

BIOGRAPHICAL RESTORYING  
FOLLOWING A HEART  
ATTACK

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## **Abstract**

Coronary heart disease remains a leading cause of chronic illness in the world. Addressing lifestyle risk factors through health-related behaviour change is a key component of managing this condition. There is a lack of understanding from the patient's perspective, of the ways in which information is used to support health-related behaviour change. This study sought an increased understanding of the social processes and interactions influencing individual health-related behaviour change after a heart attack.

A constructivist grounded theory approach was used and narrative inquiry informed the development of the theory of biographical restorying following a heart attack. A symbolic interactionist framework facilitated an increased understanding of how the life story of those who had experienced a heart attack were shaped through interaction with their social world. Twenty-five semi-structured interviews were conducted with 14 individuals. The interviews took place at approximately 3 weeks and 6 months after their heart attack.

The theory of biographical restorying proposed four different narratives of life after a heart attack. Individuals told of lives that were either continuing as before or a struggle, limited or enhanced in response to the physical sensations they had experienced during their illness episode. The cycle of acting and reflecting on those sensations informed, adapted and reinforced both illness beliefs and health related concepts.

Medical practitioners were the most valued source of knowledge for those who experienced a heart attack. However, illness perceptions interpreted by those who had experienced a heart attack were different to those of medical personnel. Participants of this study increased their lay-knowledge to create a narrative around the causes, consequences and controllability of their condition. The internet was not widely accessed for health-related information by this group.

The theory offers insights into the timing of interventions designed to support the adaptation of specific illness beliefs and an approach to cardiac rehabilitation that is better suited to the needs of an individual.



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## List of acronyms

ACPICR	Association of Chartered Physiotherapists with an interest in cardiac rehabilitation
BACPR	British Association of Cardiovascular Prevention and Rehabilitation
BPS	Biopsychosocial model
CCMA	Constant comparative method of analysis
CCU	Coronary care unit
CSM	Common sense model of self-regulation
CVD	Cardiovascular disease
ECG	Electrocardiogram
GP	General Practitioner
GTM	Grounded theory method
NICE	National Institute for Health and Clinical Excellence
NSTEMI	Non-ST segment elevation myocardial infarction
MNC	Nursing and Midwifery Council
PCC	Patient centred care plan
PCI	Percutaneous coronary intervention
RCT	Randomised controlled trial
SOC	Sense of coherence
STEMI	ST segment elevation myocardial infarction
TOTE	Test, operate, test, exit processes.



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## Declaration

I declare that the research contained in this thesis, unless otherwise formally indicated within the text, is the original work of the author. The thesis has not been previously submitted to this or any other university for a degree, and does not incorporate any material already submitted for a degree







# 1 The development of illness beliefs following a myocardial infarction

## 1.1 Introduction

A significant part of my practice as a cardiac rehabilitation lead nurse is providing the education and support for patients admitted to hospital with a heart attack.<sup>1</sup> Initially, whilst they are in hospital, this involves providing information to enable patients to begin to understand what has happened to them and to identify the factors in their lifestyle and health-related behaviours that may have contributed to the development and progression of their coronary heart disease.<sup>2</sup> Following their discharge, they are offered support in modifying those behaviours and making the changes to their lifestyles which will aim to reduce their risk of future cardiac events through participating in a cardiac rehabilitation programme.<sup>3</sup>

The challenge to support some patients through this process can be considerable. Patients often express a desire to increase their levels of physical activity after a heart attack as lack of physical activity is a risk factor for coronary heart disease. They appear to understand the evidence for this change and the benefits to them as individuals. We work through a variety of tools and techniques to assess their readiness to take that step,

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<sup>1</sup> Heart attack is the common name for the medical term Myocardial Infarction, or MI. It occurs when oxygen-carrying blood stops flowing properly to part of the heart and the heart muscle is injured because it does not receive enough oxygen. Usually this is because one of the coronary arteries that supplies blood to the heart develops a blockage. Angina is the medical term for the chest pain associated with this condition.

<sup>2</sup> Coronary heart disease (CHD) is a narrowing of the small blood vessels that supply blood and therefore oxygen to the heart. The narrowing is caused by an unstable build-up of white blood cells, cholesterol and fat, referred to as a plaque. CHD is a cardiovascular disease (CVD), a general term used to describe diseases of the blood vessels and heart.

<sup>3</sup> Cardiac rehabilitation is a structured set of services that enables people with coronary heart disease (CHD) to have the best possible help (physical, psychological and social) to preserve or resume their optimal functioning in society. There is evidence that exercise-based cardiac rehabilitation is effective in reducing total and cardiovascular mortality and hospital admissions in people with coronary heart disease.

we identify any barriers to the transition and we develop a plan to support a successful change (Prochaska and DiClemente, 1983). In my practice I may see two patients who appear very similar in their outlook and desire to change their health-related behaviour after a heart attack: one achieves the desired change and the other doesn't, resulting in a sense of failure and frustration for patient and nurse in the situations where change is not achieved. In discussing these issues with patients over the years, I have surmised that those who manage to sustain health-related behaviour change have a stronger belief that the changes will help to reduce their risk of further heart attack than those who did not succeed in their expressed goal of health-related behaviour change.

In approaching this study, I wanted to understand more about the role of belief in undertaking and maintaining health-related behaviour change, and why this is so challenging from the patient's perspective. If we can understand this, then perhaps we can develop patient-centred interventions which will enable sustained long-term health-related behaviour change.

I have worked as a cardiac nurse for over twenty-five years, during which time there have been significant changes to our understanding of the causes of coronary heart disease and the treatment options we can offer those affected by the disease. An increased understanding of the pathophysiological processes (Libby and Theroux, 2005) has enabled new drug therapies such as statins<sup>4</sup> to be developed, which target specific parts of this process. Technological advances making it possible to open blocked coronary blood vessels with stents<sup>5</sup> have reduced deaths from

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<sup>4</sup> Statins are a class of drugs used to lower cholesterol levels by inhibiting the production of cholesterol in the liver. Increased cholesterol levels have been associated with cardiovascular disease. The evidence is strong that statins are effective for treating CVD in the early stages of the disease.

<sup>5</sup> In patients with coronary heart disease, stents – small expandable tubes made of metal mesh – are used to open narrowed arteries and help reduce symptoms such as chest pain or to help treat a heart attack. These types of stents are commonly referred to as cardiac stents or coronary stents and are implanted during a procedure called a percutaneous coronary intervention (PCI) or angioplasty.

heart attacks by one third (Gale, et al., 2011). These developments have changed the pathway of care for those who present to health care providers with heart attacks and angina, the common manifestations of coronary heart disease.

A perceived benefit of these changes has been a reduction in the length of stay in hospital from seven days to around three days (DOH, 2008). However, a consequence of this reduction is that care has become very technical and focused on intervention. This has reduced the time available to provide the education and support which will enable patients to begin to make sense of what has happened to them and decide on any health-related behaviour change they wish to make (Alsén, Brink and Persson, 2008; Lau-Walker, 2007; Cossette, et al., 2009).

