only when complications were encountered they realised they had become ill again.

The experiences of the carers closely mirrored the patients and those found in Sampson, O'Cathain and Goodacre, (2009; 2010). Carers were also 'pleased' the right treatment had been given, by the right professionals, in the right hospital. Knowing, hearing and seeing the patient look well and feel well, indicated to the carers that that the PPCI had worked successfully.

In contrast to the existing literature exploring experiences of PPCI, I also recruited nurses working in different clinical areas in the Heart Attack Centre (catheter laboratory, High Dependency Unit and cardiac ward). Using these three cardiac settings enabled a fuller story to be gained about what it was like to care and be involved in caring encounters with patients and carers. Analysis of their narratives drew attention to the meaning of their involvement in the delivery of care and the impact they believed they had on patients' recovery in hospital and after discharge.

Drawing upon another study measuring staff satisfaction, Carter, et al. (2010) found staff delivering PPCI services were pleased with the work they were doing. Working as part of a team and developing new skills made the work easier. Their study indicated that the unpredictability and excitement of the emergency workload was liked; something noted by my nurse participants. Smallwood and Humphreys (2007)

also reported nurses feeling excited about aspects of their work. The researchers concluded an overwhelming desire for nurses to do their best for patients. In particular, nurses highly valued providing effective treatment to improve patients' well-being. The nurses believed their expertise knowledge and skills were worthwhile because they were making a difference. The net result was nurses felt proud and respected by others. Although, Lundén, Lundgren and Lepp (2012) did not draw any conclusions about their radiographer's emotional states it was acknowledged that genuine concern and interest was reflected for patients. The stories from the nurses in my study provide new understandings about what was important and mattered to the nurses in this one Heart Attack Centre.

7.3.3 Literature for the 'insecure' voice

Whilst the anxious voice was present in studies exploring the elective patient experience, the stories in my study revealed an overarching need for the three essential groups to have more personal comfort and control. Insecurity was often influenced in situations when participants did not feel in control or when there were perceived risks from care encounters, the environment and communication with others. All were noted as potential catalysts for positive and negative experiences. In some stories, participants voiced their concerns as feeling weak and defenceless, unable to protect themselves against risks that were unknown or anticipated.

The patients felt dependent on others because they were restricted by monitoring equipment and kept in a patient role by the nurses. They needed assistance from the nurses for a range of activities that often they felt well enough to do on their own. Patients and carers devised and employed different strategies to deal or avoid situations in which they felt weak and inactive. The female patients in my study reflected the female participants in Caldwell, et al. (2007) who also described feeling insecure during the procedure as they lay on the trolley. These concerns were mainly voiced by females as they referred to unmet needs around comfort. Their perceived vulnerability suggests that some participants may appraise their treatment as a potential threat to their well-being (Higgins, Dunn and Theobald, 2001; Devcich, et al., 2008; Trotter, Gallagher and Donoghue, 2011).

Compared to the males, the female's evaluations in my study were more personal. Their experiences were compared to previous experiences of being a patient. Their emotional and behavioural responses depicted the extent of their vulnerability. Their normal identities were overwhelmed by the experience and in response they constantly surveyed themselves for bodily sensations. They wanted to get on and do things for themselves and for other people. The females depended on others whereas the males seemed content to be co-ordinated by others. Williams and Irurita (2005) found during hospitalisation patients had varying degrees of personal control. The authors described how unfamiliar activities and hospital patterns contributed to poor self-esteem and value. One explanation was the loss of personal identity. The need to be dependent on others limited personal control.

The presence of the 'insecure' voice signalled the return of symptoms or complications. The accounts of the 'frustrated' travellers demonstrated that whilst the 'feeling pleased' voice served as an important coping resource it could also have a negative impact on illness experience by misleading the seriousness of the cardiac condition. In feeling so well, patients had not expected any other problems or setbacks. It was only when an 'illness event' returned they had doubts about the choices of treatment presented to them. None of the studies focusing on PPCI included patients where a further illness event had occurred.

Another significant reason for the 'insecure' voice was lack of individualised information for patients and carers. In agreement with existing studies (Astin, et al., 2008; 2009; Radcliffe, et al., 2009; Sampson, O'Cathain and Goodacre, 2009; 2010), my patients and carers also wanted information that would help them to know what they needed to do after they had returned home. Astin, et al. (2008) noted the mismatch with information provision. Patients in this study wanted information at the beginning where others wanted it later. Some patients and carers felt there was no right or wrong time and should be a continuous process during their hospital stay.

Of particular interest in my study were the nurses' motives surrounding how and when information was given by the nurses. The key objective was to enable and facilitate healthy lifestyles to prevent any further hospital admissions. Explaining the importance of the medications and promoting compliance reduced the chance of a further heart attack and prolonged the success of the PPCI. In a grounded theory study, Henderson (2003) interviewed 32 nurses and found similar findings to my research. Henderson also concluded that information provided to patients was about what they were to do rather than providing options to them. Decisions were made for

the patients rather than assisting patients to make decisions. This created an imbalance of power between the patients and nurses. There was a sense that the nurses guided the patients in this manner because they believed they knew best. Henderson noted that by restricting the amount of information given, patients were forced to become dependent upon the nurses. In viewing patients as passive recipients where information flows in one direction from nurses towards patients, it is difficult to know whether patients' information needs can be met. Nurses will need to tailor information they provide to meet patients and carers' needs but as my findings suggest there is still room for improvement.

Another under explored finding in the literature was hearing the nurses' susceptibility to feeling insecure when performing particular caring activities such as removal of the sheath. The nurses felt vulnerable when caring activities did not proceed well or when there was potential risk to the nurses or others caused by their actions. 'Handling the passengers' was one example. The nurses knew what to say but were anxious about what they should say. They wanted to protect the carers and themselves. Dealing with patients who had not yet received a PPCI was another example of nurses feeling susceptible. This was a fascinating and unique finding because the PPCI literature had previously indicated it was patients who considered themselves as 'fixed' (Astin, et al., 2009; Radcliffe, et al., 2009; Sampson, O'Cathain and Goodacre, 2009) whereas the nurses in my study also used the same phrase. This may have been the result of nurses being familiar with the research paper by Astin, et al. (2009). Alternatively, in being impressed by the PPCI, nurses may also have misconceptions about the PPCI.

The extent to which people feel vulnerable was often influenced by how much control they perceived they had and understanding what was happening to them. Vulnerability has been defined as being susceptible to harmful agents (Malone, 2000; Hardin, 2015) and weak or defenceless in the ability to self-protect against threats/risks (Rogers, 1997; Irurita, 1999; Spiers, 2000). According to Scanlon and Lee (2007) there are three types of vulnerability: social vulnerability in which anyone is potentially vulnerable to developing health problems and becoming ill; psychological vulnerability in which there is a loss of role caused by anxiety and a reduction in capacity to cope with unfamiliar situations (Cousley, Martin and Hoy, 2014); and finally physical vulnerability which relates to actual or potential harm to identity of the self, weakened by hospitalisation, illness, symptoms or treatment (Irurita, 1999; Mayou and Farmer, 2002).

Vulnerability definitely affected people's relationships with the environment, other people and their personal resources (Sellman, 2005; Mollon, 2014). My findings demonstrated the suffering experienced by some participants as they were exposed to difficult situations. To survive, was either a matter of waiting to be rescued or find a way of shielding the self (protecting self). When participants believed rescuing would be difficult, feelings of helplessness surfaced (Rogers, 1997; Cousley, Martin and Hoy, 2014). The narratives in this research contain a fragility not previously noted. They provide a way to see, hear and understand aggravating factors caused by the environment, loss of control, interactions by others, being restricted, not knowing who can help and feeling exposed.

7.3.4 Literature for the 'annoyed' voice

The 'annoyed' voice was a previously unheard voice in the PPCI literature. It was compelling to discover what differing states of the individual influenced the 'annoyed voice'. The need to feel secure meant relationships with others were continually assessed and evaluated as positive or negative. The ability and characteristics of the nurses were equated to whether they met the care needs of patients. Kralik, Koch and Wotton (1997) described patients labelling nurses as being either engaged or detached. In my study, the nurses who got involved with their patients, greatly influenced patients' levels of satisfaction. The patients liked being treated as an individual because it made them feel safe, comforted and supported.

Jacelon (2007) found nurses' attitudes influenced whether older patients admitted for acute hospitalisation had a positive or negative experience. When nurses were viewed as attentive, connecting with patients and friendly the patients believed they had a positive experience. Whereas not being aware or disregarding patients' needs was viewed as unhelpful. The net result was that patients felt neglected and devalued because care anticipated was not received. More recently, Karhe and Kaunonen (2015) explored the concept of loneliness in a group of 13 patients (11 with breast cancer and 2 cardiac surgical patients). They concluded healthcare professionals' assumptions, skills and attitudes can impose a sense of 'loneliness' on patients. They suggested professionals have a responsibility to prevent loneliness and maximise the opportunities to connect with their patients. The findings of my study will help to refocus nurses' attention upon the 'essence' of patient's experiences.

In my study, there were episodes when the nurses' behaviours did not comply with patients and carers' needs. Patients felt excluded by nurses who they perceived as either too busy to provide eye contact or disinterested, insensitive and cold. According to Shattell (2004) these types of interpersonal interactions add to the stress of being in hospital. Many studies have focused upon the effects of non-caring behaviours (Drew, 1986; Sundin, et al., 2000; Hupcey, 2000; Nydén, Petersson and Nyström, 2003; Arman, et al., 2004; Winman and Wikblad, 2004; Nakrem, Vinsnes and Seim, 2011; Edwards, Duff and Walker, 2014). Confirming that patients continue to view some nurses as having uncaring behaviours.

This strengthens the argument for patients needing interpersonal interactions and relationships with the nurses (Irurita and Williams, 2001; Williams and Irurita, 2004; 2005; 2006). This is even more important when they are feeling vulnerable (Williams, Dawson and Kristjanson, 2008). Douglas and Douglas (2004) noted after interviewing fifty patients from surgical, medical, care of the elderly and maternity settings that feeling secure and having personal comfort was always achieved by the presence of a nurse. When basic needs were not met, patients felt vulnerable and exposed.

Regrettably as Tutton and Sears (2004) and Siebens, et al. (2007) conclude nurses have a tendency to concentrate on managing physical symptoms rather than proactively creating comfort. Tutton and Sears (2004) interviewed 19 older people and 27 staff members followed by 130 hours of observation. The nurses were aware of the issues yet struggled to provide comfort because of their need to complete their routines. Consequently, patients had to fit in with the nurses' expectations to get their needs met in order to retain or regain some control. Not having their needs met caused serious discomfort. In contrast, Salminen-Tuomaala, et al. (2012) found patients with prior experiences of hospital or illness coped better because they knew how to behave. This may explain why a dominant theme in the PPCI literature was feelings of gratitude, satisfaction and feeling fixed (Astin, et al., 2009; Radcliffe, et al., 2009; Sampson, O'Cathain and Goodacre, 2009).

My findings provide further understanding about the reality of coping with such emotions. In feeling better, some patients desired more control and as a consequence perceived nurses' caring activities initially viewed as life-saving then may become an annoyance compared to those patients who were content with less control (Widäng and Fridlund, 2003). It would seem nurses' interactions either enable or inhibit emotional comfort which in turn affects personal control. Caring attitudes considered important by my patients and carers participants which were not met became a disappointment. In categorising nurse interactions as controlling, persuading and directing, negative behaviour responses were generated. Once this breakdown happened, negative feelings can be difficult to reverse. As such, these negative feelings were still very much in the forefront of their experiences. Even so, the 'annoyed' voice could be counterbalanced if something was done about the cause for this voice. The 'feeling pleased' voice signalled when efforts were deemed as successful. Examples of taking action included regained personal space by disconnecting themselves from the cardiac monitor or by protesting about the blood pressure machine as barriers for restricting their activities.

My findings suggest many patients were not happy to be kept in the patient role. Initially most patients are willing passive recipients of care, content to agree with the health professional and accept their agenda and willingly follow the plan of care. However, the implementation of PPCI has reduced hospitalisation stays and recovery times (Department of Health, 2008) and in doing so roles once clearly defined (Wade and Halligan, 2007) now have a degree of ambiguity created by changing illness patterns (Mottram, 2011). The patient participants wanted to rapidly visit and then exit the traditional patient role (tourists): the 'annoyed' voice was created when this route was blocked. When patients became well, some sought a more active role. It was interesting to note the ways in which they bargained, negotiated, challenged and in some cases opposed rules being placed upon them. Patients did not understand the restrictions being placed upon them or the need for technological equipment; they felt well and did not need protecting. They were reluctant to collaborate but equally they did not want to be classed as 'problem' patients or feel unsafe (Strandberg, Norberg and Jansson, 2003; Shattell, 2004, Sørli, et al., 2006; Eriksson and Svedlund, 2007).

