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### **What does this paper contribute to the wider global clinical community?**

- Patients readmitted with potential Ischemic Heart Disease symptoms experience high levels of anxiety related to symptom attribution.
- Patients feared experiencing further heart problems and were frightened of dying from a heart attack.
- The fast Primary Percutaneous Coronary Intervention (PPCI) treatment, early discharge and lack of illness ceremony created disbelief that they had experienced a heart attack and received treatment.

## **Abstract**

### Aim and Objectives

This study explored the experiences of patients readmitted due to potential ischaemic heart disease (p-IHD) symptoms within 6 months of Primary Percutaneous Coronary Intervention (PPCI).

### Background

Following myocardial infarction (MI) and PPCI, some patients experience p-IHD symptoms that may lead to readmission. Symptoms may be related to cardiac ischaemia, reduced psychological health or a comorbid condition.

### Design

A qualitative study involving semi-structured, in-depth interviews conducted once, mean 196 (50 to 384) days following readmission (at least 6 months following original STEMI and PPCI). This is the qualitative part of a mixed methods study.

#### Methods

Participants were purposefully selected and concurrent sampling, data collection and data analysis were used. Data were organised using Framework analysis; constant comparative analysis involving deduction and induction led to identification of cogent themes and sub-themes.

#### Results

Twenty-five participants (14 men, 27-79 years) experienced 1 to 4 readmissions; discharge diagnoses were cardiac, psychological, indeterminate, pulmonary and gastric. Three main themes emerged: 1) Anxiety, uncertainty and inability to determine cause of symptoms, 2) Fear of experiencing further MI, and 3) Insufficient opportunity to validate self-construction of illness.

#### Relevance to Clinical Practice

Fear of dying or experiencing a further MI led to patients seeking help at the time of p-IHD symptoms. Participants were anxious and lacked understanding regarding symptom attribution at the time of readmission and generally following their heart attack. Additionally, original heart attack symptoms were used as a comparator for future symptoms. Participants reported feeling well immediately after PPCI but later experiencing fatigue and debilitation often linked to p-IHD symptoms.

Increased education and information related to symptom attribution post PPCI and post readmission is worthy of exploration and may lead to increased understanding and reassurance for this patient group.

## INTRODUCTION

Primary Percutaneous Coronary Intervention (PPCI) is recommended first line treatment for ST-elevation myocardial infarction (STEMI) based on unequivocal mortality and morbidity benefits (Antman, Anbe et al. 2004, Antman, Hand et al. 2008, Kolh, Windecker et al. 2014).

However, following PPCI treatment readmission due to chest pain or potential ischaemic heart disease (p-IHD) symptoms is not uncommon. Combined mortality and readmission due to cardiac ischemia is reportedly 14% at 12 months post PPCI (Lambert, Brown et al. 2010).

At 24 months, Ortolani, Marzocchi et al. (2009) report a 21% composite mortality and myocardial infarction (MI) event rate. Although with less frequency, readmission due to causes other than ischaemic heart disease (IHD) and with comparable symptoms (to IHD) are also reported (Grace, Abbey et al. 2004). These include physiological and psychological conditions (e.g. musculoskeletal, pulmonary and anxiety and depression) and combined physiological and psychological conditions may also be present.

This paper describes the qualitative part of a mixed methods study (Iles-Smith 2012). The quantitative element of the study was a PPCI cohort study involving 231 participants, with 19% being readmitted with at least one pIHD event within six months (Iles-Smith, McGowan et al. 2014). A total of 74 readmissions were reported, more than a third (39.2%) did not receive a diagnosis and almost a quarter (24.3%) received a cardiac diagnosis, some participants experienced both pIHD and IHD events. Those readmitted due to pIHD symptoms compared to those who were not readmitted, had higher levels of Hospital Anxiety and Depression Scale (HAD) anxiety scores at baseline (9.5 v 7.5,  $p=0.006$ ) and at 6 months (9.4 v 6.0,  $p<0.001$ ). Additionally, Logistic regression modelling (investigating the relationships between physiological and psychological health, symptoms and sociodemographic factors and readmission), showed HADS anxiety as the only significant predictor (adjusted OR=1.120,  $p=0.008$ : unadjusted OR=1.097,  $p=0.008$ ) of readmission

(Iles-Smith, McGowan et al. 2014). However, due to the nature of the quantitative methodology the reasons for anxiety were not highlighted or elucidated

## **BACKGROUND**

Reduced psychological health following an MI and the deleterious effects of anxiety and depression on both mortality and morbidity have long been reported (Frasure-Smith 1991, Frasure-Smith, Lespérance et al. 1999, Dickens, McGowan et al. 2008). Additionally, this is not an uncommon problem with a third of patients experiencing anxiety (32%) and depression (30%) (Grace, Abbey et al. 2004, Grace, Abbey et al. 2005, Roest, Martens et al. 2010). However, all these studies were conducted with mixed cohorts of patients (both non-STEMI and STEMI) and were prior to the introduction of PPCI as first line therapy for STEMI and therefore limits generalisability to PPCI patients.