The reduction in the time spent in hospital following a heart attack makes it more difficult to influence the illness perceptions of individuals. Acknowledging the chronic nature of atherosclerotic heart disease, the underlying cause of a heart attack, is an example of this. This focus on the acute phase of the condition has resulted in the misconception, held by patients, that revascularisation is a cure for the condition. The perception of a heart attack as an acute event reduces the likelihood of health-related behaviour change being undertaken. This has led to a hypothesis that the short-term gains of bed days saved is lost in increased health care costs in future years (Astin, et al., 2009; Alsén, et al., 2008).

In parallel with the changes in the medical management of coronary heart disease there is a greater awareness of the impact that our lifestyles, in particular our dietary and activity behaviours, have on the rate of the progression of the pathophysiological process occurring in coronary heart disease (Bijnen, Caspersen and Mosterd, 1994; Stampfer, et al., 2000). Cognitive-behavioural psychology theories such as self-efficacy (Bandura, 1977), illness beliefs (Leventhal, Meyer and Nerenz, 1980), and self-

knowledge (Gebhardt and Maes, 2001) have been identified as influential in achieving successful health-related behaviour change across a range of disease conditions in which lifestyle impacts on outcomes. Illness belief theory (Leventhal, Meyer and Nerenz, 1980) has become widely used by behavioural psychologists researching health-related behaviour change in those who have had a heart attack.

The illness beliefs held by patients who have had a heart attack are influential in determining at which point they present for help from health care professionals (Meischke, et al., 2002; Quinn, 2005; Katz, et al., 2009; Fors, Dudas and Ekman, 2014) and in how they respond to treatment (Petrie, et al., 2002; Cherrington, et al., 2004). In the longer term, illness beliefs impact on the ways in which patients manage their condition (Weinman, et al., 1996; Macinnes, 2006; Petrie and Weinman, 2006; Fors, Dudas and Ekman, 2014; Astin, et al., 2009); they also help predict subjective experience (Murray, Manktelow and Clifford, 2000; Figueiras and Weinman, 2003; Figueiras, et al., 2015; Yuval, Halon and Lewis, 2007; Galdas and Kang, 2010).

However, we lack an understanding from the patient's perspective of the ways in which these beliefs develop (Cooper, et al., 1999; Pullen, Povey and Grogan, 2009; Cameron and Leventhal, 2003; Fors, Dudas and Ekman, 2014).

Individuals need knowledge on which to base their illness beliefs and they then need to make sense of that knowledge before making a decision on taking any action (Leventhal, Meyer and Nerenz, 1980). Our knowledge and information in relation to health can come from any number of sources, for example television, newspapers, internet, health care professionals, friends and family (Leventhal, Meyer and Nerenz, 1980; Murray, Manktelow and Clifford, 2000; Meischke, et al., 2002). An increased understanding of the interactions and social processes which are utilised when gaining and interpreting this knowledge could help explain how our illness beliefs develop and their role in influencing health-

related behaviour change (Cooper, et al.,1999; Cooper, et al., 2005; Pullen, Povey and Grogan, 2009).

This study seeks to explore these issues in the context of those who have experienced a heart attack through the following questions:

In what ways do an individual's health and illness beliefs adapt following the experience of having a heart attack?

In what ways do an individual's health and illness beliefs influence the decision as to whether or not to make a health-related behaviour change?

The aim of the investigation is:

- to construct a theory of the ways in which social processes and interactions influence the shaping and development of illness beliefs in individuals who have experienced a myocardial infarction;
- to explain the ways in which an individual's perspective of their illness beliefs related to experiencing a myocardial infarction adapt and impact on subsequent health-related behaviour change and action;
- to enable health care professionals to develop patient-centred interventions designed to influence health-related behaviour change.

In the context of this study the following definitions will be applied:

- Illness beliefs
  - These allow individuals to explain and understand why they have had a heart attack, how their coronary heart disease progresses, and the control they have over their recovery and future.
- Health-related behaviour
  - An action or actions performed over a long period of time, such as eating a healthful diet, getting regular physical

activity, and avoiding tobacco. These sustained patterns of complex behaviour are often termed 'lifestyle' behaviours and the composite of various healthful behaviours is often referred to as a 'healthy lifestyle'.

- Social processes and interaction
  - Any form of interaction which has the potential to enable the gathering of knowledge: to include verbal communication, reading magazines, newspapers, watching television or other visual media, and undertaking searches on the World Wide Web.
- Health care professionals
  - Doctors, nurses and allied health professionals such as physiotherapists, exercise physiologists, occupational therapists.
- Patient-centred intervention
  - An intervention which has been developed as a result of the shared involvement of patients and health care professionals. It should focus on the patient as a whole person who has individual preferences situated within social contexts. This is in contrast to a focus in the consultation on a body part or disease seen in the biomedical model of care.

## **1.2 Significance and implications**

The relevance of this research study is further explained and justified by considering how it might reduce the economic burden of coronary heart disease, and how it might help achieve health-related behaviour change in those at risk of developing coronary heart disease. It will reflect on how it might provide greater insight into the perspective of those who are undertaking health-related behaviour change following a heart attack.

### **1.2.1 Burden of coronary heart disease**

Improving the health of those with coronary heart disease through maintenance of health-related behaviour change could reduce the economic impact of this disease.

The cardiovascular diseases (CVD) remain the UK's biggest killer, and coronary heart disease is the major cause of death within this group. The 2015 national audit of cardiovascular disease (Bhatnagar, et al., 2015) reported that in 2014 coronary heart disease was the biggest single cause of death in the UK. Over 41,000 of the deaths occurring in people under the age of 65 were attributed to the disease.

Coronary heart disease cost the health care system in the UK around £1.6 billion in 2013/14. There is an additional estimated social cost of £6.7 billion per year to the UK economy of which just under £2 billion was due to death and illness in those of working age (Bhatnagar, et al., 2015). These figures are likely to rise in real terms in future years as mortality rates fall against a rising incidence of coronary heart disease, meaning that more people are living with the burden of coronary heart disease.

### **1.2.2 Wider benefits of achieving health-related behaviour change**

Increasing our understanding of illness beliefs and their impact on health-related behaviour change may provide strategies for achieving health-related behaviour change in those at high risk of developing coronary heart disease.

Epidemiological evidence shows that smoking, high total cholesterol, hypertension, being overweight, and having a low level of physical activity are significant risk factors for coronary heart disease mortality. Therefore, by turning these risk factors in a healthier direction, a substantial proportion of the deaths from coronary heart disease may be preventable.

The numbers of those who carry lifestyle-related risk factors for coronary heart disease are increasing. Around one third of coronary heart disease in the developed world and 63% of heart attacks in Western Europe have

been attributed to obesity (Yusuf, et al., 2004). In the United Kingdom the numbers who are overweight and obese have been increasing rapidly. The percentage of men aged 16 and over who are obese rose from 14% in 1994 to 27% in 2014. For women, the figure increased from 17% in 1994 to 30% in 2014 (WHO 2014).

A higher percentage of men (67%) than women (55%), meet government recommendations for physical activity over a week. Bhatnagar, et al., (2015). An increased understanding of the patients' perspective of undertaking health-related behaviour change may inform strategies designed to reverse these trends and reduce the increasing burden of this disease.