7.3.5 Literature for the 'protecting' voice

Throughout the nurses' narrative it was apparent the nurses wanted to help patients and carers achieve the best outcome. Their caring actions and intentions were focused upon treating the AMI and making sure the patient travelled in the right direction. They were also keen to ensure the carer was protected from harm and worry. The nurses concentrated on promoting and carrying on the good work achieved by the effects from the PPCI. They strongly believed in the quality of their caring activities and in doing so experienced a sense of gratitude and personal enrichment from being involved in the caring encounter. These findings agree with the literature. Morrison and Korol (2014) note nurses derive a sense of reward and a strong commitment to their job and roles when providing care that was in the patients' and carers best interests (Smallwood and Humphreys, 2007; Smallwood, 2009). In agreement Fackler, Chambers and Bourbonniere, (2015) and Siffleet, et al. (2015) found delivering the 'right' care was central to most nurses' emotional well-being. Other factors linked to satisfaction included working in a cohesive team and making decisions about care (Karanikola, et al., 2012; Wilson, et al., 2013; Mason, et al., 2014; Fackler, Chambers and Bourbonniere, 2015).

Previous nursing experience was identified as a contributing influence for feeling competent and confident in managing patients at the different stages of treatment and recovery. This also closely related to emotional well-being. The nurses with extensive experience believed they were able to manage different care needs and recognise complications. In addition, they believed they were role models for the junior nurses, seeing themselves as both teachers and mentors. Not possessing the necessary clinical skills or attributes meant the treatment pathway and outcomes for patients may be hindered and in doing so emotional well-being may be reduced. This study also demonstrated that regardless of the nurses' years of experience, some nurses found it difficult to explain why particular decisions were made choosing instead to provide reasons for 'their priorities'. Whilst life threatening conditions do dictate certain priorities, the nurses' actions seemed bound by the need to 'must do' at a 'pre-determined time' whatever their level of expertise. Failure to do so was viewed as being poorly organised, providing poor patient care with potentially severe consequences for patients and the nurses themselves.

One compelling finding from my study was the way in which the monitoring equipment validated the presence of a patient being viewed as sick. In being deemed as sick, it was assumed patients would set aside their normal roles and adopt the behaviour of a sick person whether they wanted it or not. Compliant patients and carers were labelled as 'good' but those less co-operative were viewed as 'problematic' (Nairn, 2009). The patient was not expected to be active or knowledgeable. Instead it was expected they would behave in a passive manner. The nurses in my study believed that by keeping patients in the role of a sick person they were protecting the patients from harm. Looking at the patient for clues and determining the amount of technological equipment surrounding the patient affected the way nurses looked at and cared for their patients.

Alasad (2002) explored the experiences of 22 critical care nurses and also noted technology was viewed as a central part for managing patient care. The nurses felt reassured by the presence of the machinery; it gave them a sense of control over the care situation. The monitoring devices produced a type of knowledge which shaped their interactions with the patients. Almerud, et al. (2007; 2008) explained how nurses had to 'juggle' being a master and slave to technology because of how it could inadvertently draw nurses away from aspects they regarded as highly important, putting them at a distance to their patients.

Similar findings have also been reported in environments such as critical care units (Barnard, 1997; 2000; 2002; Barnard and Sandelowski, 2001; Parcels and Locsin, 2011). In agreement with others, Conley Wichowski (1994) and Kiekkas, et al. (2006) found nurses emphasised the usefulness of technology, in that it saved time, was helpful to patients and enabled role expansion. Nurses in Barnard's (2000) study also concluded that whilst medical devices were useful for meeting medical needs, it was often the principal factor for failing to spend time with the patient. The pressure from recording data and monitoring patients reflected a tension. The results informed nurses of changes in their patients' conditions but their activities with the technology distracted them away from meeting the basic care needs of their patients.

7.4 Findings in relation to theory

The plots that emerged resonated with the theoretical perspectives of the Self-Regulatory model and Attachment theory.

7.4.1 The Self-Regulation model

Astin, et al. (2009) and Dullaghan, et al. (2014) both used frameworks based on Leventhal's Cognitive Model of Illness Perception to understand the complexities of patients' beliefs surrounding PPCI. This enabled the researchers to understand how patients made sense of symptoms, illness and treatment situations. The model proposes that these perceptions influence coping strategies and subsequent behaviours (Cameron and Leventhal, 2003). Astin, et al. (2009) and Dullaghan, et al. (2014) concluded that the successful effect of the PPCI significantly lowered fear messages about the illness event (AMI). Patients believed the AMI could be controlled and 'fixed' by the PPCI (Astin, et al., 2009; Radcliffe, et al., 2009; Sampson, O'Cathain and Goodacre, 2009; 2010). These researchers were concerned that behaviours surrounding lifestyle changes would be short-lived. Patients may not attend cardiac rehabilitation programmes meaning behavioural changes and attitudes may only be adopted temporarily. This was a notable fear for the nurses in my study.

In contrast, Dullaghan, et al. (2014) found patients who had received PPCI were committed to making changes. Similar to my patients there were some misunderstandings about the PPCI but overall they were intent on returning to a state of wellness. My patient participants realised the seriousness of the heart attack in that it could have resulted in death. They were keen to avoid returning to an illness state again, determined to put 'right' aspects that may have caused their heart attack such as high cholesterol. Having viewed their symptoms as serious they wanted information but as highlighted by Astin, et al. (2008) they wanted and needed information that was different to what they actually received. The patients and carers wanted individualised information which included attention to their personal risks and information that would manage the high fear messages that were apparent when they returned home. The potential threat was still woven in their voices when they were interviewed within 2 weeks of hospital discharge.

The components of Leventhal's Common Sense Model of Self-Regulation, proposes that information is processed from internal (previous events and actions and memories) and external (other people) sources. This allows individuals to make sense of threats to their physical and psychological well-being (Leventhal, Meyer and Nerenz, 1980). The personality and emotional state of the individual at the time of the experience and afterwards also influences subsequent behaviours and coping strategies. My participants encountered different threats at different times during their journeys. These began with onset of the AMI, effects from the treatment, loss of control and comfort, returning to an illness state after being well, loss of the normal self as they felt restricted in the patient role. Even after returning home there was uncertainty and a not knowing what next threat may be encountered and how this would be managed.

As individuals tried to determine the significance of their situation, past experiences were drawn upon and contrasted against to help make sense of the situation. Attempts were taken to rebalance, restore or sway control and a sense of comfort again and finally the help of others was always required in the end. Any initial coping was about trying to make the situation in-hospital manageable. They were trying to protect themselves. According to Johnston, et al. (1999) these sources are used to predict what may happen at the onset of the illness, diagnosis or treatment and what action may be required to reach a desired goal or outcome. This information is then organised to manage an experience. If used effectively with positive outcomes then the action is likely to be used with subsequent experiences (Cameron and Leventhal, 2003). However, if the situation is unexpected or has not previously been experienced, there may be a discrepancy between the person's goal and the action required to reach that goal. This aligns with the types of voices heard in my study.

To answer concerns regarding cardiac rehabilitation attendance (Astin, et al., 2008; Radcliffe, et al., 2009; Sampson, O'Cathain and Goodacre, 2009; 2010), patients in my study wanted to help themselves and gain control of their condition. In addition to perceived health benefits there were also important social benefits. The patients wanted to be able to continue to socialise and go on holidays planned prior to the AMI or return to work. Most of all, they desired to be independent again. Notably, the female participants worried more than the males about symptoms still remaining or returning. Whereas the males wanted to carry out particular activities. Overall, the patients and carers had a positive attitude for information received that would enable them to cope.

Information from nurses who were seen as enthusiastic, able to give advice or explanations and make suggestions that would benefit their health, influenced patients' and carers' perceptions about what could be achieved. In agreement with the self-regulatory model, negative perceptions were enhanced by nurses who gave information that was deemed (afterwards) as unhelpful. Similar to Radcliffe, et al. (2009) and Sampson, O'Cathain and Goodacre (2010) this research concluded patients noting a poor response from health professionals in the primary care setting. Patients and carers commented they were still waiting to be contacted by the community nurse or doubted whether their own doctors would have the necessary knowledge to help them. The findings of my study and concerns raised in the literature all confirm that nurses need to understand the meaning of events for patients and carers surrounding the PPCI if they are to recognise the importance of the information they deliver, when it is delivered and the format of delivery.

7.4.2 Attachment theory

A useful framework for understanding the roles and relationships between patients, carers and nurses is the attachment theory. This theory originated from Bowlby's (1982) studies of young children's relationships with their parents but the theory can also be extended to other relationships such as patient, carer and health providers. It provides a route to understanding how individuals of any age feel when they feel secure or insecure. When emotional security is present or needs to be re-established, adults rely on attachment to regulate their emotions to protect the self from (potential) harm and restore emotional well-being.

The attachment theory is based on 'mental models' about the 'self' and 'other'. The 'self' is about how positively the individuals view their own self-worth. The 'other' is about how supportive or available a person expects others to be. However it is not always clear whether individuals are aware of these systems (Harding, et al., 2015). Bowlby proposed that if an individual has both positive 'self' and 'other'; they see themselves as self-worthy and trust others to be supportive. When a patient becomes ill (and a carer seeks comfort), the nurse is an ideal figure to attach to and seek security.

The patients and carers that described good relationships with the nurses and others reflected an enhanced level of emotional support and trust. Participants described their ability to share their fears with nurses, feeling secure enough to depend upon them. In contrast the negative 'self' and 'other' indicates insecure attachment. Patients with negative attachment styles can have difficulty in benefiting from support of others and maybe less receptive to social interactions with others (Maunder and Hunter, 2001). Consequently, they may be less likely to perceive help is useful or seek help. There are also risks for individuals with a negative 'self' and a positive 'other' because whilst they may want to seek support they may fear rejection if they do so. Similar results have been noted in oncology settings (Coffey, 2006; Dowling, 2008; Beaver, Williamson and Chalmers, 2010; Harding, et al., 2015). Thompson and Ciechanowski (2003) noted the timing of the threat was significant in relation to how the 'self' and 'other' was activated.

The patients and carers in my study reflected a mix of secure and insecure attachment. The securely attached individuals gave accounts of their experiences in which there were many positive events. They were not anxious or defensive when describing their experiences ('long distance' travellers and 'accepting' passengers). They valued their connections with and their dependence on others, speaking positively about their experiences. Sometimes there was a curiosity about the "how" and what had happened. These types of individuals seemed to adopt and possess skills (Maunder and Hunter, 2001) that could be used in a time of crisis. They managed dependency and independence, happily relying on others (fellow patients, nurses and family members).

In contrast, insecure attached individuals found attached relationships stressful. Negative emotions were quickly dismissed from their mind ('reluctant' traveller) to emphasise a sense of normality, independence and strength rather than admit difficulties or distress. These individuals seemed less well equipped to regulate their emotional states. They tended to resist or argue recommendations put forward by the nurses ('disappointed' travellers and passengers and 'reluctant' travellers) viewing some nurses as wonderful and others as difficult (Salmon and Young, 2009).

It was noted by the nurses that some individuals made being cared for or caring actions more difficult. This insecurity was dealt with by exerting or attempting to exert constant pressure on others. As such, insecure individuals were at risk of conflicting with the coping mechanisms of others (patients, carers and nurses). Those who had a positive view of the 'self' took pride in trying not to be dependent on others. However, in doing so they were not always able to create and maintain meaningful, intimate relationships with the nurses ('disappointed' travellers). Thompson and Ciechanowski (2003) noted that in trying to avoid establishing a relationship with the nurse there was evidence of down-playing their illness ('frustrated' and 'reluctant' travellers). Individuals with a negative view of the 'self' tended to be more clingy ('worried' and 'helpless' passengers and 'disappointed' travellers). These individuals experienced reduced comfort and wanted needs to be met. They were emotional, anxious, constantly seeking help and reassurance. They wanted to be genuinely cared for but there were particular aspects that mattered to them.

Patients becoming ill again ('frustrated' travellers) were negative of the 'self' and 'other'. They either thought they were unworthy of care or that others were untrustworthy of giving appropriate care. In some cases, patients felt rejected by those who they attempted to gain support from. Tan, Zimmerman and Rodin (2005) examined palliative relationships with patients and clinicians finding some nurses were described as hostile or potentially threatening. This usually coincided when patients felt their needs were not being met but as noted by Salmon and Young (2009) attachment styles can be modified. This was evident in the 'frustrated' travellers who after becoming ill again finally regained wellness. When the nurses were viewed as trustworthy they felt rescued and secure in the 'self' and 'other'.

The carers also demonstrated different styles of attachment but often these were influenced by the patient's responses. The similarity of the responses may have been influenced by the patient and carer both being present during the interview or because they had shared their experiences with each other indirectly influencing the others account. Five carers presented an insecure style, negative of the 'self' but positive of 'others' ('lost then found', 'helpless' and 'worried' passengers). One carer had a positive view of 'self' but negative view of 'others' ('disappointed' passenger) and the two remaining had secure attachment styles ('accepting' passengers).

In examining the application of the attachment theory, different attachment styles can have an impact on patients and carer's experiences. However it is less clear whether these styles can adversely affect patient's ability to comply with advice about lifestyle, medications and cardiac rehabilitation. Potentially the different types of attachments being incurred at different points may have a significant influence upon how patients and carers cope as they regulate their emotions. Attempts may be more focused on restoring emotional well-being rather than listening to information given by health professionals. In additions, relationships formed with and against nurses may also have a contributory role.