Acute Coronary Syndrome (ACS) patients can sometimes find it difficult to distinguish between IHD and non IHD symptoms (due to psychological e.g. anxiety and depression, or other physiological causes e.g. gastritis, musculoskeletal or pulmonary) (Ros, Armengol et al. 1997, Zerwic, Ryan et al. 2003). Likewise physicians can also find establishing a diagnosis challenging due to the non-specific nature of many symptoms such as chest pain, particularly when routine clinical investigations are negative. This is particularly difficult when anxiety and depression are present, as certain International Classification of Diseases (ICD)-10 related to mental disorders (ICD-9.0) such as anxiety and depression, include symptoms such as chest pain, palpitations and increased awareness of bodily sensations due to hypervigilance. The ICD is a standard diagnostic tool for epidemiology and health management and aids classification of diseases (World Health Organisation 2015).

A number of qualitative studies have explored the experiences of PPCI patients. Dullaghan, Lusk et al. (2014) found that STEMI patients (treated with PPCI or thrombolysis) viewed their illness as serious and life-threatening and were committed to making lifestyle changes.

Generally, patients in receipt of PPCI report that they are highly satisfied with the initial PPCI treatment (Radcliffe, Harding et al. 2009, Sampson, O'Cathain et al. 2009). However, Astin, Closs et al. (2009) and Sampson, O'Cathain et al. (2009) report that patients were shocked and found it difficult to comprehend that they had had a heart attack. Feelings of shock were exacerbated due to the speed of treatment, which consequently acted as a barrier to information absorption. Additionally, patients reported receiving insufficient information related to symptom management post PPCI (Astin, Closs et al. 2008).

In all these studies patients were interviewed soon after PPCI and had not experienced readmission. Little is known about the experiences of patients who are readmitted due to p-IHD symptoms and their understanding of symptom attribution following PPCI or why they seek help and the influence of the initial PPCI experience or their post readmission recovery.

This study explored the experiences of PPCI patients who had been readmitted due to p-IHD symptoms within 6 months of STEMI. This included their reasons for seeking help related to the readmission and the relationship of the original PPCI, symptom management and health beliefs.

## **METHODS**

The study was the qualitative part of a mixed methods study involving a prospective cohort study (n=231) investigating the prevalence and factors related to readmission (due to p-IHD symptoms) within 6 months of PPCI (Iles-Smith 2012, Iles-Smith, McGowan et al. 2014).

The mean for first readmission was 76.5 days (11 weeks). In-depth interviews on one occasion were used to explore emerging concepts (Charmaz 2006) and to add depth and meaning to the quantitative findings. Participant selection, data collection and analysis were conducted concurrently. Participants were recruited for the qualitative interview over a three year period (between 2007 to 2010).

The principles outlined in the Declaration of Helsinki (World Medical Association 2013) were adhered to and the study was approved by the Stockport Local Research Ethics Committee (LREC 06/Q1401/77).

### **Participant selection**

Potential participants were identified from the larger prospective cohort study (Iles-Smith, McGowan et al. 2014). At six months patients were telephoned to screen for readmission; they were asked whether they had been readmitted within the six months since their heart attack and what symptoms had led to this. Those readmitted with the perception that their symptoms were a further heart attack, were purposefully selected. As the study progressed maximum variation sampling was introduced to ensure diversity of the study population, including a range of ages, both genders and a variety of final readmission discharge diagnoses. Varied readmission diagnoses were sought to establish whether the diagnoses influenced the participant's experience. Twenty five (14 men, mean age 57 years (27 to 79), 24 Caucasian and one Asian) participants were interviewed at mean 196 (50 to 384) days following readmission (at least 6 months following original STEMI for most participants).