### **1.2.3 Increasing the focus on the patient perspective in health and illness models**

Interventions which are patient centred may impact positively in increasing patient engagement, adherence and satisfaction with care. Studies such as the one proposed here have the potential to increase the focus on patients' perspectives which are currently viewed as important in improving the standards and effectiveness of health interventions (NICE, 2014). Patient-centred care is based on deep respect for patients as individuals in the context of their own social worlds. In delivering this model of care patients are listened to, informed, respected, involved in their care and there is an obligation to care for them on their terms (Epstein and Street, 2011).

The biopsychosocial (BPS) model of health care (Engel,1977) proposed a move from the dominant reductionist biomedical model to one which took account of the patient and the social world in which they live with their illness. The emergence of 'preventable' diseases, such as cardiovascular disease, and drug and alcohol abuse in the 1950s had exposed the limitations of the biomedical model in addressing conditions which had a psychological and social component. The BPS was conceived to address these shortcomings (Hatala,2012).

The BPS model has been widely adopted in nursing research and practice (Shapiro, et al., 2009). However, there has been limited success in embedding the model both in the medical curriculum (Shapiro, et al., 2009) and in clinical practice (Alonso, 2004). Currently the role of the BPS within medicine is contested. Clinical medicine perceives it as a means of emphasising the psychosocial elements of disease whilst psychiatry views it as a means of limiting the medicalisation of their speciality (Ghaemi, 2009).

However, within the field of health psychology the BPS model is advocated as a theoretical framework. The BPS offers a framework for understanding the complex health behaviours associated with disease risk which are the target of health-related behaviour change (Ghaemi, 2009; Ogden, 2007).

Western society's scepticism of non-biological explanations of disease perpetuates the three-hundred-year-old biomedical model (Duncan, 2000). A cultural position which allows responsibility for managing illness to be passed to others maintains the strength of the biomedical model within both medicine and the wider society.

Societal support for technology and the pharmaceutical industry's focus on developing medicine to treat 'preventable' disease perpetuate the position (Kontos, 2011; Mehta, 2011). Thus, there are pressures within both medicine and society to maintain the status quo of the biomedical model, not least those which advocate passing all responsibility for treating disease, including preventable ones, to the medical profession.

Within cardiac rehabilitation in the United Kingdom, the health psychologist's use of the BPS underpins the national standards (BACPR , 2017).

## 1.3 Context of the study

### 1.3.1 Researcher perspective

I am a 56-year-old female nurse with over 25 years' experience in cardiac nursing. My initial training was as an undergraduate on the University of Edinburgh nursing degree programme in the early 1980s and my academic training was strengthened by completing a Master's in Nursing degree in Cardiff in the early 1990s.

My clinical career has been in the field of cardiology where I worked in cardiothoracic intensive care in a variety of teaching hospitals in the UK prior to taking up my present post as a cardiac rehabilitation specialist. The cardiothoracic intensive care unit is an area of clinical practice in which the biomedical model of care is very strong. The everyday practices of monitoring and treating patients according to their physiological response reinforced the utility of this model.

I have always recognised that dogmatic application of these scientific principles did not work with every patient. I have been in situations in which patients have been able to undertake activities their physiological condition would suggest were not attainable but have been achieved through their individual self-belief.

I have always been challenged by the different ways patients respond in similar situations and, specifically in recent years, their attitudes towards health-related behaviour change following coronary artery bypass surgery.<sup>6</sup> Developing these interests led me from the intensive care unit to the cardiac rehabilitation service where supporting patients to achieve health-related behaviour change is a key part of the role.

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<sup>6</sup> Treatment option for those with coronary heart disease. Coronary artery bypass surgery is open-heart surgery in which a section of a blood vessel is grafted from the aorta to the coronary artery to bypass the blocked section of the coronary artery and improve the blood supply to the heart.

My theoretical perspective has been influenced by the works of Dickoff and James, (1968), Paterson and Zderad's, (1988) writing on humanistic nursing and, most specifically, Carper, (1978) and her work on ways of knowing in nursing. Reflection from these works had a limited impact on my practice. Benner's (1984) seminal work on nursing knowledge learned in clinical practice has been and remains a huge influence on my daily practice as a nurse, manager and educator.

I actively seek feedback and reflect on my position on this continuum from novice to expert in each of these aspects of my role. I assume the work of Benner, (1984) will continue to influence my practice as a novice researcher aiming to be at least competent by the end of this doctoral journey.

My previous experience in research is limited to one small qualitative study, undertaken as part of my Master's degree. Utilising semi-structured interviews and thematic analysis I examined the effectiveness of an in-service education project in supporting newly qualified nurses to work in the intensive care setting. I have also been involved in service improvement patient experience projects utilising similar methodological approaches.

My current clinical practice and academic background has sensitised me to the research topic and my personal stance on the social processes which were investigated is discussed in Chapter 3. I needed to ensure that my own personal assumptions and views did not overshadow those of the participants in the study (Charmaz, 2006a; 2014), and so I have adopted a reflexive stance and methodology which supported an interrogation of my familiarity with the area of practice being investigated.

Undertaking the study in an area where I was a lead practitioner required a consideration of ethical and practical issues. These are explored as a part of the reflective stance of the study and are also discussed in Section 3.6. The fact that I was known to the nursing staff who were asking patients to be potential participants aided in recruitment of participants.

The nursing staff perceived they had a stake in the research through my connection with the clinical area. I ensured they were aware of their key role in facilitating my access to potential participants.

Throughout the data collection and analysis period, reflexive reactions to the data were documented separately from the actual data in reflexive memos, and excerpts from these are used in this thesis where they enhanced the data or analysis. A reflective diary enabled a continuous self-scrutiny of the research processes throughout the research project.

## **2 Literature Review**

### **2.1 Background to the study**

This study will use a grounded theory approach, the justification for which is presented in Chapter 3 (Section 3.2). A grounded theory study should not begin with an extensive review of the literature as this has the potential to lead researchers towards existing theoretical concepts as opposed to allowing the theory to be generated from the data (Glaser and Strauss, 1968; Charmaz, 2006a; Birks and Mills, 2011).

However, a preliminary review of the literature was undertaken to place the present study within the context of previous research undertaken in the area of study. This also ensured the proposed research question had not already been answered and had the potential to identify other gaps in our knowledge which may be filled by this study (Birks and Mills, 2011).

The preliminary literature review covered four main areas:

2.2 The evidence for health-related behaviour change in coronary heart disease

2.3 Health belief theory

2.4 Illness belief theory

2.5 Gaining knowledge through social processes and interaction

The search was conducted on online electronic databases in the fields of health and psychology. The Cumulative Index of Nursing and Allied Health Literature (CINAHL)®, PubMed®, PsycINFO® and SPORTDiscus® were the core databases used. The keywords used in Boolean searches were myocardial infarction, common sense, risk behaviour, lay belief, attribution, representation, causal explanation, subjective perception, perceived cause, health beliefs (Appendix 9.1). The technique of snowballing in which references from key articles are then sourced and more literature sought was also utilised.