Different styles of attachment were recognised in the nurses in my study. The experienced nurses appeared to be securely attached. They had a positive image of the 'self' and 'others'. They felt able to respond to patients and carer's needs and at times, challenge and confront patient needs. The less experienced nurses felt insecure but were still able to care and be caring. Regardless of their length of experience as a nurse and working in the Heart Attack Centre, personal fulfilment, connecting with patients and making a difference were strongly evident in all of the nurses' stories. The perceptions of the patients and carers mattered to the nurses. This was notable when the nurses were shown the vignettes towards the end of their interviews.

Nurses are clearly influential in the formation and development of relationships particularly when individuals are feeling insecure and vulnerable. Therefore the attachment theory could provide a route for examining nurses' communication and relationship skills with their patients. It may help nurses to understand why they communicate in the way they do. If nurses can effectively engage with their patients then they can predict and anticipate the best way to treat patients and carers. Screening patients and carers for types of attachment styles may enable education to be tailored to 'keep patients on the right track'.

7.5 Summary

This thesis started by looking at the different voices that were reported in the literature surrounding the experiences of PPCI. It found there was lack of clarity about the different perspectives of patients, carers and in particular nurses. This chapter highlighted relevant factors that threatened and promoted individual's well-being, the different relationships and the resources used to adapt the self in these encounters. Two theoretical perspectives were presented to provide a route for explaining the mechanisms that produced these events and the circumstances that generated the self-identity and perceptions of others. Implications for clinical practice and education, recommendations and the strengths and limitations of the study are presented in the following chapter.

Chapter 8

Listening to the voices

8.1 Introduction

This thesis has reported a narrative-based study to gain a greater understanding of patients', carers' and nurses' experiences surrounding PPCI. The voices emerging from the literature informed the study design but only provided limited understanding of what was known about patients', carers' and nurses' experiences. My research study has uniquely built on what was already known by using the lens of narrative theory to explore the evaluations and interpretations of the participants. This methodology facilitated a route to the participants' 'truths'. In doing so, a journey approach incorporating the voices has conceptualised the findings of this study. A framework representing the voices of the patients, carers and nurses is re-presented. This chapter summarises the key findings yielded from the extensive narrative data. This will be used to address the research questions. The reasons for using a narrative approach, the strength and limitations, the implications for clinical practice, research and nurse education are presented. The contribution to new knowledge is also presented. The chapter concludes with final reflexive thoughts about my thesis.

8.2 Summary of findings

8.2.1 Patients

The sample was consistent with previous studies exploring patients' experiences (Astin, et al., 2009; Radcliffe, et al., 2009). The aim was to capture 'fresh experiences' of PPCI. Patients with a previous heart attack and/or PPCI were excluded because I wanted to recruit people who had not previously experienced an acute cardiac condition to hospital. My intention to recruit between 7-10 patient participants was achieved allowing me to build a rich understanding of the issue under exploration (Elliott, 2005; Bold, 2011).

The research questions were purposively broad. The first research question I asked was: what can patients' stories tell us when they describe their experiences of Primary Percutaneous Coronary Intervention (PPCI)? I felt this was clearly answered by the ten patients. Their findings are summarised as follows:

Reduced levels of comfort: There were times when reduced levels of comfort were accepted such as before and during the PPCI. Some coped with this in a passive manner throughout their journey whereas others protested, felt disappointed and annoyed by the actions of the nurses. Being overly dependent or reliant upon the nurses could also reduce patients' level of personal comfort. Being unable to make decisions or actively participate in care induced certain emotional states (insecurity, disappointment, worry, annoyance). Attempts were made to address the causes of discomfort with the nurses to find a resolution. On occasions where patients felt ignored or believed inappropriate control was being exerted, steps were taken to ignore the nurses' decisions. As a consequence some patients then lowered their expectations of the nurses or chose to only seek attention for certain aspects.

Vulnerability: Patients experienced vulnerability at different times of their journey. This could be induced by feeling sick and unwell or when they felt powerless and dependent upon others. Sometimes this state was welcomed other times it was protested. The onset of the heart attack was the first event to cause vulnerability; most sensed and knew something bad was happening. Discomfort caused by laying still on the PPCI trolley, tubes being inserted, activities being restricted, being confined to lay down flat after the PPCI, disturbed sleep because of the monitoring equipment, lack of privacy and for some loneliness meant different strategies had to be activated to manage the self. The different types of travellers indicated the ways in which patients managed: 'long distance', 'frustrated', 'reluctant' and 'disappointed' travellers. Additional help came by getting to know the nurses or by having a laugh with them. Fellow patients who had experienced the same journey helped to reduce vulnerability; although some patients found they enhanced vulnerability because they were made to feel guilty by non-emergency patients.

Not feeling in control: The PPCI, feeling well, nursing care activities, being dependent on others, not knowing and enforced restrictions induced a bewildering effect of not feeling in control. Patients were pleased the PPCI was done and evaluated successful by the nurses and consultant. In feeling well, they could not understand why they could not become themselves again, why certain activities were forced upon them and why they had to be dependent upon nurses for basic needs. Patients felt devalued, impatient and ignored. The patient role was enforced upon them. It was not their choosing. Some patients were content to take on the role. Re-encountering illness re-instated a feeling of not being in control. Negative perceptions were sometimes stronger with the second encounter. They believed their concerns were ignored. Negotiating and bargaining activities were used to restore control.

Information needs: The lack of information was evident throughout the patients' journey. They wanted information that would protect them from further problems. Information given needed to meet their specific needs. They did not know what they needed but they expected the nurses to know and tell them. They were disappointed when explanations were not given or reasons were not justified or they were left wondering what they could and should be doing when they were at home.

8.2.2 Carers

The carers were nominated by the patient; as such I had no choice over who this was. The criteria for the carer was the individuals' partner, the individuals' children, the individuals' parents, the individuals' relatives, the individuals' friends or a professional carer. The carers also needed to be willing to be interviewed within 14 days of hospital discharge. Different to Sampson, O'Cathain and Goodacre (2009) who also explored patients and carers experiences, I disclosed the gender and relationship to the patients. The second research question I asked was: what can carers' stories tell us when a person closely associated to the carer requires a Primary Percutaneous Coronary Intervention (PPCI)? I felt this was clearly answered by the eight carers who consisted of six wives, one husband and one daughter. Their findings are summarised as follows:

Needing help from others: This was a travelling experience that could not be managed alone. The carers all recognised help was needed from others (family, strangers and nurses) to be able to survive the experience. This included finding the whereabouts of the patient in the Heart Attack Centre as well as preparing the self for what would happen. The carers were not always certain they could initially manage.

Information provision: Not knowing was a constant struggle for the carers. Some had not been with the patient when they became ill but even carers who had been present were uncertain. The waiting room did not help; there was no information available and the nurses told them very little. The nurses showed the patient and carers a DVD. They were given information about risk factors which was helpful but they felt unprepared for what happened afterwards when they were at home.

8.2.3 Nurses

This was the first study to explore nurses' experiences of caring for patients before, during and after PPCI. Four nurses worked in the cardiac catheter laboratory. This was the first location visited by patients before being transferred up via a lift to the High Dependency Unit (HDU) and then finally to the ward. The remaining six nurses rotated between the ward and HDU. The third research question asked about the experiences of nurses working in a Heart Attack Centre as expressed through their stories of caring for patients requiring Primary Percutaneous Coronary Intervention (PPCI) and carers in the cardiac environment. The ten cardiac nurses in this study discussed a vast array of actions that were used to manage caring situations to ultimately support and promote survival. Their findings are summarised as follows:

Feeling in control: The emotions and behavioural responses in the nurses' narratives highlighted the need to be in control during patient encounters. The intention of their actions was to protect patients from harm. Certain activities made some nurses feel in control. These included being informed of the arrival of patients, acquiring the 'right' information, having time to prepare the 'right' equipment and having the 'right' team members present. Having the 'right' knowledge, skills and attitude was also important for making some caring situations and activities less stressful. Caring activities needed to be completely in a timely and safe manner. Being able to fix the problem made the situation manageable as did being able to respond to different situations. Some patients' behaviours threatened nurses' ability to remain in control. For example, patients who did not follow nurses' instructions. These patients posed a risk to both themselves and the nurses. Disliked nursing activities also posed a risk and triggered a coping response. Whereas, making decisions for others when knowing the outcome would benefit patients gave the nurses a sense of pride in their achievements. This confirmed their sense of commitment and duty.

Prioritising certain actions: There were two priorities; to ensure patients received the PPCI in a timely manner and recovered safely. In the catheter laboratory caring was performed at a distance; there could be no disruptions to the PPCI. In the HDU, monitoring equipment was used to detect problems and ensure recovery. Patients were continuously watched, treated and managed with certain caring and technological tasks. Nurses attached different levels of importance to caring needs according to previous experiences encountered. Keeping patients restricted was an important strategy for preventing complications. The need to do the 'right' things, at the 'right' time and in the 'right' way was always to protect patients, carers and the nurse from harm.

Feeling insecure: The inability to not be able to provide high quality nursing care posed a threat to the nurses' professional integrity. It affected their ability to feel in control of the situation. These threats did not result in unsafe practice or omissions of care but did induce a high level of stress and vulnerability. Providing effective nursing care was very important to the nurses. When they struggled to do something well, they felt insecure and at risk. These negative emotions were concealed from patients and other nurses. Instead ways were found to manage the caring activities by prioritising the needs of the patients over their needs.

Provision of information: It was the nurses who decided when and how much information was delivered to the carers and the patients. In relation to preparing the carers, the nurses were anxious not to give too much information, just in case there was a problem. The nurses believed they knew best what was right for patients. They knew what would happen if their advice and the information was not followed. Patients and carers who did not want to listen or take advice from nurses' frequently generated negative responses (annoyance, frustration, discomfort). Whilst the nurses were in a position of power and influence for much of the journey they were not in control of patients' behaviours and choices. This loss of control created emotional distress for the nurses.

8.2.4 Pulling the findings together

The fourth research question asked what these stories can tell us about the meanings of events for patients, carers and nurses surrounding a Primary Percutaneous Coronary Intervention (PPCI). Structural analysis of the narratives revealed events/situations that were significant. The participants evaluations and interpretations identified their emotional and behavioural responses that reflected the ways in which these events and situations were managed and the effects of actions taken. The intention of using narrative theory and a realist approach was to draw attention to particular events and relationships that may otherwise have gone unnoticed. Although a real world exists our knowledge of that world is socially constructed (Blaikie, 2007). By examining different experiences from patient to patient, carer to carer, nurse to nurse these research findings offer a new perspective for understanding the different mechanisms influencing patients', carers' and nurses' evaluations surrounding PPCI.

My study has revealed the difficulties and struggles with responding and managing different types of threats. Understanding what mattered to the patients, carers and nurses was an important aspect for this study.

For the patients, this involved feeling seriously ill, not knowing whether they would survive. Then suddenly they felt well, sooner than anticipated. However in feeling well, unexpected threats came from restrictions imposed upon them by caring actions and technological equipment. Different types of patients were identified:

- The 'long distance' traveller
- The 'frustrated' traveller
- The 'reluctant' traveller
- The 'disappointed' traveller

For the carers, the initial onset of the heart attack threatened their well-being as they faced the possibility of losing a wife, husband or mum. In addition they had to struggle with knowing how to manage their self either alone or with the help of others. Different types of carers were identified:

- The 'lost then found' passenger
- The 'helpless' passenger
- The 'disappointed' passenger
- The 'worried' passenger
- The 'accepting' passenger

My findings demonstrated it was not just a matter of being unwell and then feeling well but the subsequent experiences as they reached the point of being *rescued* and feeling *rescued*. Different things were wanted when patients felt ill and well or when seeing a family member ill and then well. Before, during and after the PPCI, some patients and carers wanted choices, most valued information and some wanted involvement where others were completely overwhelmed by the experience. Faced with serious illness they wanted the nurses to help them. The patients and carers believed that by being in the right place, receiving the right treatment by the right people, the nurses should be able to manage their needs. However on some occasions there was a mismatch between providing care and understanding patients and carers' needs.

For the nurses, the primary aim was to treat patients with the PPCI as quickly as possible after patients had arrived to the Heart Attack Centre. Then it was a matter of taking the patient on a route of pre-determined caring activities that were known to *rescue* patients. There were times when nurses felt in control and times when that control was tested. Throughout the journey the goal was to ensure the best outcome for the patients and the carers. The different routes taken by the nurses to manage the patients and carers were identified as:

- Getting the job 'done'
- Taking a 'familiar' route
- Handling the passengers
- Managing 'difficult' situations
- Keeping patients on the 'right' track

At the beginning of this research, I had expected to hear positive voices surrounding the experiences of PPCI. Comparing my findings with other relevant studies (Astin, et al., 2008; 2009; Radcliffe, et al., 2009; Sampson, O'Cathain and Goodacre, 2009; 2010) I have heard a wider range of voices. The experiences narrated revealed the events significant for the three essential groups. Structural analysis was used to discover the context for these events, for individuals' evaluations, for the behavioural responses to these events and the actions taken to manage these situations. The voices identified were:

- The 'quiet' voice
- The 'feeling pleased' voice
- The 'insecure' voice
- The 'annoyed' voice
- The 'protecting' voice

Rather than providing simple descriptions of the participants' experiences my aim was to explore, analyse and conceptualise these experiences. Three journeys were identified and incorporated the different types of voices. These journeys reflected the different experiences encountered by the patients, carers and nurses. Often the journey before, during and after the PPCI followed the expected 'straightforward' route but for some individuals the journey took a sudden change in direction ('diverted') or was more 'bumpy' than anticipated because aspects expected did not happen.