Across all participants a total of 42 (1 to 4) readmission events were experienced with a range of readmission diagnoses including, indeterminate/no diagnosis (17), Cardiac related (14), anxiety/or depression (4), Collapse (1), Pulmonary embolism (1), Gastric (3), Pulmonary (1).

### **Data collection**

In-depth, semi-structured, face to face interviews lasted mean 80 minutes (range 60 to 100 minutes), on one occasion, in the participants' home by the author at approximately 8 months (mean 246 (206 to 302) days) post PPCI. The interview script was created by the author (HIS) a cardiology research nurse, in discussion with the co-authors (CD and LMcG, both nurse academics, LMcG and HIS having previous qualitative research experience), based on previous qualitative PPCI studies (Astin, Closs et al. 2009, Sampson, O'Cathain et al. 2009) and following discussions with a number of PPCI patients. The interview script initially included the patients' perception of the cause of readmission symptoms, reasons for seeking help and emotional experiences of investigations and treatments. The script was piloted with a PPCI patient and adapted to include further topics (Table 1). It was flexibly applied and further scripts were adapted using emergent themes from previous interviews. Contextual information, including the participants' body language, environmental surroundings, emotional expressions and sociodemographics (such as employment, marital status, gender, age, etcetera) were recorded through field notes and reviewed during the analysis to aide the researchers interpretation of the participants intention and meaning. Interviews were audio-recorded and transcribed.

### **Analysis**

Data were analysed (using deduction and induction) concurrently with data collection. NVivo 8 was used to manage the data and Framework analysis was used to organise data (Ritchie and Spencer 1994). Framework analysis involves five stages: Familiarisation, indexing,

charting, mapping and interpretation. Familiarisation of the data was achieved by listening to the audio-recordings and reading interview scripts, deduction was used to devise the thematic framework. The thematic framework (Table 2) was used as a basis for indexing (coding), which involved inductive reasoning to explore new topics and emergent themes; new meaning and fresh concepts were added to the existing framework (Iles-Smith 2012). Charts were developed for each emerging theme and subsequently mapping and interpretation were used to develop the final list of themes and sub-themes. Transcription was undertaken by an independent transcription service and analysis performed by the author and co-authors acting as data verifiers. Data saturation was reached once no new concepts were identified.

Trustworthiness of the study is assured through good record keeping, the use of Framework and the involvement of the co-authors in the analysis; enabling others to audit the study procedures and the data, additionally aides trustworthiness.

## **FINDINGS**

Three main themes emerged from the analysis:- 1) Anxiety, uncertainty and inability to determine cause of symptoms, 2) Fear of experiencing further MI, and 3) Insufficient opportunity to validate self-construction of illness.

### **Anxiety, uncertainty and inability to determine cause of symptoms**

Anxiety levels were high for most participants. In particular participants were anxious about differentiating between symptoms both at the time of readmission and following the readmission discharge. Chest discomfort, tiredness and debilitation with a need to slow down were reported. Self-diagnosis and self-medication were used involving multiple treatments (i.e. for both indigestion and angina). *“I get a dull pain in me chest and I suffer terribly with, erm, heartburn..., which I was told, erm, can either be reflux acid or angina and it’s difficult*

*to distinguish which it is” “but I don’t know whether that’s just stress” “it will go when I take that (Glycerine Nitrate- used for the treatment of angina), erm, and it’ll also go...*

*because I take the Ranitidine as well, so I don’t know which it is” (participant 14). Many participants were confused and uncertain of the cause of their readmission symptoms particularly when not provided with a diagnosis. “it could have been just indigestion or something I’d eaten or whatever, I don’t know... ..within an hour or so, it had cleared up...but they (Accident and Emergency staff) said there was something there (on the electrocardiogram) but they couldn’t say what it was and then it just...don’t know, faded away, whatever it was” (participant 6). Uncertainty of whether it was normal to experience symptoms and the possibility of concurrent cause of symptoms following a heart attack were expressed. Stereotypical symptoms and those reported by the media and relatives were often relied upon to interpret symptoms.*

*Additionally, fatigue and debilitation were problematic, particularly for some of the men. “I might pick up a bag of groceries when I go to the shop one day and I’m okay and then all of a sudden I’m whoo and I’m thinking to myself.....you’re capable of doing something more strenuous than that” (participant 20). Some individuals denied the impact that the heart attack had had on their body. “the doctor said I would just be the same (after heart attack), so I was thinking ‘I shouldn’t be this tired’, you know, ‘cause I knew I couldn’t... I got up for work and I felt as tired as I went to bed” (participant 6).*

### **Fear of experiencing a further heart attack**

*At the time of readmission participants believed that their symptoms were related to their heart or due to a heart attack. “my anxiety has been about having another heart attack, and...dying from it, that’s what my anxiety has been about” (participant 11). They also feared experiencing further heart problems and were frightened of dying from a heart attack,*

thoughts of death were relatively common. *“(crying) on the phone today, up at the hospital... and erm... she said I need congenital (cognitive) thinking therapy or something, because of the way I think about things, because... (crying), (whispers) I’m scared of dying...(crying)”* (participant 4).