Additionally, internet sites such as Google Scholar® were accessed to identify literature in other fields. For example, when searching for information on the ways in which knowledge is used, this source identified articles from the business arena. I then undertook a fuller search incorporating databases from that discipline. Reading articles from the business arena and reviewing my own data from that perspective aided in abstraction of my data. This was a necessary part of developing a theory within my chosen methodology.

## **2.2 The evidence for health-related behaviour change in coronary heart disease**

As already discussed in Section 1.2.1, the burden coronary heart disease places on both the health budget and general economy is predicted to increase in the future (Bhatnagar, et al., 2015). Health-related behaviour change is considered important within the context of managing lifestyle-related risk factors in national guidelines in Europe and North America. All of these evidence-based guidelines promote health-related behaviour change as a key factor in addressing the burden of coronary heart disease (Lynch, 2006; McMurray, et al., 2012; NICE, 2013).

There is currently no cure for coronary heart disease. Some medications and invasive treatments such as stent insertion and coronary artery bypass grafts can reduce symptoms but they do not reduce or cease disease progression (Michaels and Chatterjee, 2002). The goals of management are to reduce symptoms and prevent or at least slow down progression of the atherosclerotic process<sup>7</sup> through secondary prevention<sup>8</sup>

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<sup>7</sup> Atherosclerosis is a process through which an artery wall thickens as a result of the accumulation of calcium and fatty materials such as cholesterol and triglyceride. It reduces the elasticity of the artery walls and therefore allows less blood to travel through. When this occurs in the arteries of the heart, coronary heart disease is diagnosed.

<sup>8</sup> Secondary prevention measures attempt to prevent asymptomatic disease from progressing to symptomatic disease and to reduce the damage caused by symptomatic disease.

measures (NICE, 2013). Disease progression is slowed through comprehensive risk factor management. This can lead to improved survival, reduced need for interventional procedures and improved quality of life for those living with the disease (Lynch, 2006). The risk factors for coronary heart disease are listed in Table 2-1

Comprehensive risk factor management lies in addressing those factors which can be modified through medication and through lifestyle adaptation. They include ensuring adherence and concordance<sup>9</sup> with medication therapy and supporting lifestyle changes through health-related behaviour change programmes (NICE, 2013; Davis and Addis, 1999).

Adapting behaviour following a heart attack can increase length of life, reduce the risk of recurrence, the severity of the disease and improve overall functionality (Jolliffe, et al., 2001; Aldana, et al., 2003). Regression of severe coronary atherosclerosis has been demonstrated after one year of comprehensive lifestyle changes (Ornish, et al., 1998).

Non-modifiable	Modifiable through medication and lifestyle adaptation	Modifiable through lifestyle adaptation
Age Gender Ethnicity Family History	High blood pressure High cholesterol levels Diabetes mellitus II	Smoking Dietary intake Obesity Physical activity levels

Table 2-1 Risk factors associated with the development of coronary artery disease.

However, there is consistent and substantial evidence, over the last decade, from large multi-national trials in Europe and North America that comprehensive risk factor management is not currently achieved (Kotseva et al 2016, Kotseva, et al., 2009; Lynch, 2006). Cessation of smoking is the most common change successfully achieved in those with heart

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<sup>9</sup> Concordance describes a shared process between the health care prescriber and patient leading to the agreement of the overall aims of any prescribed drug treatment and how they are to be achieved.

disease, with around 40% of smokers quitting. However, only 10% achieve dietary changes and increased levels of physical activity are the least successful change achieved (Newsom, et al., 2012).

Increasing our understanding of the complexity of health-related behaviour change is considered important in increasing the numbers who undertake such changes following a heart attack (Newsom, et al., 2012).

### **2.3 Health belief theories**

A general understanding of the theories utilised in health-related behaviour change studies helped sensitise me to potential concepts during early data analysis. This understanding provided a starting point for conceptualisation of the data. The role of psychological factors in the cause, advancement and consequences of health and illness is the focus of health psychology.

Specifically, health psychology aims to develop and test theories explaining the role of behaviour in illness then support their implementation into practice (Ogden, 2007). These theories, adopted from the cognitive behavioural psychology discipline, are increasingly being applied in the health and illness arena. The theories focus on an aspect of self-regulation.

Self-regulation theories are systematic processes in which individuals consciously moderate their thoughts, emotions and behaviours to achieve goals within a changing environment (Zeidner, Boekaerts and Pintrich, 2000). The theories utilise systems such as feedback loops and TOTE processes (Test, Operate, Test, Exit). Self-regulation theories offer a perspective of the ways in which individuals direct and monitor their behaviours to achieve their goals. They have contributed to the design of effective health interventions (Cameron and Leventhal, 2003). Self-regulation theories can be either general or specific. Selection of a theory should be based on the health-related behaviour being considered.

General self-regulation theories include those such as self-efficacy (Bandura, 1977) and self-knowledge (Gebhardt and Maes, 2001). When general theories are applied to health-related behaviour, an individual's belief in their ability to undertake their desired behaviour change is considered crucial if the behaviour is to be successfully adopted.

The health-specific models such as the common-sense model (Leventhal, Meyer and Nerenz, 1980) are designed to capture critical aspects of health and illness such as the threat to survival posed by a heart attack. The general theories are more suited to complex health behaviour such as exercise or dietary changes. The health-specific theories are useful in simpler behaviours such as seeking medical help for serious symptoms (Cameron and Leventhal, 2003).

The 'self' within self-regulation theories is seen as a multidimensional, multi-faceted dynamic structure that is systematically implicated in all aspects of social information processing (Marcus and Kitayama 1991). However, it is not possible to have all self-identities accessible at all times and so there is now a concept of the 'working self'. This is the self that is in use at a specific point in time (Cantor and Kihlstrom, 1987). This concept of the working self resembles the symbolic interactionist<sup>10</sup> view of self as an object of one's own action (Blumer, 1969).

Cognitive and behavioural processes are operating simultaneously to control the objective health issue. Cognition operates at both a conceptual level (for example, 'coronary heart disease is narrowing my coronary arteries') and an experiential level ('I know what a heart attack looks like from watching medical programmes on TV'). The experiential process is reported to have a greater influence on health-related behaviour change than the conceptual process (Brownlee, Leventhal and Leventhal, 2000).

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<sup>10</sup> Symbolic interactionism is a sociological perspective derived from the work of George Mead and articulated by his student Herbert Blumer in 1969. Symbolic interactionism provides the theoretical framework for this study which is justified and explored in Chapter 3.

The range of approaches utilised in supporting health-related behaviour change following a heart attack and their varying degrees of success suggests there is not one solution. The application of self-regulation theories to health-related behaviour change in those with coronary heart disease will now be critically reviewed.

### **2.3.1 Self-efficacy theory**

Self-efficacy theory describes a confidence in the ability to achieve a desired goal. This confidence determines the initial decision to undertake a behaviour change, the effort expended and the persistence applied to maintain that change (Bandura, 1977, 1982). Self-efficacy is a complex concept in which information is gathered from a range of sources such as previous experience of undertaking an activity, vicariously experiencing activities, and verbal and emotional responses to those experiences and activities.