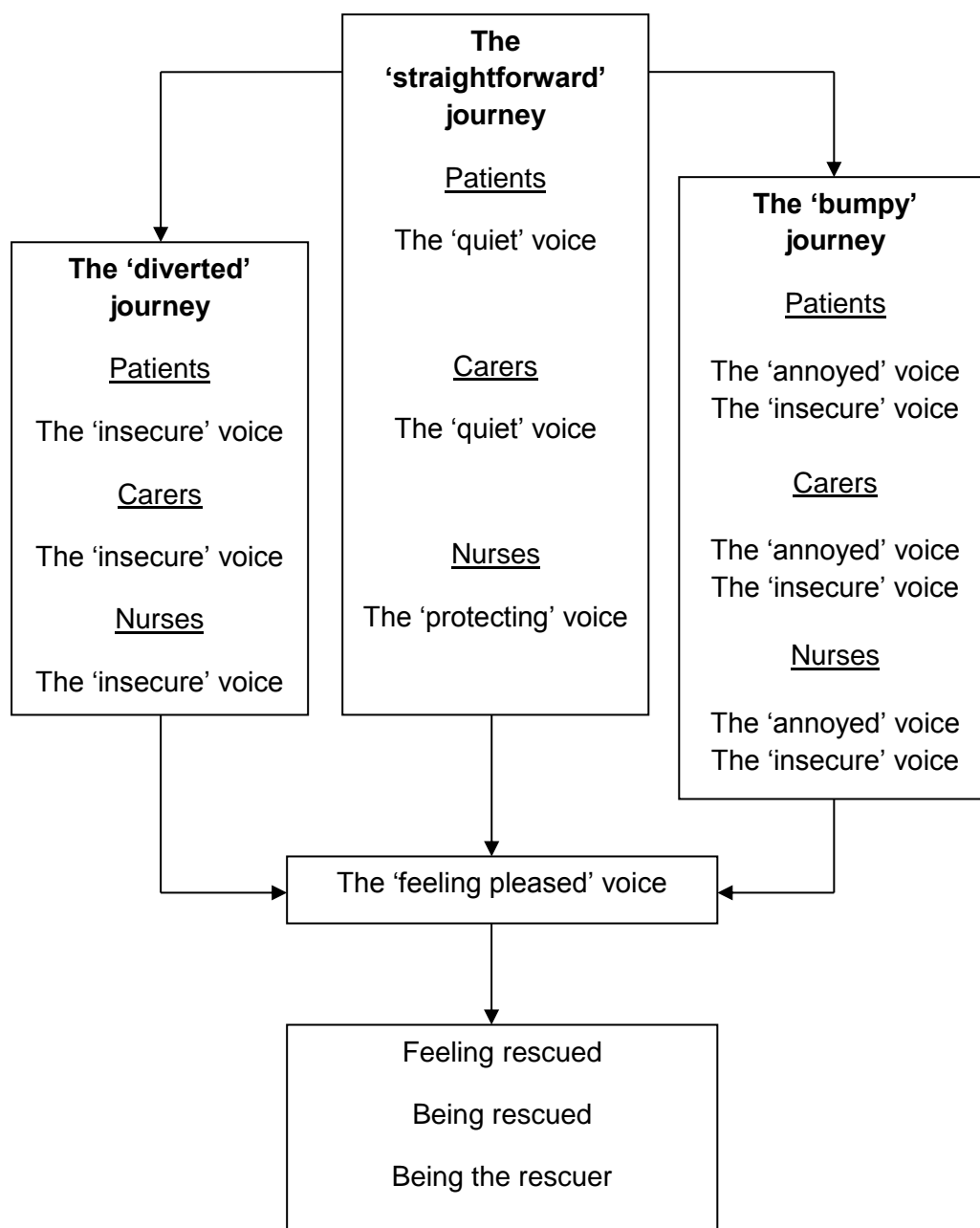
The journeys are presented as follows:

- The 'straightforward' journey involved the 'Long distance' traveller and the 'accepting' passenger. For the patients and carers, it was a **'quiet'** voice which accompanied the journey. Getting the job 'done' and taking a 'familiar' route indicated to the nurses, the journey had been successful. This was reflected by the **'protecting'** voice because care had been delivered as planned.
- The 'diverted' journey involved the 'frustrated' traveller, the 'lost and found' passenger, the 'helpless' passenger and managing 'difficult' situations. In this journey, the **'insecure'** voice was firmly registered for patients, carers and nurses. Diversions for the patients resulted from having to revisit illness again after feeling well following the PPCI. For the carers, diversions meant experiencing difficulties in being able to find the patient, seeing the patient and then struggling with managing the self-afterwards. From the nurses' perspective, managing 'difficult' situations meant the route was hampered. These included dealing with sick patients, dealing with death and dealing with disliked activities. These episodes all indicated a vulnerability for the self.
- The 'bumpy' journey involved the 'reluctant' traveller, the 'disappointed' traveller, the 'disappointed' passenger, the 'worried' passenger, 'handling the passengers' and keeping patients on the 'right' track. This journey was associated with the 'annoyed' voice and 'insecure' voice. The **'annoyed'** voice was heard in the patients, carers and nurses. Being annoyed with someone was a way of expressing an inner frustration at not being able to protect the self or protect others from potential harm. It indicated a dissatisfaction that an expected need had not been met. The **'insecure'** voice reflected the patients, carers and nurses' difficulties as they tried to keep a sense of control.
- Regardless of which journey was taken all participants experienced the **'feeling pleased'** voice at the end of their journeys.

It should be noted that within the different journeys, participants could experience other types of voices.

The conceptual framework presented in section 2.10 was revised and developed to reflect the voices and journeys taken by patients, carers and nurses (Figure III).

Figure III Revised Conceptual Framework



8.3 Using a narrative approach

Using a narrative-based approach was an appropriate way to understand patients, carers and nurses experiences surrounding PPCI and what these experiences meant to them. The narratives revealed what mattered, what concerned them and what was important to the participants. They were instructive in terms of understanding their decisions, influences, actions and behaviours. These were their views of their social worlds. It was an approach that enhanced collective knowledge and understanding and was different to the descriptive qualitative methods (Radcliffe, et al., 2009; Dullaghan, et al., 2014) and mixed methods (Astin, et al., 2008; 2009; Sampson, O’Cathain and Goodacre, 2009; 2010) used in existing literature.

Using structural analysis provided a fuller understanding. It was not simply about the content but also how the stories were told (Blaikie, 2007; Holloway and Freshwater, 2007; Andrews, Squire and Tamboukou, 2008). The images and metaphors described were about how they had engaged in their world (Webster and Mertova, 2007; Riessman, 2008). This enabled the identification of different types of voices. Using long chunks of narratives enabled the emotional states and corresponding voices to be more visible and auditable.

By adopting a narrative methodology I have been able to hear negative voices that others previously found difficult to hear (Sampson, O’Cathain and Goodacre, 2009). Narrative theory has been of interest at an interpretative and methodological level. It has provided a conceptual orientation that enabled the meaning-making of different experiences. As an approach it has linked theoretical perspectives with personal experiences (Fraser, 2004; Murray, 2008). In doing so it has highlighted issues that were important to the participants. The emotional context of the narrative approach has facilitated a space for stories to be told and to be listened to. It should be noted not everyone talked in a way that illuminated content. Being quiet was as significant as speaking loudly.

8.4 Strengths and limitations of this study

My study was the first narrative study to include patients, carers and cardiac nurses with the aim to understand their experiences surrounding PPCI. The findings from my research suggest that when patients', carers' and nurses' needs are met or unmet it will greatly influence their emotional states. These emotional states facilitate or disable the ways in which individuals manage themselves. This research has revealed the compelling and diverse ways in which strategies were taken to protect the self or others from harm and the reasons for these active behaviours.

It is important to recognise that the research presented in this thesis does have some limitations that need to be made transparent. One possible limitation is only having one type of data collection tool. My reason for solely using interviews was because the factors influencing negative aspects was unclear in existing literature. It was unclear whether positive and negative views were linked to the entire experience or certain aspects. I decided to use interviews to develop current understanding of these experiences. Like, Astin, et al. (2009) and Sampson, O'Cathain and Goodacre (2010), I could have employed a quantitative arm for exploring and understanding the nurse's experiences but I was aware using interviews would generate a large amount of data. Developing a questionnaire for the quantitative arm may have provided some trends but due to the small number of nurses working in the one Heart Attack Centre, this could have only been labelled as a pilot study.

A second possible limitation was the time period of interviewing patients and carers within 14 days of discharge from the hospital. This period was selected because other studies had recognised how poor recall could affect experiences presented (Radcliffe, et al., 2009). Had I interviewed participants again several months following the event, the stories would have evolved and been influenced by other ongoing factors. My interest was on experiences before, during and after the PPCI.

Selection of the patient participants could have been influenced when the nurses invited patients into the study. They may not have approached certain patients because they believed they were not appropriate for this study. There may have been concerns about evoking anxiety in some patients. Clinical priorities may also have constrained recruitment. The findings in my research suggest at discharge the nurses deemed patients as well and suitable for inclusion. In recruiting nurses, it was acknowledged that the health care team was made of different disciplines. However due to the paucity of literature on nurses' experiences surrounding PPCI I decided to focus on their experiences.

Even with protecting confidentiality it was possible some participants may not have felt comfortable to share experiences which could reflect less well for the Heart Attack Centre or for the nurses working there. To enable participants to share their experiences, the purpose of the research was explained at the beginning and the end of each interview. As seen in chapters 4, 5 and 6 the participants were happy to tell stories about their experiences. They wanted their experiences to be heard. I valued their honesty in sharing their experiences with me.

My initial aim was to interview the patient and carer separately. However in practice, each interview was conducted one after the other, whilst both patient and carer were present in the room. All patient carer dyads (husband-wife, wife-husband and mother-daughter) wanted to be together. It felt inappropriate to separate them. Initially, I was concerned the discussion may be constrained because of the presence of the other person or the direction of the conversation may be steered by particular concerns. On reflection, the patient carer dyads seemed to be at ease with each other. In all cases the nominated person was either a spouse or immediate relative. Had there been any difficulties in the relationship between a patient and a carer then the outcome may have been different. This may have been a reason for why some patients did not nominate a carer to participate with them in the research.

The unexpected challenges I had to manage were recognising I was capturing individual constructions and co-constructed accounts of their experiences. This was notable in the accounts of Helen (patient) and Peter (carer) who both used the 'annoyed' voice within their experiences. It was possible they influenced one another when sharing their experiences in front of the other. One unexpected outcome with having dyads rather than single interviews was that I had less control over the interview. Each patient carer dyad had prior knowledge of each other meaning the style of each interview set differed, putting myself at a disadvantage. However in having a less active role, I found I settled into a role of a listener, less anxious about having questions asked in a set order, wanting to hear what mattered to them. Whilst it is impossible to be sure if the stories would have been the same if told singly, it may well be that the process of co-construction reflects the way in which patient carer dyads live with their shared experiences.

My study did not set out with a specific theory, instead a framework emerged after data analysis. The adoption of the journey and voice approach was a useful framework for organising and representing the data. This approach has strengthened existing literature by providing reasons for patients' and carers' emotional and behavioural responses. Mapping my findings against two theoretical models has assisted in explaining the findings.

I had initially viewed the study as a way to establish whether care for patients with AMI would be affected by moving to a different care setting. This highlighted two issues. It was important to ensure I did not just hear what I wanted to hear and look for particular findings. I was aware of my own lens, being a coronary care nurse could have influenced my world view. In actual fact, my lack of knowledge of caring for patients receiving PPCI and my own personal experiences of being ill and being a carer meant I was receptive to the data and able to suspend prior assumptions.

8.5 Implications for clinical practice

The findings from this study have implications for improving patient care and patient participation. This study revealed the emotionality of the experience of PPCI from the perspectives of patients, carers and nurses. The key findings have discovered the variability in the three groups' experiences as they viewed the PPCI before, during and after and the extent to which these experiences influenced the well-being and outcome for the individual (self). The study has also drawn attention to the ways patients, carers and nurses work together and against each other.

In practice, the findings will help to understand what it means to patients when they become unexpectedly ill with an AMI and how they cope with being a patient and the sick role. The findings have uncovered the complex journey that can then ensue as patients and nurses compete for who has control or who is allowed to have control. The findings also emphasise the importance of information provision for both patients and carers. Both need information to help them understand and make sense of their situations. Carers not knowing and not being told means the worst is feared. Patients not understanding the cause of the AMI also led to fears returning. For nurses involved in caring for patients, the findings highlight the importance of patient engagement and prioritising discussion about the illness and treatment. There was a tendency to just get the job 'done' rather than explain what was happening and why. The provision of encouragement and reassurance were characteristics welcomed and needed by patients and carers whilst they felt vulnerable.