### **Insufficient opportunity to validate self-construction of illness**

All participants reported being impressed by the speed and efficiency of PPCI treatment. However, the fast treatment, early discharge and lack of illness ceremony seemed to create disbelief regarding what had happened. *“It all happened that fast, you didn’t really have time to think” “I felt fantastic when I got there (to coronary care) to tell you the truth I could have come home [laughter] and they wouldn’t let me out”* (participant 16). This appeared to lessen the seriousness of the event and created confusion for some participants particularly when receiving information from different sources. *“I said to him (GP) ....now I’ve had this heart attack how’s it affected me heart?.....so he said of well you’ve got diseased heart now,... anyway well I never said anything .....when I came out I said to my husband....the hospital said I was alright they never mentioned a diseased heart”* (participant 1). Generally, participants spoke of receiving either no or only limited information and education related symptom attribution.

### **DISCUSSION**

The findings of this study suggest that anxiety due to difficulty determining symptoms and fear of death due to a further cardiac event, were implicated in the majority of the readmissions.

Primarily, participants believed that they were experiencing a further heart attack and therefore sought help which resulted in readmission. However, participants also expressed

uncertainty and anxiety regarding cause of symptoms (prior to and following seeking help) and questioned whether they were due to non-cardiac causes. In most cases this uncertainty and anxiety regarding symptom attribution continued beyond six months and was expressed widely by interviewees.

This is the first time that the experiences of STEMI patients and their anxiety related to symptom attribution and re-admission have been reported within six months of experiencing a heart attack. However, Astin, Closs et al. (2009) previous qualitative findings (interviews conducted mean 7 days post PPCI) reported that the main information needs were how patients might recognise symptoms related to a cardiac event. Vosbergen, Janzen et al. (2013) similarly found that heart attack patients felt anxious and required increased levels of information to help recognise and prevent a future cardiac event. Interestingly Moser, Kimble et al. (2006) reported that previously experiencing a STEMI led to delaying seeking medical help during another event, suggesting a potential inability to recognise symptoms, a sense of denial or experiencing symptoms that are different to those associated with the original heart attack.

In the current study some participants' experiences of the illness ceremony surrounding their heart attack did not match their expectations, which were aligned to stereotypical symptoms conveyed in the media, or by relatives who had previously suffered a heart attack. 'Illness ceremony' refers to the procedures, events and social rituals surrounding STEMI and treatment (Iles-Smith 2012). Historically, a STEMI was viewed as having severe immediate and longer term health consequences (Reynell 1975). Prior to the introduction of thrombolysis in the 1980's care often included a lengthy hospital admission with initially strict bed rest, intravenous (IV) infusions and continuous close monitoring (Levine and Lown 1952, Pentacost, Mayne et al. 1967, Crampton 1973, McNeer, Wallace et al. 1975). All these events and procedures are likely to have created a sense of ceremony and may have aided the

patients' ability to take on the sick role as described by Parsons (1951) and start the process of coping with an acute, and potentially a chronic illness (Charmaz 1997).

In the current era the patient journey challenges the historical sick role for STEMI patients, as PPCI is timely with initiation of treatment within 90 minutes of onset of pain. The treatment also brings about dramatic, almost immediate, improvement in the patient's condition, with prompt resolution of pain and feelings of wellness (Astin, Closs et al. 2009). Patients also return to the ward with few visual clues such as IV infusion and a small dressing to the wrist or groin. Furthermore, post medical review is often infrequent and discharge within three to five days. All these factors are likely to lead to the lack of or a reduced illness ceremony and may influence the patient's ability to make sense of the acute and later chronic nature of their illness.