This information is then processed internally and the degree of self-efficacy evolves. Self-efficacy is not a fixed state but is continuously influenced through feedback loops. It is this ability to influence self-efficacy which has made it a target for interventions aiming to influence both general and specific behaviour change.

Self-efficacy in achieving a task does not guarantee success and Bandura, (1977) differentiated between efficacy expectations and outcome expectations. Thus, an individual may believe they can undertake a specific task but a successful outcome will also require skills, knowledge and motivation.

Self-efficacy is further split into general and specific self-efficacy. General self-efficacy relates to beliefs in one's general capacity to perform tasks. Specific self-efficacy refers to beliefs in one's ability to perform specific tasks such as stopping smoking.

Scales to measure both general and specific self-efficacy have been validated and used in research designed to influence behaviour change

(Sherer and Maddux, 1982; Marlatt, Baer and Quigley, 1994). Lau-Walker, (2004) identified that a greater general self-efficacy predicted better overall coping with the consequences of a heart attack.

However, high specific self-efficacy was required to effect and maintain increasing levels of physical activity (Lau-Walker, 2004; Everett, Salamonson and Davidson, 2009). These small quantitative studies support a role for self-efficacy in behaviour change following a heart attack but they do not identify the mechanism by which self-efficacy evolves or adapts in this situation.

### **2.3.2 Role of self-knowledge**

The role of self-knowledge in motivating behaviour change in patients with coronary heart disease was explored by Fleury and Sedikides, (2007). This was a secondary analysis of interview data from a previous study which had explored the motivation for cardiovascular health-related behaviour change (Fleury, 1991;1996). Self-knowledge is a component of the whole self-system and is concerned with what we know about ourselves. Our current self-knowledge influences how new information is interpreted, how we adapt behaviour as a consequence of this, and the manner in which we assign meaning to events.

Fleury and Sedikides' (2007) analysis identified three mechanisms through which self-knowledge operated. It represented hopes and fears for the future; it provided a framework of goals and expectations for health behaviour; and it facilitated actions to achieve these goals and expectations. Self-knowledge was identified as having a central role in health-related behaviour change.

Fleury and Sedikides (2007) also postulated that self-knowledge is a critical antecedent of motivation in behaviour change. Motivation implies a change from present to the future with self-knowledge being seen to operationalise and represent motivation. This study supported the finding of traditional motivation theory that both the self and self-knowledge have a role in guiding behaviour change.

The study also linked self-knowledge to personal efficacy. As self-knowledge strengthens motivation, then self-efficacy is increased as is the hope of achieving the goals. Rimal, (2000) identified that knowledge-based behaviour change was a function of an individual's perceived barriers or ability to achieve the change. He proposed self-efficacy as a mediator between knowledge and behaviour. This reinforces Bandura's, (1977) assertion that no one element can account for behaviour change.

### **2.3.3 Action planning theory**

A range of studies have identified that action planning can aid dietary and physical activity related behaviour change after a cardiac event (Bennett, et al., 1999; Jackson, et al., 2005; Luszczynska, 2006; Gollwitzer, 1999). Overall, however, this approach does not appear effective in maintaining lifestyle change in cardiac patients over the longer term (Bock, et al., 1997; Jackson, et al., 2005).

Sniehotta and colleagues, (2005) identified a need to augment motivational plans for change with volitional plans for action and maintenance to achieve long-term change. Additionally, those plans which had both an action component and a component for coping with barriers demonstrated greater success in achieving maintenance of behaviour change (Sniehotta, et al., 2005; Conner, Sandberg and Norman, 2010).

These studies reiterated the outcomes of other studies. Behaviour change is multifactorial but indicators of high self-efficacy were observed in those achieving maintained behaviour change (Sniehotta, et al., 2005).

Luszczynska and Schwarzer, (2003) propose that phase-specific risk perception is the basis of any lifestyle change but it is self-efficacy, and planning which are the direct predictors of exercise adherence (Luszczynska and Schwarzer, 2003; Schwarzer, et al., 2008; Luszczynska, 2006).

The early literature review identified small studies, both qualitative and quantitative, investigating behaviour change in cardiac patients. They acknowledged self-efficacy, self-knowledge and action planning as

interrelated parts of achieving health-related lifestyle behaviour change following a heart attack. However, as most of the qualitative studies focus on one aspect of behaviour change in one risk factor, the nature of this overlap is not fully explored.

The quantitative studies utilised questionnaires to assess these component parts. They identified interventions which supported the initiation and maintenance of change but these are frequently small-scale single-centre studies. Their small sample sizes and subsequent lack of power does weaken the claims they can make within the scientific community.

Hankins and colleagues (Hankins, French and Horne, 2000) suggested that using alternative analysis tools may reduce this as a criticism of the research within the scientific community. The studies also tend to be cross-sectional or prospective designs which can only demonstrate inter-variable association rather than causality. Undertaking randomised controlled trials (RCT) would address this issue but achieving sufficient numbers to power such studies would be challenging. The research question is not always suited to such a methodology.

These studies guided early thoughts about the potential direction of the study. The original focus of these theories was on behaviour change from the perspective of being and remaining healthy, although the theories discussed so far have been applied in groups experiencing ill-health or chronic illness. The starting point for this study is behaviour change from the perspective of being ill. This may help explain why the review did not identify any specific gaps in the current knowledge base which might address my questions regarding individuals' success in achieving health-related behaviour change.

## **2.4 Illness belief theory**

Individual beliefs which relate to ill-health exist within the context of beliefs concerned with being healthy (Ogden, 2007). Illness, and health, beliefs are a component part of self-knowledge and have been shown to influence

the trajectory of a range of long-term conditions (McAndrew, et al., 2008; Kennedy, Rogers and Bower, 2007; Horne, et al., 2013). The health-specific common-sense model of illness beliefs (Leventhal, Meyer and Nerenz, 1980) has been applied in studies looking at the health behaviours of those who have coronary heart disease in the United Kingdom (French, et al., 2001; Darr, Astin and Atkin, 2008; Furze, et al., 2005).

These studies have influenced the development of cardiac rehabilitation programmes within the United Kingdom. The common-sense model of illness beliefs currently underpins the standards of the national organisation the British Association for Cardiovascular Prevention and Rehabilitation (BACPR, 2017) and patient-centred interventions (Furze, et al., 2003). Given the prominence of this theory within current UK practice and its influence on my own practice it was critiqued in more detail than other less utilised self-regulation theories.

Studies of illness beliefs generally adopt one of two ways of conceptualising them. Ethnographic and sociological studies treat them as collective interpretations of medical conditions which are shared by members of a socio-cultural group (De Kok and Widdicombe, 2010). Psychological studies on the other hand treat illness attributions as individuals' cognitions about the illness (Leventhal, Meyer and Nerenz, 1980). This study is concerned with the ways in which individuals make sense of these collective interpretations of illness beliefs.