Understanding more about nurses' own values, beliefs and assumptions will be important for enhancing and informing caring activities. The importance of a trusting atmosphere to enable individuals to feel safe and secure was a prominent voice. Nurses have the skills and knowledge to make a huge difference but in doing so they have to move away from the presumption that patients should act in certain ways when deemed sick. Patients and carers questioning nurses about their actions and decisions are not being non-compliant or difficult rather the findings suggest they simply want to know more about the reasons for why they are being treated in certain ways. Addressing these issues will afford nurses greater priority in promoting patient outcomes. Rather than reacting to symptoms, sickness and monitoring equipment nurses need to be active creators of their own practice. The narratives gathered will be useful for nurses new to cardiac care but also for experienced nurses who may be unaware of patterns of caring.

The knowledge gained from my study can inform innovative models to create a space that understands individual differences rather than individuals being categorised as being sick or well, secure or insecure, confident or vulnerable. Rather there is a need to restore the balance so individuals feel comforted and valued. The identified voices and journeys bring individuals' concerns to the fore. This can be used to add onto existing knowledge for nurses working in cardiac settings who are caring for patients waiting, receiving and recovering from PPCI and supporting carers. This thesis has shown that whilst managing symptoms and the AMI are important for all concerned, it is also about the individual at the centre of the experience. Recognising the emotional states and assessing the different ways in which individuals manage their selves is crucial. By understanding the different types of journeys and voices, nurses will be able to guide patients and carers more effectively through the entire landscape (hospital, home and cardiac rehabilitation).

These findings should spur others on to keep asking questions. The more we understand about the challenges facing individuals, the choices they make and the reasons for doing so, the more it will be possible to understand how different situations are reacted to and perhaps more importantly why these came about. Nurses need to be asking questions about systems of care and processes, what is considered as routine and standard and what is not.

8.6 Future direction of research

The following areas for future research that have emerged have real potential to impact patients', carers' and nurses' experiences in the acute cardiac setting but also in all areas of nursing. There is a need to bring forward the voices of participants so the meanings, concerns and issues important are heard by others. Improving patient outcomes is not just about the effectiveness of treatments but also understanding the risks and benefits of individuals' emotional states for the lay person and professional. Further studies are warranted to investigate the findings of my study.

More theoretical work needs to be undertaken on understanding the internal and external factors that influence and affect caring situations. The attachment theory has provided a useful perspective for understanding how the 'self' and 'other' are affected. Further research could examine different types of individuals to understand whether different strategies are adopted to manage PPCI and the effectiveness of these.

It was intriguing to see the way conflict occurred when patients adopted behaviours seen as unacceptable to nurses and the ways patients became annoyed when nurses failed to behave in a way they had expected. In particular, conflict was noted when patients did not behave as a sick patient. The perceived expectations widely differed. Exploring the ambiguities and conflicts of the patient role are important aspects to research because of the emotional aspects of hospitalisation.

One of the key concerns raised in existing literature and in my findings was the way in which information was provided to patients and carers and how it was received. There are many ways this can be achieved but it is imperative that nurses and other health professionals understand individual differences. This may account for why some patients and carers are struggling but this is such an important issue because patients may have readmissions so healthcare costs will soar. It is an issue that needs to be addressed as soon as possible.

8.7 Implications for nurse education

The narratives collected in this study will be of use in a variety of ways. Whilst it is recognised the narratives could cause sensitivity because of the different voices used to characterise caring encounters with nurses, it is the meaning of the participants' experiences that have the potential to inform educational programmes and clinical teams. These narratives reflect the ways in which individuals managed themselves when dealing with different challenges and struggles. In understanding their

evaluations and interpretations there is much to be gained with regards to the following:

- Importance of explaining rationale for care activities
- Provision of information and health education
- The importance of multiple interactions with patients and carers
- Ways to reduce emotional distancing and emotional distress
- Awareness of the impact of technology upon caring and patients

To help facilitate this, nurses will require provision of training and support. Nurses need to develop ways during their short contact with patients and carers to initiate a dialogue which identifies patients' needs. Instead of concentrating on biological needs (treatment of symptoms) there needs to be more attention on improvements in activities of daily living, self-worth and self-esteem. Addressing these factors may be effective for promoting, challenging and increasing health behaviours. Nurses often felt more in control when they were able to do something and take action. However, my findings have shown that sometimes just sitting quietly and empathetically with a patient who has recently received a PPCI, can be more beneficial.

It was unclear in my study whether a model of health was endorsed within the cardiac care setting. Whilst some of the nurses advocated collaboration with patients and carers to empower patients, there remained a prescriptive influence on the nature of education. Therefore education needs to address the role of nurses in the cardiovascular field to make sure patients and carers are given meaningful information which will support their capability to self-care and care for the self.

The findings of this study suggest nurses understand their caring work from the standpoint of making patients well again and keeping them safe from harm. The interpretation and discussion of these narratives could be used as a starting point for examining the caring practices of less-experienced nurses. It was noted in the findings that nurses new to cardiac care were anxious and felt 'insecure' about how they could accomplish care in the emergency setting. Different responses could be explored and discussed. Mindful emotion regulation can enable nurses learn to recognise when they are trying to regain a sense of control by exercising control over patients or when coercing a patient to do something which is important to the nurses. At a time in the NHS when pressures are high, the importance of learning how to manage different situations in the midst of chronic pressures, time conflicts and competing demands will benefit nurses and patient's well-being.

8.8 Contribution to new knowledge

The methodology and findings of my study differ from existing studies surrounding individuals' experiences of PPCI. The inclusion of cardiac nurses in addition to patients and carers has meant I have gathered different experiences and different outlooks. I have added new knowledge. This study extends the literature by shifting the focus from hearing predominantly satisfied voices to understanding self-identity and emotions. This research brings new appreciation to these three essential groups.

The types of journeys and voices provided understanding about what it is like and how experiences are interpreted and evaluated. Some of these voices had not previously been heard. Even though the interventional treatment (PPCI) was the same for all; no journey was the same. Whilst all the patients, carers and nurses 'felt pleased' at the end, the dominance of feeling insecure and vulnerable was heard on occasions in almost all participants. Nurses experienced similar voices to the patient and carers when their personal comfort and control was also reduced. We must listen to these voices.

The manner in which the research has been undertaken is a novel and innovative approach. Firstly the experiences of patients, carers and nurses have never been explored in this way before. Secondly, using vignettes was a different way to giving the nurses an insight into patients and carers experiences. My intention for developing these was to stimulate reflection, discussion and potentially improve understanding. I wanted to give something back from the first phase of data collection to the nurses. I felt it was important to share preliminary findings from my study with the nurses and potentially have an impact on their understanding of patient and carer experiences in the research setting. I realised this was an innovative way to use the vignettes. Doing so made the research accessible to those providing care to understand their representations of their experiences. These vignettes can also be used to educate nurses working in cardiac care.

In summary, several issues have emerged from the findings. My findings will help to understand and compliment patterns where there is a sudden onset of illness and effective treatment to remove those symptoms. This study has emphasised aspects of hospital care, interactions with others and illness can reduce or enhance personal control and comfort and influence the value of the self. Inadvertently, the culture of nursing activities can keep patients dependent on others by keeping patients as non-participants in care.

The emotional responses and behaviours identified in my study raises some important issues relevant to those providing care. The findings show that whilst the interplay between these factors are individualised, there is much that can be done to promote success and reduce failure, so that individuals can be helped to cope. The personal gain of achieving a good outcome outweighed the difficult times. These stories provide understanding from fresh perspectives and can be used to plan care and inform others. By listening and engaging with individual's experiences it has been possible to understand what mattered to patients, carers and nurses surrounding their experiences of PPCI. Findings from this research will be shared through different routes. A compilation of the stories will be published in specialist cardiac journals as well as general nursing journals so that these findings can reach a wide audience. A report summarising the key findings will also be given to the Heart Attack Centre.

8.9 Conclusion

This research study has addressed a gap in the literature and built upon the work of others who have examined the experiences of PPCI. A key theoretical contribution was the recognition of different voices heard within the patients', carers' and nurses' experiences. These voices represented different journeys and was a new way of exploring systems of care, relationships with others and managing the 'self'. The need to support patients, carers and nurses was notably highlighted because there were times when they all felt at risk, insecure and vulnerable. This thesis has provided an important contribution to nursing knowledge.

8.10 Final reflexive statements

I undertook this PhD because I wanted to discover more about the experiences of patients, carers and nurses surrounding PPCI, following changes to the treatment pathway. From the outset, the intention was to make a contribution to knowledge and understanding in this area of cardiac care. After completion of my MSc I wanted to do more research and develop more skills.

Like most PhD students, my own journey has gone forwards, backwards and sideways. Just like my participants, I have had to deal with vulnerabilities and insecurity. These have related both to the doctorate, my own personal illness and family illness encounters. In my own way, I have also experienced three journeys. At the beginning my doctorate seemed relatively straightforward. I knew the direction in which I was headed. I knew this journey would be long and probably uphill for the majority of its duration. There were diversions that I had not expected to encounter but to keep the journey going I have had to find ways to get it back on track. These were the times when I felt I needed rescuing. This journey has definitely been 'bumpy' and has resulted in much revising, re-mapping and re-routing of my thinking.

I also have listened to my different voices. The 'quiet' voice has reflected my constant thinking, searching and doing. The 'feeling pleased' voice is having the privilege to listen to my participants narratives and of knowing the findings from my research will provide a better understanding of PPCI experiences for nurses working in the cardiac setting. The 'insecure' voice has been present for the majority of my doctorate and is the voice that made me ask questions and re-examine my thesis. The 'annoyed' voice has also driven this thesis forward. Until now I had not realised the inner strength and ambition I had within me. Finally the 'protecting' voice concerned the completion of this thesis. I wanted to explore the experiences of patients, carers and nurses surrounding PPCI to find out what was important and what mattered to them.

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Appendix I Studies informing types of voices

Studies surrounding PPCI and PCI

Author and year	Design and Methods	Sample	Voice Types and Themes
Astin, Jones and Thompson, 2005	Quantitative Questionnaire & scale	140 PTCA patients	Anxious High anxiety scored pre-PTCA. Reduction in symptoms and perceived threat of CHD decreased scores significantly post-PTCA.
Astin and Jones, 2006	Quantitative Questionnaire	117 PTCA patients	Feeling fixed Patients believed intervention would cure illness. Beliefs were confirmed when symptom-free.
Astin et al, 2008	Qualitative Interviews 3-12 days post discharge	29 PPCI patients	Uncertain Information did not always meet needs. Unclear of what they were allowed to do post-discharge. Satisfied Satisfied with style of delivery, timing and format of education. Written information considered valuable before and after PPCI.
Astin et al, 2009	Mixed Interviews & Questionnaire 3-12 days post discharge	29 PPCI patients	Feeling fixed Patients amazed they felt well so quickly. Believed PPCI had cured and controlled AMI. Uncertain Mismatch in expectations and reality. Expected to have a scar or have surgery. Speed of events enhanced uncertainty. Quiet Patients were fearful about the future pre-PPCI. During the PPCI, disconnected from what was happening; gave control to health professionals. Satisfied Pleased with outcome for self. Relieved symptoms went away as soon as PPCI was finished. Realised they may have died without PPCI. Knowing Patients believed they were in the hands of experts; who knew how to care for them.
Astin et al, 2014	Quantitative Questionnaire	254 PTCA patients	Uncertain Patients felt better prepared when given information pre-procedure.
Bowling et al, 2008	Quantitative Self-reported survey	53 ACS patients admitted from A&E	Feeling fixed Treatment choice based on benefits to returning to health. Angioplasty ranked higher than surgery and medications.
Caldwell et al, 2007	Qualitative Interviews 2 days–11 weeks pre-PCI	20 PCA patients	Anxious Physical and psychological lack of control during procedure. Fears related to not known outcome and risk of complications from procedure. Women experienced more fears than men.

Carter et al, 2010	Mixed	7 hospitals delivering PPCI 222 staff	Knowing Staff voiced pride in undertaking work that saved lives. Immense job satisfaction. Liked the unpredictable workload.
Corones, Coyer & Theobald, 2009	Qualitative Interviews 4-6 weeks	10 PCI patients	Uncertain Misconceptions about reasons for requiring PCI. Lack of pain, absence of scar and simplicity.
Dullaghan et al, 2014	Qualitative Interviews < 4 weeks of diagnosis	15 AMI patients 5 x PPCI; 5 x thrombolysis; 5 x NSTEMI	Feeling fixed Viewed PPCI as a life-saving treatment. Speed of treatment and rapid recovery. Uncertain Confidence wavered about whether important lifestyle changes could be achieved. Quiet Let those caring for them take control. Did not always know what was happening to them. Anxious Urgency of PPCI indicated seriousness of illness. Realised gravity of risks for them. Satisfied Had received the right treatment at the right time. The quick recovery confirmed impressions.
Higgins, Dunn and Theobald, 2000	Qualitative Interviews 1 month post	11 PTCA patients	Anxious Concerned about future health. Used a problem-solving approach to cope and regain control. Recovery viewed as 'good or bad'.
Higgins, Dunn & Theobald, 2001	Qualitative Interviews 1 month post	11 PTCA patients	Quiet Confidence in medical team dispelled fears and made patients feel safe. Anxious Fear of ongoing chest pain and anxiety related to the unknown. Patients had to 'gear up' for PTCA.
Hirani, Pugsley & Newman, 2006	Quantitative Questionnaire	214 patients	Feeling fixed Patients believed PCI improved well-being. PCI valued higher than surgery and medications. Believed it could cure CHD and shorten illness.
Lenzen, Gamel & Immink, 2002	Mixed Questionnaire & Interview	86 PTCA patients First time or repeater	Anxious Increased anxiety in repeat-PTCA group compared to first-time patients. Anxiety related to return of symptoms rather than procedure.
Lyons & Fanshawe, 2002	Qualitative Interviews	17 patients PCA or PTCA	Uncertain Differed from what was expected to happen. Surprised about sensations experienced.
Lundén, Bengtson, Lundgren, 2006	Qualitative Interviews	14 PCA/PCI patients	Quiet Dependent on others during and after procedure. Anxious Had to distance self from procedure to cope.
Lundén, Lundgren & Lepp, 2012	Qualitative Interviews	14 nurses radiographer catheter laboratories	Knowing Wanting to form a therapeutic relationship quickly to make patients feel safe. Satisfaction from creating dialogue and managing difficult situations.