In our study, soon after PPCI participants believed that they had been 'fixed' with few long-term consequences to their heart attack and in some cases disbelieved that they had actually experienced a heart attack. This is similar to Astin, Closs et al. (2009) and Sampson, O'Cathain et al. (2009) findings, who reported participants feeling 'fixed' and well immediately after PPCI. Additionally, Astin, Closs et al. (2009) reported that soon after (within 7 days) PPCI, patients believe their illness to be less severe and shorter than expected. It is possible that the reduced illness ceremony leads to a lack of clarity, for patients, regarding the longevity and severity of their illness. Additionally, in our study participants continually referred back to their original heart attack and PPCI. They used the original experience as a reference point and as a means to compare their readmission and any further symptoms. They appeared to find understanding and making sense of further symptoms (post PPCI) challenging. The occurrence of symptoms appeared to conflict with the participants' beliefs that their illness was not serious and was short lived; it is possible that the reduction in

illness ceremony influenced their inability to contextualise new or recurrent post PPCI symptoms, although further research is needed to explore this concept.

Contrasted to the post PPCI early feelings of wellbeing, in our study participants spoke of experiencing fatigue, debilitation and physical limitation/weakness during recovery often combined with p-IHD symptoms. Some of the men were particularly frustrated that symptoms had reduced their physical abilities, leading to 'slowing down' or inability to return to work. Feelings of fatigue and weakness may well have been related to reduced psychological health, a known concept in MI patients (Alsén, Brink et al. 2008, Dickens, McGowan et al. 2008, Alsén, Brink et al. 2010). Symptoms may have challenged participants' initial belief that they had been fixed and resulted in conflicting beliefs, possible confusion and reinforcement of anxiety in relation to health status. This potentially has implications for the patient's ability to make appropriate adjustments to their lifestyle and comprehend the usefulness of follow up and attendance at cardiac rehabilitation.

Participants reported receiving little education and information related to symptom attribution. Therefore, additional research related to the increased availability and inclusion of symptom attribution education in cardiac rehabilitation programs would be worthy of exploration.

One of the main limitations of the study was that all those interviewed had experienced readmission due to pIHD symptoms. It is possible that those who were not readmitted and, those who attended their general practitioner, may also have experienced anxiety and uncertainty regarding symptom attribution. Additionally, the lack of cultural diversity and limited ethnicity of the participants (only one non-Caucasian) limits the generalisability of the data.

A number of strategies were used throughout the study to assure trustworthiness, including good record keeping, the involvement of the co-authors in the analysis and interpretation and the use of 'Framework' to enable others to audit the process of analysis.

## **CONCLUSION**

This study shows that post PPCI patients who are readmitted due to p-IHD symptoms experience a great deal of anxiety related to symptom attribution and are fearful of experiencing (and potentially dying) of a further heart attack. Additionally, they have little understanding of their symptoms and find them difficult to interpret.

Immediate post PPCI feelings of wellness were challenged once subsequent pIHD symptoms were experienced creating a sense of confusion and anxiety. The lack of illness ceremony experienced due to the speed and minimal invasive PPCI treatment also appeared to create a sense of disbelief when pIHD symptoms and feelings of fatigue and debilitation ensued.

Increased nurse led education and information related to symptom attribution is worthy of exploration and may lead to increased understanding and reassurance for this patient group.

## **FINANCIAL SUPPORT**

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Table 1: Interview Script

### **TOPIC AREAS TO BE DISCUSSED:**

#### **Experience of readmission**

- What was the route of readmission and how long were they admitted for?
- What were they doing at the time symptoms occurred?
- What did they believed to be the cause of symptoms?
- How did symptoms compare to STEMI?
- Who called for help?
- If someone else called for help would they have done so and why?
- What investigations did they experience and what was the diagnosis?
- Did they experience and thoughts of death or dying?
- Attitudes towards final diagnosis and participants level of understanding

### **Future symptom recognition**

- Could the participant differentiate between symptoms again in the future?
- What would help them to differentiate between symptoms?
- Has the participants returned to work?
- Has the participant returned to full physical activity?

### **Information and education:**

- What information was received relating to symptoms and diagnosis?
- Did the participant receive verbal or written info in hospital?
- Was future symptom and healthy life style advice received, if so when?
- Was the participant invited to cardiac rehab and if so did they attend?
- If they attended was it helpful or why didn't they attend?

**Is there anything I have missed in our discussion that you consider to be important?**

Table 2: Thematic Framework devised for analysis

<b>Thematic Framework</b>	
1	Anger and hostility
2	Anxiety and depression
3	Construction of illness events
4	Information needs
5	Making a recovery
6	Other support
7	Readmission
8	STEMI acute event
9	Symptoms