Leventhal and colleagues (Leventhal, Meyer and Nerenz, 1980; Leventhal, Brissette and Leventhal, 2003), health psychologists, first developed the self-regulatory common-sense model of illness in the late 1970s. This cognitive behavioural model proposes that individuals act as common-sense scientists when forming beliefs about their illnesses (Leventhal, Brissette and Leventhal, 2003, p49). They choose to cope with illness in ways consistent with their understanding of their illness-related experiences.

Interpretation is grounded in cognitive representations of the illness the individual is currently experiencing. The purpose of the model was to enable the generation and testing of interventions which would increase compliance with medical regimes such as taking medication (Leventhal, Meyer and Nerenz, 1980; Leventhal, Brissette and Leventhal, 2003).

The model has two assumptions (Leventhal, Meyer and Nerenz, 1980). The first is that people are active, self-regulating individuals who problem solve to avoid and treat illness threats. The second assumption is that individuals develop beliefs about health and illness through their current and past experience and from information derived from family, friends, and social and media sources. Research to date has focused on testing the first of these assumptions.

This research has led to the identification of five domains of illness representations in which people seek to gain control and self-regulate their illness-related activities (Leventhal, Meyer and Nerenz, 1980; Meyer, Leventhal and Gutmann, 1985; Leventhal, Brissette and Leventhal, 2003). The five domains are:

- how the patient describes the illness and the symptoms they associate with it, the domain of **identity**;
- how long they believe the illness will last, the domain of **timeline**;
- their personal beliefs and ideas of what caused their illness, the domain of **cause**;
- what they expect in terms of effect and outcome, the domain of **consequences**;
- how they will recover from or how much control they have over the illness, the domain of **cure** or **controllability**.

These domains were developed from qualitative interview-based research (Leventhal, Meyer and Nerenz, 1980) and have since been validated through other quantitative and qualitative studies (Lau and Hartman, 1983; Bishop and Converse, 1986; Hagger and Orbell, 2003). An illness perception questionnaire was developed to assess the beliefs of

individuals across the five domains of identity, timeline, cause, consequences and cure / controllability (Weinman, et al., 1996; Moss-Morris, et al., 2002).

Illness perception has been shown to influence adherence to health-related behaviour change in a range of long-term conditions. This includes patients with chronic pain (Jensen, Turner and Romano, 1994), hypercholesterolemia (Coutu, et al., 2003), osteoarthritis (Hampson, Glasgow and Zeiss, 1994), asthma (Horne and Weinman, 2002), and rheumatoid arthritis (Scharloo, et al., 1998). This supports illness perception theory as valid for applying to those with a long-term condition such as coronary artery disease.

There is recognition in studies utilising the illness perception questionnaire associated with the common-sense model that, to the patients, perceptions of their symptoms are as important as the symptoms displayed (Goulding, Furze and Birks, 2010; Lau-Walker, Cowie and Roughton, 2009; Petrie and Weinman, 1997). This was supported by work undertaken in patients with chronic respiratory disease by Lacroix, et al., (1991). Petrie and Weinman, (1997) have suggested that the illness beliefs around myocardial infarction may be more influential in the ultimate level of recovery achieved than the severity of the myocardial infarction, as measured by the level of cardiac muscle functioning after the event.

Evaluation of prospective cohort studies from North America, the Antipodes and northern Europe using the illness perception questionnaire have identified the importance of patient beliefs in undertaking health-related behaviour change following a period of cardiac-related illness (Cameron, et al., 2005; Horne, et al., 2000; Weinman, et al., 2000; Petrie and Weinman, 2012). The results indicated that many of these illness beliefs are formed before the cardiac event and influence a range of aspects of recovery from the cardiac event.

The studies identified that an individual's belief that their condition was **controllable** and attributable to elements of their lifestyle (**cause**)

increased the numbers attending cardiac rehabilitation programmes and undertaking health-related behaviour change (Petrie and Weinman, 1997; Cooper, et al., 1999; Lau-Walker, 2007; Alsén, Brink and Persson, 2008; Pullen, Povey and Grogan, 2009). Those who perceived their condition to be short term (**timeline**) experienced lower levels of physical disability, and returned to social and domestic functioning, including paid employment, sooner than those who saw it as a long-term illness (Petrie and Weinman, 1997; Juergens, et al., 2010).

Adherence to medication for those with long-term conditions was associated with the perceived **consequences** of the condition. Those with a negative perception of their condition are shown to be less adherent with taking their medications (Horne, Clatworthy and Hankins, 2010; Horne and Weinman, 2002). These studies were based on either a single point in time or associated with follow-up of less than six months after the index event. Outcomes based on such a short time scale are of limited use in chronic illness when the aim of intervention is to effect long-term change.

In one of the studies looking at the longer term, Lau-Walker and colleagues, (2009) have shown beliefs around the identity and cure or control domains, measured at the time of their event, to be associated with higher quality of life scores in the physical domain at three years following a cardiac event. This is in comparison to other studies reporting that behaviour change undertaken immediately following a heart attack was not maintained at a year following the event (Newsom, et al., 2012; Luszczynska, 2006).

A statistically significant relationship between self-efficacy and illness perception at three years' post event was identified by Lau-Walker, (2004). In this group of 140 patients the greater the belief that their illness was controllable, the greater their self-efficacy for long-term independent exercise. This supports the evidence from studies with health belief theories discussed in Section 2.3 that health-related behaviour change is linked to multiple variables and identifying independent variables is unlikely to be successful.

The use of the illness perception questionnaire has enabled the relationships between illness beliefs and intentions or outcomes to be quantified. The cross-sectional design of these studies assesses both belief and either the intention or outcome simultaneously. This assessment is most commonly undertaken on the premise that beliefs predict behaviour.

However, as a self-regulatory theory, these constructs are likely to be constantly changing. This makes it difficult to measure which of the variables are cause and which are effects. It is highly likely that at times behaviour may predict beliefs. The use of questionnaires has led to suggestions that the questions themselves can change beliefs through suggestibility (Ogden, 2007), and bring to a conscious level thoughts which would otherwise never have been considered. This may increase the already present risk of participants selecting the response they believe the researchers desire as opposed to one in line that is with their own views.

Specifically, within the illness perception questionnaire the domains are not mutually exclusive. A belief around how long an illness would last could be considered either a control or a consequence domain for different individuals depending on their strategies for coping with illness. The need to account for variance further challenges the applicability of quantitative methods in complex situations such as illness beliefs and their impact on health-related behaviour change. Undertaking multiple levels of statistical analysis in an attempt to explain variance can reduce the applicability of the research to the real-life situations where such control is not possible.

A qualitative approach using interviews has been put forwards as the optimum way to gather information on illness beliefs. This is difficult to undertake on a large scale because of the time required to both gather and analyse data, and to date only a number of small qualitative studies have been published. These studies confirm the complexity of undertaking health-related behaviour change and the role of illness beliefs in this process.

Irrespective of the method selected, the research does support the concept that the beliefs an individual has about their illness impact on the way in which the illness is then managed. There is much less clarity as to the specific ways in which this occurs and it is clarity in this area which would enable the development of specific interventions to support health-related behaviour change.