Lundén, et al, 2013	Mixed Interviews and questionnaires	42 PTCA patients	Uncertain Felt insecure about events before, during and after PTCA. Heightened by lack of information, loss of control and fear of complications. Anxious Worried about outcomes and possibility of surgery. Anticipated as painful procedure.
Page, Jackman, Snowden, 2008	Qualitative Interviews 4-6 weeks post discharge	11 PTCA patients	Anxious Removal of sheath provoked anxiety because it was painful. When viewed as routine, procedure caused less anxiety.
Radcliffe et al, 2009	Qualitative Interviews 13-90 days after PPCI	15 PPCI patients	Feeling fixed Short hospitalisation reflected wellness. Uncertain Unanswered questions post-discharge. Surprised by limitations on activity because patients felt so well. Quiet Unable to comprehend the situation. Did not want to make decisions. Satisfied Pleased with overall service particular because of the short length of treatment and recovery. Knowing Patients trusted the healthcare professionals looking after them.
Sampson, O'Cathain and Goodacre, 2009	Qualitative Interviews 1-4 weeks post PPCI	10 PPCI patients & 6 carers	Feeling fixed Patients felt so well after the PPCI. Amazed by speed of treatment and recovery. Quiet Life and death situation. Felt unwell; left the decision making to others. Content to relinquish control. Satisfied Satisfaction linked to whole experience; grateful for all aspects of care. Knowing The patient had been cared for in the right place with the right treatment by people who had the right knowledge.
Sampson, O'Cathain and Goodacre, 2010	Mixed Interviews pre & post-survey 4 weeks post-AMI	10 patients 6 carers 595 patients 418 carers 17 patients	Uncertain Felt unprepared by information given about AMI and medications. Satisfied High satisfaction with overall care. Patients and carers impressed by speed of treatment and smoothness in care delivery. Unexpected optimism.
Trotter, Gallagher & Donoghue, 2011	Quantitative Questionnaire Pre-PCI, day 1 post-PCI, 1 week post-PCI	100 PCI patients	Anxious Anxiety highest pre-PCI. Worried about outcome, risk of surgery, puncture site, immobility and having chest pain. Existing anxiety and depression strong predictors. Anxiety reduced post-PCI.

Studies surrounding cardiac surgery, carers of critically ill patients and cardiac nurses

Author and year	Design and Methods	Sample	Voice Types and Themes
Ågård and Harder, 2007	Qualitative Interviews	4 spouses 3 parents Critical care	Uncertain Carers struggled with thinking about the past, present and future. Had to endure uncertainty and find ways to cope and adapt.
Almerud, et al. 2007	Qualitative Interviews	9 patients post-critical care admission	Quiet Being a patient meant being dependent on others for everything. Patient felt disconnected by their illness, the environment and the nurses.
Auerbach, et al. 2005	Quantitative Questionnaire	40 relatives Critical care patients	Uncertain Relatives did not respond well to doctors who were seen as unfriendly.
Chein, et al. 2006	Quasi-experimental Pre and post-test	66 carers Critical care patients	Uncertain The manner in which health professionals provided information could increase or reduce uncertainty. When families believed health professionals made a conscious effort to improve the ways they gave information to relatives, uncertainty reduced.
Doering, McGuire & Rourke, 2002	Qualitative Telephone interviews	89 cardiac surgical patients	Quiet Felt depersonalised. Expectations did not match recovery expectations. Did not feel health professionals listened to them.
Dougherty, Pyper & Benoliel, 2004	Qualitative Interviews 1, 3, 6, 12 months	15 partners of cardiac arrest patients	Uncertain Even though the immediate risk had been managed, risks for the future remained post-defibrillation insertion.
Eggenberger and Nelms, 2007	Qualitative Interviews	11 families of critical care patients	Uncertain Carers experienced vulnerability and insecurity. The experience was overwhelming and exhausting.
Engström and Söderberg 2004	Qualitative Interviews	7 spouses of critical care patients	Uncertain Fearful about the future and possibility that something else bad would happen to the patient. Did not feel in control.
Gardner, et al. 2005	Qualitative Interviews 6 months post-surgery	8 patients cardio-thoracic surgery	Quiet Patients felt sick. Reported varying degrees of pain and physical disruption during recovery. Eventually reached a 'turning point' where they felt better (well).
Holm, et al. 2012	Qualitative Interviews	9 carers of post-arrest patients	Uncertain After discharge, carers frightened about how they would cope when patients returned home.

Hughes, Bryan and Robbins, 2005	Qualitative Interviews	8 relatives of critical care patients and 5 nurses	Uncertain Having to speak to different doctors and nurses' exacerbated uncertainty and distrust.
Johansson, Hildingh & Fridlund, 2004	Qualitative Interviews	18 relatives/ close friends	Uncertain The present and future was uncertain when the patient was ventilated and unconscious.
Karlsson, et al. 2011	Quantitative Questionnaire	35 relatives of critical care patients	Uncertain Information needed at regular intervals. When doctors were unavailable, uncertainty increased.
Kutash and Northrop, 2007	Qualitative Interviews	6 visitors Critical care waiting room	Uncertain The entire experience was full of uncertainty but the waiting room was a place where support could be sought from other families.
Lapum, et. 2010	Qualitative Interviews & diaries 4-6 weeks post-surgery	16 cardiac surgical patients	Quiet The effect of being attached to cardiac monitors made patients view their bodies in a different way. There was a reliance on the machinery to protect them. The responsibility lay with others caring for the machines.
Larsson, et al. 2013	Qualitative Interviews 1.5-6 weeks	20 relatives Post cardiac arrest	Uncertain Relatives initially found the situation felt unreal. There was uncertainty as to whether they could manage again. Difficult to assimilate information.
Leegaard, Fagermoen 2008	Qualitative synthesis	Cardiac surgical patients	Quiet Patients allowed health professionals to care for them. A sense of disruption, loss and fear.
McKiernan, McCarthy, 2010	Qualitative Interviews	6 family members of critical care patients	Uncertain Information was a necessary requisite for managing the unknown situation.
Smallwood and Humphreys 2007	Qualitative Interviews	12 nurses Initiating Thrombolysis	Knowing Nurses' wanted to do their best for patients. They knew they had the skills and knowledge to provide care which would make a difference.
Smallwood 2009	Qualitative Interviews	7 nurses in a cardiac team	Knowing Nurses' priorities were to obtain a diagnosis quickly in order to provide correct and necessary treatment. Used their skills, experience and competence to provide the necessary information.
Svedlund, Danielson & Norberg, 1999	Qualitative Interviews	34 coronary care nurses	Knowing Caring situations were managed by clues acquired from the patient. These clues were used to decide how to manage the situation.

Appendix II**Patient demographic form**

Patient Code	
Patient's Name	
Marital Status	
Date of Birth	
Telephone Number	
Address	
Email	
Date & time of Interview	
Consent form signed prior to Interview	
Date of Heart Attack	
Length of hospital stay	
Date of Discharge	
Type of Carer	
Permission to contact G.P.	
G.P. Contact Details	

Appendix III

Letter sent to GP

Address:

Tel.

Email:

Date

Dear

Research Title: Exploring experiences of treatment for a heart attack

I am writing to inform you that (insert participant name) has agreed to participate in a research study.

The focus of the research study is to discover the experiences of patients who have undergone a primary angioplasty for the treatment of their acute myocardial infarction. It is hoped that by asking and listening to their experiences I will get information and understanding that may otherwise not have been known. Discovering what issues are important to them will provide a better understanding of the situation so that relevant interventions might be taken by health care professionals to identify and address the needs of patients.

Who is organising the study?

Ms Mary Edmonds, a PhD student at Anglia Ruskin University and Senior Lecturer in Cardiac Care is carrying out the study at Hospital name. I am supervised by (name of supervisors) at Anglia Ruskin University, Cambridge.

What does it involve?

On the day of the patients discharge, your patient was given an information sheet explaining what the study involves, the voluntary nature of participation, issues of confidentiality and how to make a complaint. Following agreement to participate, an interview will be arranged within two weeks of their hospital discharge. Patients will complete a consent form immediately before the interview. The interview is expected to last approximately one hour and will be digitally-recorded. It will be conducted in private and can be stopped at any time. Following transcription, the patients will be sent a copy of a transcript of their interview. They will be asked to read through the transcript and to check whether it was a true reflection of what they said. A stamped addressed envelope will be provided for the participants to return the transcript. This will be the last point of contact between the researcher and patient.

If you have concerns regarding this patient's participation in this study or would like to discuss anything further please do not hesitate to contact me.

Yours sincerely

Mary Edmonds

Appendix IV**Nurse demographic form**

Nurse Code	
Nurse's Name	
Length of time qualified	
Qualifications	
Length of time working in heart attack centre	
Place of work	
Date & Time of Interview	

Appendix V

Letter inviting patients into the study

Address:

Tel:

Email:

Date

Dear Sir/Madam

Research Title: Exploring experiences of treatment for a heart attack

You are being invited to take part in a research study. Permission to approach you has been sought from the Cardiac Consultant. Before you make your decision, it is important for you to understand why the research is being done and what it will involve. Please take time to read the enclosed Participant Information Sheet. If there is anything you are not clear about or would like more information please feel free to contact me (use above contact details).

If you would like to participate in this research, you can contact me by telephone or email or complete the attached response form and return in the stamped addressed envelope. Following agreement to be interviewed I will arrange a time, date and venue convenient for us to meet. The interview will need to happen within two weeks of your discharge from hospital.

I would also like to invite the participation of your main carer into the research study. The main carer can be your partner; parent; relative; professional carer; friend. A Participant Information Sheet is enclosed. It is hoped that by asking you and your main carer directly and listening to your experiences, I will get information and understanding that may not otherwise have been known. If your main carer does not wish to participate, this will not exclude you from participation. Written consent will be obtained immediately before the interview.

Yours sincerely

Mary Edmonds

Appendix VI

Participant Information Sheet for Patients

Exploring experiences of treatment for a heart attack

You are being invited to take part in a research study. Before you make your decision, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. If there is anything you are not clear about or would like more information please feel free to contact Mary Edmonds.

What is the purpose of the study?

Patients diagnosed with a heart attack are transferred directly to a cardiac catheter laboratory where they undergo an emergency treatment called primary angioplasty. Following 2-3 days in hospital they are discharged home. This is still a relatively new area of care in the UK, rather than treating elective patients, nurses are now managing patients who are dealing with an emergency event. Given that the nurse-patient relationship has a central role in the management and journey of these patients, it is important that the concerns and needs of the patients and their family are recognised and addressed by nurses. Patients have a unique point of view on their experience of the treatment they received for their heart attack and it is hoped that by asking you directly, and listening to your experiences of being in hospital, we will get information and understanding that we may not otherwise have known. Discovering what issues are important to you will provide a better understanding of the situation so that relevant interventions might be taken by health care professionals to identify and address the needs of patients.

Do I have to take part?

Your participation in the study is entirely voluntary. If you decide to take part you will be given this information sheet to keep. You are under no pressure to take part and may withdraw from the study at any time without having to explain why. In the event you choose to withdraw, your interview data will be retained and continued to be used in this research. If you choose not to participate this will not influence the care you will receive.

What will happen to me if I take part?

If you agree to take part in the study, you will be interviewed about your experiences of the treatment you received in hospital for your heart attack. The interview is expected to last approximately one hour and will be recorded by digital recorder. It will be conducted in private and can be stopped at any time. The interview will be arranged at a venue and time convenient for you within two weeks of your discharge from hospital. A transcript of your interview will be sent to you so that you may check that it is a true reflection of what was said. A stamp addressed envelope will be provided to send this back in the post.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researcher who will do their best to answer your questions. You can also contact the researcher's supervisors (contact details below). If you remain unhappy and wish to complain formally, you can obtain advice and support from the Patient Advice and Liaison Service. If you have clinical concerns these should be directed to the care team as the researcher is in a research capacity to discuss your experiences only.

Will my taking part in the study be kept confidential?

No other person will be present at the time of the interview and the contents of your interview will remain strictly confidential. This is to preserve your privacy and also to encourage you to speak freely about your experiences about the treatment. You will not be identified on the digital recording and only the interviewer will have access to your identity. If during the interviews something was said that could indicate harm or malpractice I would be bound by my professional code to disclose this, should you wish to make a complaint I would refer you in the first instance to PAL's.