The other major assumption of the early model which the original research sought to increase understanding of is:

the patient's ideas are shaped by information from various media and social sources such as family, friends and the medical care system, from his past illness experience and current symptomatic sensations  
(Leventhal, Meyer and Nerenz, 1980, p10)

This assumption does not appear to have been tested by the research. Cooper, et al., (1999), Leventhal, Brissette and Leventhal, (2003) and Pullen, Povey and Grogan, (2009) have acknowledged that there is still a gap in our understanding of the patients' perspective of their recovery and how their illness beliefs develop in the first place.

Identifying the processes by which the domains are shaped and how the input from different sources can improve individual self-regulation continues to be a priority  
(Leventhal, Brissette and Leventhal. 2003, p58)

Increasing our understanding of the ways in which these beliefs develop and their role in undertaking and maintaining health-related behaviour change was the aim of this study. This may also increase our ability to develop patient-centred interventions which will enable sustained long-term health-related behaviour change.

## **2.5 Gaining knowledge through social processes and interaction**

There is an acknowledgement that patients' information on health issues comes from the medical care system, media and social sources such as family and friends (Leventhal, Meyer and Nerenz, 1980). Physicians have traditionally considered themselves to be the gatekeepers in providing

health care information and services to their patients (Arora, 2003).

However, the explosion in medical information and support groups found in the mass media has many physicians questioning their traditional role as most trusted counsellors (Jacob, 2002; van Woerkum, 2003).

Research into the availability and use of medical information on the internet alongside the potential role of the internet in supporting physicians is receiving increasing attention (Eysenbach, 2008). Increasingly, the role of the internet, television and newspapers is recognised as an asset in educating and motivating patients toward better health (Rice, 2006; McMullan, 2006; Cline and Haynes, 2001).

The mass media, in particular the internet, is influencing people's perceptions as more information is readily accessible (Murray, Manktelow and Clifford, 2000; Meischke, et al., 2002; Karner, et al., 2005). Traditional media such as entertainment and the news media are also presenting an ever-increasing breadth of health and illness discussions (Kline, 2003). This has placed an unprecedented amount of health information within reach of the lay person.

It is estimated that up to two thirds of internet users access health-related information online (Hesse, et al., 2005). Use of the internet for health or medical information is generally more common among under the age of 65. Trust in the internet as a health information source is divided, with about a quarter of the responders in a survey expressing a lot of trust and a similar proportion expressing no trust (Hesse, et al., 2005).

The changing communication dynamic between health care professionals and patients as a result of the availability of more information has the potential to increase shared decision making (Smith, 1997; Briss, et al., 2004). Ciechanowski, et al., (2001) noted that those patients who feel involved in decision making have an increased understanding of their condition. This makes them more likely to acknowledge health problems, understand their treatment options, modify their behaviour accordingly, and adhere to their medication prescriptions.

With detailed technical information on prevention and treatment options available online (Chen and Siu, 2001; Voelker, 2003), many patients now look for information online before attending medical consultations (Neuhauser and Kreps, 2003; Hesse, et al., 2005). This has resulted in the requesting of certain procedures, tests or medications based on the information they have gathered (Berland, et al., 2001; Coelho, 1998; Murray, Manktelow and Clifford, 2000).

The role of the internet as a means of supporting health-related behaviour change or beliefs about illness is changing. Wantland and colleagues, (2004) reported a 12-fold increase in MEDLINE citations for Web-based therapies between 1996 and 2003. Two meta-analyses (Webb et al. 2010; Wantland, et al., 2004) reported that web-based programmes designed to change behaviour could be as successful as non-web-based programmes.

The greatest success in web-based programmes was achieved in those which were based on the theory of planned behaviour and used communication adjuncts such as motivational text messages (Webb et al. 2010). These meta-analyses only reviewed programmes supported by health care professionals. The lack of professional or commercial interest in peer-supported interventions has led to less information on their usefulness in supporting health-related behaviour change being studied (Eysenbach, et al., 2004).

Chou, et al., (2009) reported that the use of online support groups was associated with poor health and or psychological distress but this study was not designed to report outcomes of usage. Their study did, however, suggest that the low usage of social media in those over the age of 55 currently limited the value of this mechanism in supporting health-related behaviour change in chronic illness (Chou, et al., 2009).

The literature review undertaken prior to data collection identified a relationship between illness beliefs and health-related behaviour change associated with a myocardial infarction. However, there was no clear evidence to support the premise of many studies that belief predicted

behaviour or to explain the role of media and social systems in the development of illness beliefs. Thus the research questions were confirmed as:

- In what ways do illness beliefs adapt following a myocardial infarction?
- Do these adaptations influence decisions regarding whether or not to make a health-related behaviour change?

### **3 Methodology**

This chapter will justify the methodological approach selected to address the research questions:

In what ways do illness beliefs adapt following a myocardial infarction?

Do these adaptations influence decisions regarding whether or not to make a health-related behaviour change?

It will explain my ontological, epistemological and theoretical position as researcher. It will validate the selection of constructivist grounded theory as the methodology best suited to this research question.

The main elements of a constructivist grounded theory will be explained and the manner in which they were applied in this study will be described. The ways in which narrative theory and typologies informed the study will be explained. The use of symbolic interactionism as the theoretical framework for this constructivist grounded theory study will be justified. The chapter will end with a discussion of the approaches used to ensure that ethical and methodological rigour was applied throughout the study.

#### **3.1 Ontology and epistemology**

When undertaking qualitative research, the ontological and epistemological position of the researcher needs to be congruent with the philosophical underpinnings of the adopted methodology. My clinical experience had informed me that the range of knowledge sources available were used and interpreted in very individual ways by those who had had heart attacks. The ontological and epistemological perspective also had to be able to allow for this individuality.

I wanted to increase understanding of the ways in which individual patients gather and use knowledge after a heart attack and the ways in which this knowledge influenced any health-related behaviour changes they may or may not make. I was researching an area familiar to me but this study

required that I give the participants a voice to tell of their experience of recovering from a heart attack. This study is therefore underpinned by a relativist ontology and social constructionist epistemology.

### **3.1.1 Ontology**

A relativist ontological position asserts that there may be many truths but no single truth (Wuest 2007), and that reality for the individual is contextual and relative to their situation (Crotty, 1998; Robson, 2002).

Implicit within relativism is a belief that the same phenomena are interpreted differently by individuals at different times and different places and that people do not interpret the same phenomenon in a similar way.

The different understandings of a situation are contextual. I would understand a heart attack from the perspective of a health care professional functioning within a biomedical perspective. The understanding of the participants would come from a lay perspective. A relativist ontology allows for these multiple historical and culturally based interpretations to exist, if not always harmoniously, in the real world (Crotty, 1998).

### **3.1.2 Epistemology**

Social constructionism is an epistemological standpoint which is compatible with a relativist ontology (Crotty, 1998). It is a standpoint based on the assumption that knowledge is created and sustained by the social interaction occurring in the societies in which we live (Schwandt, 1994; Burr, 2003). This was congruent with the aim of this study to identify the ways in which social interactions influenced health-related behaviour change after a heart attack.