When the interview is finished, the digital recording will be numbered and kept in a locked cabinet, until its contents are typed up word for word. The recording will be listened and typed up by the researcher or an administrator. All data will be analysed by the researcher. The transcript will remain confidential and be kept in a locked cabinet at Anglia Ruskin University. Extracts from participants' interviews may be used when the researcher interviews nurses about their experiences of the treatment for a heart attack. The researcher intends to read some extracts about patient's experiences and gather the nurses' responses to these. These extracts will be anonymised so that you cannot be identified. All digital recordings will be stored for up to 12 months once the study is complete and then be destroyed. Any reports or publications made as a result of this study will not identify your name.

What are the possible disadvantages and risks of taking part?

Recalling your experiences of the treatment for your heart attack may be upsetting for you, as you will be interviewed not long after your heart attack has happened. If you become distressed, the researcher will listen to your concerns, provide additional support if required, end the interview temporarily or permanently, encourage you to contact your GP and/or support network (cardiac rehabilitation team).

What are the possible benefits of taking part?

There are no obvious benefits to you. However we feel it is very important to find out about your experiences of the treatment you received for your heart attack. It is hoped that this information will enable us to change practice and improve patient and carer experience.

Involvement of the General Practitioner/Family doctor (GP)

Your GP will be informed by letter of your participation in this research.

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 by the -----Research Ethics Committee and was given a favourable ethical opinion of the research.

Who is organising the research?

Mary Edmonds is the lead investigator. This study will form part of a PhD qualification. Mary Edmonds is currently working as a senior lecturer at Anglia Ruskin University, Cambridge providing education on cardiac care for student nurses and for qualified nurses involved in the care of patients with cardiac disorders.

Contact for further information:

Supervisors for Research:

Thank you for taking time to read this information sheet

3 copies required: top copy for researcher; one copy for patient; one copy to be sent to GP and be kept with research subject's medical notes.

Appendix VII

Participant Information Sheet for Carers

Exploring experiences of treatment for a heart attack

You are being invited to take part in a research study. Before you make your decision, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. If there is anything you are not clear about or would like more information please feel free to contact Mary Edmonds.

What is the purpose of the study?

Patients diagnosed with a heart attack are transferred directly to a cardiac catheter laboratory where they undergo an emergency treatment called primary angioplasty. Following 2-3 days in hospital they are discharged home. This is still a relatively new area of care in the UK, rather than treating elective patients, nurses are now managing patients who are dealing with an emergency event. Given that the nurse-patient relationship has a central role in the management of these patients, it is important that the concerns and needs of patients and their family are recognised and addressed. A heart attack can be a sudden and unexpected event for the person experiencing the heart attack but it is also a challenging time for the carer. Very little research has been undertaken to find out about the experiences of carers surrounding the treatment for a heart attack. It is hoped that by asking you directly and listening to your experiences we will get information and understanding that we may not otherwise have known. Discovering what issues are important to you will provide a better understanding of the situation so that relevant interventions might be taken by health care professionals.

Do I have to take part?

Your participation in the study is entirely voluntary. If you decide to take part you will be given this information sheet to keep. You are under no pressure to take part and may withdraw from the study at any time without having to explain why. In the event you choose to withdraw, your interview data will be retained and continued to be used in this research. If you choose not to participate in this research your partner/relative is still able to participate should they wish to do so.

What will happen to me if I take part?

If you agree to take part in the study, you will be interviewed about your experiences of the treatment your partner/relative received in hospital for their heart attack. The interview is expected to last approximately one hour and will be recorded by digital recorder. It will be conducted in private and can be stopped at any time. The interview will be arranged at a venue and time convenient for you within two weeks of your discharge from hospital. A transcript of your interview will be sent to you so that you may check that it is a true reflection of what was said. A stamped addressed envelope will be provided to send this back in the post.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researcher who will do their best to answer your questions. You can also contact the researcher's supervisors (contact details below). If you remain unhappy and wish to complain formally, you can obtain advice and support from the Patient Advice and Liaison Service. If you have any clinical concerns these should be directed to the care team as the researcher will be there in a research capacity when you discuss your experiences about the treatment.

Will my taking part in the study be kept confidential?

No other person will be present at the time of the interview and the contents of your interview will remain strictly confidential. This is to preserve your privacy and also to encourage you to speak freely about your experiences about the treatment. You will not be identified on the digital recording and only the interviewer will have access to your identity. If during the interviews something was said that could indicate harm or malpractice the researcher would be bound by her professional code to disclose this.

When the interview is finished, the digital recording will be numbered and kept in a locked cabinet, until its contents are typed up word for word. The recording will be listened and typed up by the researcher or an administrator. All data will be analysed by the researcher. Extracts from participants' interviews may be used when the researcher interviews nurses about their experiences of the treatment for a heart attack. The researcher intends to read some extracts and gather the nurses' responses to these. These extracts will be anonymised so that you cannot be identified. The transcript will remain confidential and be kept in a locked cabinet at Anglia Ruskin University. All digital recordings will be stored for up to 12 months once the study is complete and then be destroyed. Any reports or publications made as a result of this study will not identify your name.

What are the possible disadvantages and risks of taking part?

Recalling your experiences of the treatment for your partner/relative's heart attack may be upsetting for you, as you will be interviewed not long after the heart attack has happened. If you become distressed, the researcher will listen to your concerns, provide additional support if required, end the interview temporarily or permanently, and encourage you to contact your GP.

What are the possible benefits of taking part?

There are no obvious benefits to you, however we feel it is very important to find out your experiences surrounding the treatment your partner received for their heart attack. It is hoped that this information will enable us to change practice and improve patient and carer experience.

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 by the ----- Research Ethics Committee.

Who is organising the research?

Mary Edmonds is the lead investigator and is not involved as a member of the clinical team. This research will form part of a PhD qualification with Anglia Ruskin University, Cambridge.

Contact for further information

Supervisors for Research:

Thank you for taking time to read this information sheet

3 copies required: top copy for researcher; one copy for patient; one copy to be sent to GP and be kept with research subject's medical notes.

Appendix VIII

Letter inviting nurses into the study

Address:

Tel:

Email:

Date

Research Title: Exploring experiences of treatment for a heart attack

You are being invited to take part in a research study. Your Unit/ward manager has given you an information pack regarding this research study. Before you make your decision, it is important for you to understand why the research is being done and what it will involve. Please take time to read the Participant Information Sheet. If there is anything you are not clear about or would like more information please feel free to contact me (contact details above).

If you would like to participate, please complete the response form and return it in the stamped addressed envelope within the information pack alternatively you can email me. I will then contact you to arrange a time, date and venue convenient for us to meet. The interview will not conflict with your clinical duties. Written consent will be obtained immediately before the interview.

Yours sincerely

Mary Edmonds

Appendix IX

Participant Information Sheet for Nurses

Exploring experiences of treatment for a heart attack

You are being invited to take part in a research study. Before you make your decision, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. If there is anything you are not clear about or would like more information please feel free to contact Mary Edmonds.

What is the purpose of the study?

The application of primary percutaneous coronary interventions (PPCI) has had a significant impact on decreasing mortality and improving blood flow to the myocardium. Patients with an acute myocardial infarction (MI) are transferred directly to a cardiac catheter laboratory where they undergo primary angioplasty. Following 2-3 days in hospital they are discharged home. This is still a relatively new area of care in the UK, rather than treating elective patients, nurses are now managing patients who are dealing with an emergency event. Given that the nurse-patient relationship has a central role in the management and journey of these patients, it is important that the concerns and needs of the patients and their family are recognised. Very little research has been undertaken to find out the views of nurses surrounding the treatment for a heart attack. It is hoped that by asking you directly and listening to your experiences, we will get information and understanding that we may not otherwise have known. Discovering what issues you feel are important to the patients and their family will provide a better understanding of the situation so that relevant interventions might be taken by health care professionals.

Do I have to take part?

Your participation in the study is entirely voluntary. If you decide to take part you will be given this information sheet to keep. You are under no pressure to take part and may withdraw from the study at any time without having to explain why. In the event you choose to withdraw, your interview data will be retained and continued to be used in this research.

What will happen to me if I take part?

If you agree to take part in the study, I will interview you and encourage you to talk about your experiences of the treatment given for a heart attack. The interview is expected to last approximately one hour and will be digitally recorded. It will be conducted in private and can be stopped at any time. The interview will be arranged at a venue and time which will not conflict with your clinical duties. A transcript of your interview will be sent to you so that you may check that it is a true reflection of what was said. A stamp addressed envelope will be provided to send this back in the post.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researcher who will do their best to answer your questions (see contact details below). Alternatively you can contact your Unit/Ward manager.

Will my taking part in the study be kept confidential?

Any opinion, perspective or experience you share during the interview will be kept strictly confidential. In the event of a disclosure that is perceived as a threat to patient care, all nurse registrants are required to take appropriate action to ensure both safe care and public protection. All nurses are under the obligation to comply with the Nursing & Midwifery Council Code of Conduct, which would take precedence over any agreement entered into as part of this study. If during the interviews something was said that could indicate harm or malpractice the researcher would be bound by her professional code to disclose this.

When the interview is finished, the digital recording will be numbered and kept in a locked cabinet, until its contents are typed up word for word. The recording will be listened and typed up by the researcher or an administrator. All data will be analysed and known only to the researcher. The transcript will remain confidential and be kept in a locked cabinet at Anglia Ruskin University. You will not be identified on the digital recording and only the interviewer will have access to your identity. All digital recordings will be stored for up to 12 months once the study is complete and then be destroyed. Any reports or publications made as a result of this study will not identify your name.

What are the possible disadvantages and risks of taking part?

There may be some inconvenience as the interview will be arranged in your own time. The researcher will negotiate a time and venue which is suitable for you. If you become distressed, the researcher will listen to your concerns, provide additional support if required, end the interview temporarily or permanently.

What are the possible benefits of taking part?

There are no obvious benefits to you, however I feel it is very important to find out your experiences surrounding the treatment for an acute MI. It is hoped this information will enable us to change practice and improve patient and carer experience.

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 by the ----- Research Ethics Committee.

Who is organising the research?

Mary Edmonds is the lead investigator and is not involved as a member of the clinical team. This research will form part of a PhD qualification with Anglia Ruskin University, Cambridge.

Contact for further information

Supervisors for Research:

Thank you for taking time to read this information sheet

2 copies required: top copy for researcher; one copy for nurse.

Appendix X

CONSENT FORM for Patient

LREC Reference Number:

Title of Project: Exploring experiences of treatment for a heart attack.

Name of Lead Investigator: Mary Edmonds

Please initial box

I confirm that I have read and understand the information sheet dated 06/09/2010 (version 1) for the above study and have had the opportunity to ask questions.

☐

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

☐

I agree to the interview being recorded.

☐

I agree to my GP being informed of my participation in the research.

☐

I agree to take part in the above study.

☐

Name of Research Subject

Date

Signature

(Please print)

Name of Research Team member

Date

Signature

(Please print)

3 copies required: top copy for researcher; one copy for patient; one copy to be kept with research subject's medical notes.

Appendix XI

CONSENT FORM for Nominated Carer

NREC Reference Number:

Title of Project: Exploring experiences of treatment for a heart attack.

Name of Lead Investigator: Mary Edmonds

Please initial box

I confirm that I have read and understand the information sheet dated 10/11/10 (version 2) for the above study and have had the opportunity to ask questions.

☐

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

☐

I agree to the interview being recorded.

☐

I agree to access to the study notes to be given to (name of hospital) and professional bodies who may be auditing the study.

☐

I agree to take part in the above study.

☐

Name of Research Subject

Date

Signature

(Please print)

Name of Research Team member

Date

Signature

(Please print)

2 copies required: top copy for researcher; one copy for nominated carer.

Appendix XII

CONSENT FORM for Nurse

NREC Reference Number:

Title of Project: Exploring experiences of treatment for a heart attack.

Name of Lead Investigator: Mary Edmonds

Please initial box

I confirm that I have read and understand the information sheet dated 10/11/10 (version 2) for the above study and have had the opportunity to ask questions.

☐

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

☐

I agree to the interview being recorded.

☐

I agree to access to the study notes to be given to (name of hospital) and professional bodies who may be auditing the study.

☐

I agree to take part in the above study.

☐

Name of Research Subject

Date

Signature

(Please print)

Name of Research Team member

Date

Signature

(Please print)

3 copies required: top copy for researcher; one copy for patient; one copy to be kept with research subject's medical notes.

Appendix XIII Patient vignette for nurse interviews

Patient's experiences

The following passages are constructed from patient's accounts surrounding their treatment experiences for an AMI.

"There were three or four doctors waiting when I arrived at the hospital. The ambulance reversed to the back door and they whipped me straight into the theatre." "They explained to me what was going on and got me to sign a document to agree to the treatment, although the signature on it doesn't bear any relationship to my usual signature." "I was then transferred onto another bed; people were everywhere taking things off and explaining what they were going to do. They were so professional, there was about six or eight of them in there, all knowing what they are doing, nobody asking what they should do, they were all just getting on with it and from that point of view you know you are in the right spot." "At the same time they are quite calmly asking you questions, they were getting the information they needed as they walked in with the stretcher. There was no time wasted at all. It was very slick." Not everyone went straight to the lab, one patient had to wait: "I think there were three heart attacks that morning and I was the third one to arrive. The second was still in the theatre being sorted and so I had to wait. They gave me some morphine and that eased the pain, it didn't take it fully away but I was comfortable. By the time I got to the theatre I hadn't really got any pain."

There was initial uncertainty about what would happen to them. Patients talked about having both "their wrist and the groin prepared." "The doctor was scrubbing my arm and strapping me on the board and then a nurse nipped in with a razor and shaved me down below to cover both angles. However the wrist was adequate so I didn't need to have anything through the groin." Not having to have their chests opened up was a big relief but also led to confusion. "I thought it would be quicker for the surgeons to cut you open and find where your heart is rather than working on your right arm when the heart was over on the left side". It was only when they "I didn't have an anaesthetic I realised I was going to having surgery."

The first sensation many felt was "a cold feeling" from the local anaesthetic. Some patients "felt something happening inside their upper arm, some movement, feeling that something was going through and reaching up to their shoulder. Every time the surgeon pushed a length in, it made contact with my hand but that was the only sensation I got." Another reported "feeling somebody on their leg." "I thought what are they doing with my leg, they should be up here on my chest, I really couldn't understand that." One man felt "a burning and concentrated pain which lasted about

10-15 seconds.” Another described “feeling some heat when he was told the dye was going in.” Most patients were aware “of a big photographic machine going one way and then zooming backwards” but they were unsure of whether this was “an x-ray or some kind of photography.” Those who watched the screen described “seeing a hook cleaning their walls”, “seeing their heart moving on the screen and a little alien wire sort of poking around.”

Patients were “in no doubt that the PPCI was a necessary and life-saving treatment; without this they knew the doctors would not have been able to scan all the arteries, nor could they have checked for other problems and so repaired the damage to their heart.” Many were “surprised at the speed of it all and the ease of the whole thing. I was wondering when this thing was going to finish, so I said how far have we got and he said it’s done.” Putting in the cannula caused the most discomfort. This was described as “horrific and painful”, “when they could not find my veins they kept pushing and pushing”. Many reported “bruising”, “swollen hands” and “difficulty moving their arms afterwards.”

“By the time it had finished they were wheeling me down all of these corridors and all I could see were these ceilings. The next thing I knew I was on the HDU, it was amazing. I remember them sort of sliding me off the trolley bed onto a proper bed saying don’t move, don’t move, just relax we will do the work, you just lay there and all that.” “The nurses started putting these things all over the place and connected them up to this big monitor.” Even when “nobody was beside the bed” patients knew the nurses were “keeping an eye on me, they kept taking my blood pressure and they kept looking at the monitor.” There was mixed feelings when the machines disturbed their sleeping. “One patient’s would go first and that would wake someone else up, then mine would go.”

Patients were constantly reminded “not to move their legs”, “to not cough or laugh to prevent bleeding.” One patient said “who is going to laugh but then said as it happened I did laugh a lot.” Patients wanted “to stand up but they were told they couldn’t” even though they felt really well. “They wouldn’t even allow me to get out of my bed onto a commode that first day. It was a horrendous experience because the stupid cardboard bedpan things are absolutely useless because you have to lie flat on your back, trying to go to the loo and I thought I shall give myself another heart attack. The effort of wanting to go and trying to go meant that the bed got wet and had to be changed twice and I thought this is a stupid arrangement.”

"You end up there as an emergency with nothing. They have to strip you completely; they took everything off and put all your clothes in a bag so then you have got absolutely nothing there what so ever. I ended up wearing a gown with a split down the back. I mean to start with you don't care, but as soon as you feel a bit better it is not. They produce this little toothbrush, toothpaste, comb, bar of soap and they provide a towel and a pack of face cloths. So that was nice because you want to comb your hair as soon as you can and the rest of it so I thought that was a nice touch."

Patients recalled nurses "regularly checking their groin or wrist." The "nurses had to press on my groin" or "wrist area", for some this was "the most painful bit and longer than I thought". One patient described "the nurses checked my wrist every 15 minutes for quite a few hours, they didn't tell me why but I guess they were waiting for the clot to really get a grip."

The next day many patients felt really good and ready for home which was "amazing when you think what had happened in that one moment you are practically at death's door and then you can go home 3 days later." "They took me to the ward but I still had to be monitored. I said I wanted to go to the toilet; it was only about twenty yards from my bed, so the nurse said she would watch me. When I could go to the toilet it was hallelujah but of course every time you get up the monitor goes off and the thing rings at the nurse's station. I got told off for unplugging myself but then later they took it all off me."

"Everybody was so nice, the nurses, doctors, cleaners, the people who brought the food they were really friendly. There were always a couple of nurses and doctors around; my bed was close to the reception so I could always see someone. The first thing they said you don't shout out nurses you call our name so that was very good." "The nurses kept asking me how I was feeling; even when I went to the ward the same nurse popped into see me a couple of times." A patient noted how "one nurse seemed to light up the ward, she was smiling, she had got time to talk to all of the patients, she was explaining whatever she was doing, she had got time to listen to what you were saying and she came in a cheerful way and she went out in a cheerful way, she was superb but they were all good. It sort of boosts you up." "They seemed so confident in what they were doing; they made you feel relaxed and confident. There was no panicking, they had a routine and you knew what was going on." Not everyone felt the same, a female patient felt she "needed more reassurance and information than was given; the nurses didn't talk they were just busy doing in the ward but then they sort of disappeared and I didn't see anybody."

Once the decision about discharge was made “it was just a matter of waiting.” Patients made comments about “when you are feeling good the time does drag very much in there, you are reading and having a cup of tea to pass the time but effectively you are bored but you are also happy if you know what I mean.”

Post discharge many of the patients were uncertain about what they were allowed to do and what sort of checks they would require. “It occurs to you who is going to take my blood pressure, how will I know if it is up or down, will my GP know what to do because he is not a heart doctor.” Many were “still waiting” to be contacted by the cardiac rehabilitation team. There was surprise upon “being told that 90% was blamed on hereditary which was a relief for many as they were thinking why me.”

Appendix XIV Carer vignette for nurse interviews

Carer's experiences

The following passages are constructed from carer's accounts of their experience.

"When we got to the hospital we did not know where to park, you know you are looking for a building not a car park. We saw a porter and he said can I help you? I will phone up and find out where the patient is, so he did. He told us where to go and everything, which was really helpful. You know you are anxious and you can't find how to get in and it is frustrating."

Carers who had arrived in the ambulance described how upon their arrival "people were waiting for them outside. Their husbands were unloaded onto the bed and then these people just strolled out and they found themselves having to run to keep up with them." Carers found themselves "being handed over to a nurse and taken up to the ward, they said your husband's being taken straight in, they are going to do an angiogram so if you would like to wait in the day room and I will come and let you know a bit later what is going on and then that person disappeared."

Carers described how they "sat there for what seemed like ages. I kept sort of looking up and I kept sort of looking you know. There was two patients sitting in the dayroom with their bags, they had to vacate their beds because the ward was so busy and they were waiting to go home. They both said don't worry the staff are really amazing, they will sort them out, they are ever so good. It was reassuring to hear and see people who had received the treatment because when you are waiting you don't know what is going on, you imagine all sorts of dire things happening. After a while a nurse who worked in the operating theatre came to the visiting room to say what stage they were up to with the procedure and to not to worry, it really is nothing, but it's really always something important when it concerns the heart."

The dayroom "was a bit bleak, there was an in-house magazine and one or two novels to read both unsuitable in view of the circumstances. There was a jug of water but it was empty. I asked the nurse is there any chance of some water which she did get for me. Is there any anywhere I can get something to eat, oh I think there is a vending machine in the ward opposite, I went but was only able to find a Twix bar. They were of course looking after my wife brilliantly and of course that's the highest priority, they have a job to get done, obviously I was of secondary importance."

"Eventually I was taken to the high dependency area. The nurses told me to be aware of the tubes and things. I was absolutely dreading it when I walked in, the severity of

it all started hitting me, I thought they are not going to look very good, I was afraid to expect anything but when I saw my husband a huge relief came over me, they looked so fantastic. I was surprised, I wasn't expecting them to look I thought they would be, but they were sitting up in bed looking fine and we were able to have a conversation. You know everything looked so normal and I kept asking are you feeling better. Is everything alright? You know I hadn't realised how grey he had looked, how ill he had looked beforehand."

The nurses were "very helpful and friendly. It was handled so well by everyone, the paramedics, the staff, the doctors, the cleaners, the ones that do the tea, it was more like a family everyone was working together. It made you feel safe. There was a personal feel. You felt that they were actually interested and really cared. They were really nice, I couldn't ask for more, I couldn't expect more. Everything was sort of flowing, even though you can see people are busy, people are constantly coming into hospital and going somewhere, everything around you functions, there was no sort of nervousness, probably because you know they are the finest in their field, they are doing what they are trained to do. When I went home I felt happy to leave knowing they were safe and they were going to be okay there."

"Visiting seemed so easy, on the first day we were told we could stay longer than usual but even on other occasions the nurses were good about the visiting. Twice we were there at the end of visiting or just a little bit after when they made their rounds and they were quite happy for me and my daughter to stay a while, they looked after my husband and then they turned to us. Normally they only allowed two by the bed but because we all had just arrived they let us stay that afternoon the three of us. On one of the days I had something happening with my little boy so I said I might need to bring in my mum's stuff a bit earlier and the nurse said that was no problem and there was no problems with me going in. When you phoned they would actually take the phone to the patient, they said oh yes here they are and put the patient on which was so reassuring. When I came home the night after he was admitted they gave me the mobile number for the actual HDU unit so instead of just having to ring the desk I could ring straight through and I actually spoke to my husband while he was in there which was so nice."

"Any questions you asked they did not have a problem they would answer." However some carers felt "they could have been given more explanations about the recovery phases." One carer noted that "whilst a chart in the waiting room stated what to eat and what not to eat, they had not received a booklet on this which they were really surprised about." It was acknowledged workshops would be attended where upon

everything would be explained but there was a need to know what should happen in the meantime “to reduce the risk of another heart attack.”

The carers were grateful to have had their relatives treated at the hospital even though it was a long way to reach. They “were relieved that patients were in the right place, getting the treatment that had to be given by staff who knew what they are doing. If you are going to have a heart attack, have it near here. We are so fortunate to have somewhere like this hospital and that does inspire tremendous confidence.”

Appendix XV Interview questions for patients

Opening of Interview

- Expression of thanks for participating in the study
- Recap on purpose of study and what will be involved in interview
- Assurance on confidentiality
- Remind participant can withdraw at any time and a reason does not need to be given for withdrawal
- Signing of consent form

Can you tell me about your experience of realising you were having a heart attack and needing to go to hospital to have treatment?

1. What happened when you reached the hospital?
2. Can you describe what happened to you when you had the treatment?
3. Were you aware of anything during the treatment?
4. How necessary do you think it was to have this treatment?
5. Was it better or worse than you had thought?
6. What happened to you afterwards?
7. Did you have any worries or concerns during your hospital stay?
8. What made a difference to your experience?
9. Is there anything else I should have asked you?
10. Is there anything you would like to ask me?

Closure

- Explain what will happen to the information
- Explain that they will receive a copy of the transcript for them to read through and check that it is a true reflection of what they said
- Expression of thanks

Appendix XVI Interview questions for carers

Opening of Interview

- Expression of thanks for participating in the study
 - Recap on purpose of study and what will be involved in interview
 - Assurance on confidentiality
 - Reminder that the participant can withdraw at any time and a reason does not need to be given for withdrawal
 - Signing of consent form
-
1. Can you tell me what it was like for you when ----- was taken to the hospital to have treatment for their heart attack?
 2. What happened when you arrived to the hospital?
 3. How/what were you expecting?
 4. How important was it for..... to have the treatment?
 5. Was there anything you were worried about?
 6. Is there anything else I should have asked you?
 7. Is there anything you would like to ask me?

Closure

- Explain what will happen to the information
- Explain that they will receive a copy of the transcript for them to read through and check that it is a true reflection of what they said
- Expression of thanks

Appendix XVII Interview questions for nurses

Opening of Interview

- Expression of thanks for participating in the study
 - Recap on purpose of study and what will be involved in interview
 - Assurance on confidentiality
 - Remind participant can withdraw at any time, a reason does not need to be given for withdrawal
 - Signing of consent form
-
1. Can you describe your experiences of caring for patients who require PPCI?
 2. What are your key objectives for the patients when providing care?
 3. What are your main roles/responsibilities?
 4. Do you enjoy caring for PPCI patients and why?
 5. What do you think is important to the patients whilst they are in hospital and why?
 6. What worries or concerns do you think patients have about the treatment?
 7. Could you tell me what happens to the carers when they first arrive?
 8. What are your key objectives when looking after the carers?
 9. What do you think is important to the carers and why?
 10. What do you think carers are worried or concerned about?

The nurses are asked to read two accounts constructed from data from interviews with patients and carers. The nurses will be told that the identity of the participants has been protected. After reading each account ask:

What is your immediate reaction to the narratives?
Do you have anything else to say about accounts?

Is there anything else I should have asked you?
Is there anything you would like to ask me?

Closure

- Explain what will happen to the information - They will receive a copy of the transcript for them to read through and check that it is a true reflection of what they said.
- Expression of thanks and future plans for research