Within social constructionism, it is acknowledged that as human beings we have individual subjective views about objects. We live in a society which develops a collective meaning, structure and action about those objects over time as opposed to holding a fixed objective reality (Cohen, Duberley and Mallon, 2004). Individual meaning arises from our engagement with

our social world and becomes our reality (Crotty, 1998) and our social constructions of the world then inform our actions (Burr, 2003).

Social constructionism provided a standpoint from which to view and understand the social world of those who have experienced a myocardial infarction. This included the ways in which individuals gathered, interpreted and acted on information, attitudes and beliefs that were available to them as they realigned themselves as someone who had experienced a heart attack.

In a study underpinned by a social constructionist epistemology both participant and researcher had a role in constructing the findings (Mills, Bonner and Francis, 2006b). These findings are a re-presentation of the data collected to tell of the ways in which social processes and interactions influenced health-related behaviour change after a heart attack.

Social constructionism assumes our understandings of the world are culturally and historically specific (Burr, 2003). This assumption required me, as researcher, to constantly reflect on the role my own position and background of a clinical career in the biomedical world had on the study (Section 1.3.1) and to ensure the data reflected the shared experience of myself and the participants (Mills, Bonner and Francis, 2006b). This involved a consideration of the potential power imbalance associated with interviewing patients (Section 3.5.3).

Thus amongst other things I ensured I did not provide care to the participants in the study, meaning they knew me primarily as a researcher and not as a nurse. Secondly, I interviewed them in their own homes: a setting within their social world as opposed to the world of medicine.

From a social constructionist perspective, language is the medium through which sense is made of the social world in which we live, knowledge is created through this use of language and a common understanding is reached (Berger and Luckmann, 1991; Gergen, 2009). This reality is not

fixed but changes over time and is dependent on the current time, place and dominant discourse.

One of the initial thoughts which triggered the development of this study was the degree to which health-related information available on the World Wide Web was accessed by those experiencing a heart attack. The health-related information available comes from a variety of sources and discourses. The traditional biomedical model used within medicine, underpinned by the absolute truth of positivism, continues to be a dominant discourse but this is increasingly challenged by postmodern discourses. The extent to which postmodern discourses have allowed the complexities of living in the real world to be acknowledged and given a voice within the biomedical world became a part of this study.

### **3.2 Selecting a methodology**

The question I wanted to answer arose from my desire to understand more about the way in which knowledge is gathered, used, and made meaningful by those attempting to make changes in their health-related behaviour following a heart attack. The aim of understanding meaning from the participant's perspective required that I look for a standpoint that was compatible with dealing with questions about human behaviour.

I wanted this increased understanding to generate a theory to explain how these individuals make sense of knowledge within the social world in which they live. This aim of developing a theory led to the selection of grounded theory. It is the only qualitative approach in which the development of theory is an explicit goal (Wuest 2007). Grounded theory is centred on documenting and understanding the social processes central to change in our social world (Morse, 2009).

#### **3.2.1 Grounded theory**

Grounded theory is a systematic qualitative research methodology in which a theory is generated from the data. The theory explains the way that the participants have managed the phenomenon under investigation.

Grounded theory was developed by Barney Glaser and Anselm Strauss (Glaser and Strauss, 1968) who argued for systematic generation of theories directly from the research data at a time when qualitative research in sociology was losing ground to quantitative techniques (Morse, 2009).

Since its inception in the 1960s, during the second of six moments of qualitative research (Denzin and Lincoln, 2005), grounded theory methodology has evolved in response to the historical context and sociological influences of the moments. In this evolution, new interpretations with different philosophical underpinnings emerged resulting in debate and sometimes dispute between the various developers. These disputes have led to grounded theory being considered to be a contested concept (Bryant and Charmaz, 2007).

Bryant applied the criteria of a contested concept,<sup>11</sup> to demonstrate the ways in which grounded theory met the criteria (Bryant and Charmaz, 2007, p3). The contested concept was proposed by Gallie in 1956 and has since been applied to many scholarly terms. Despite its contested status, the grounded theory versions which have developed over the years have generally been seen as enhancing grounded theory. The various iterations have also raised further debate as to whether they are variations on a theme or different methodologies altogether.

Holton, (2007) has claimed that grounded theory should now be considered a research paradigm in its own right, given its ability to accommodate any type of data sourced and expressed through any epistemological lens. The application of grounded theory methodology across a range of diverse disciplines including information systems, education and religion would appear to support this call (Strauss and Corbin, 1998; Gottheil and Groth-Marnat, 2011; Urquhart, 2007).

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<sup>11</sup> The term contested concepts denotes concepts over which there are endless disputes about their proper uses on the part of their users and these disputes cannot be settled by appeal to empirical evidence, linguistic usage, or the canons of logic alone (Garver 1990).

One of the criteria for claiming that grounded theory is contested is that the theory is 'used aggressively and defensively' (Bryant and Charmaz, 2007), and the public disagreement between the founders of grounded theory can attest to that. There has been more recent evidence of a mellowing of opinions with grounded theory being proposed as a 'family of methods' (Babchuk, 2011; Bryant and Charmaz, 2007). This is a position in which the similarities across the variants, as opposed to the differences, are highlighted.

There is debate as to whether grounded theory is a methodology or a method; certainly Glaser and Strauss considered the original variant to be a method of analysing data but Corbin, (2009) refers to the Straussian variant as a methodology. In their handbook of grounded theory, Bryant and Charmaz, (2007) use the term Grounded Theory Method (p3) as an overarching term to encompass all variants. I consider grounded theory to be a means of analysing data; therefore the term grounded theory method will be used in this study.

Glaser and Strauss brought very different philosophical positions together in the development of grounded theory. Glaser had a traditional quantitative research background and worked with Strauss, a sociologist from the pragmatist symbolic interactionist influences of the Chicago School of Sociology to undertake a study on dying in California hospitals (Glaser and Strauss, 1966). This study developed a new method for undertaking qualitative research and was described in the seminal grounded theory text *The discovery of grounded theory* in 1968. Teaching in the oral tradition, they moulded and adapted the theory (Bowers and Schatzman, 2009), encouraging students to use the various strategies flexibly (Charmaz, 2006a).

Glaser and Strauss never worked together again on a specific study and their views on how the grounded theory method should be applied began to diverge (Kools, et al., 1996). This divergence has resulted in a number of different versions and some of the early students of Glaser and Strauss – Janice Morse, Kathy Charmaz and Adele Clarke – have become leading

proponents of these variant methods. These students developed grounded theory into a way of thinking about data which will vary according to the question being asked and the context in which it is being asked (Morse, 2009). The links of the most prominent variations to the original authors is shown as a genealogy in Figure 3-1.

Following the divergence of the two original collaborators, Phyllis Stern, (1995) labelled these versions Straussian and Glaserian. They have since been alternately named emergent (Glaser) and evolved (Strauss and Corbin) by Babchuk, (2011), or traditional (Glaser) and evolved (Strauss and Corbin) by Mills and colleagues (Mills, et al., 2007), reflecting a more evolutionary development of the method. Stern's original terms, Glaserian and Straussian, will be used in this study as an aid to readily identifying the version being discussed.

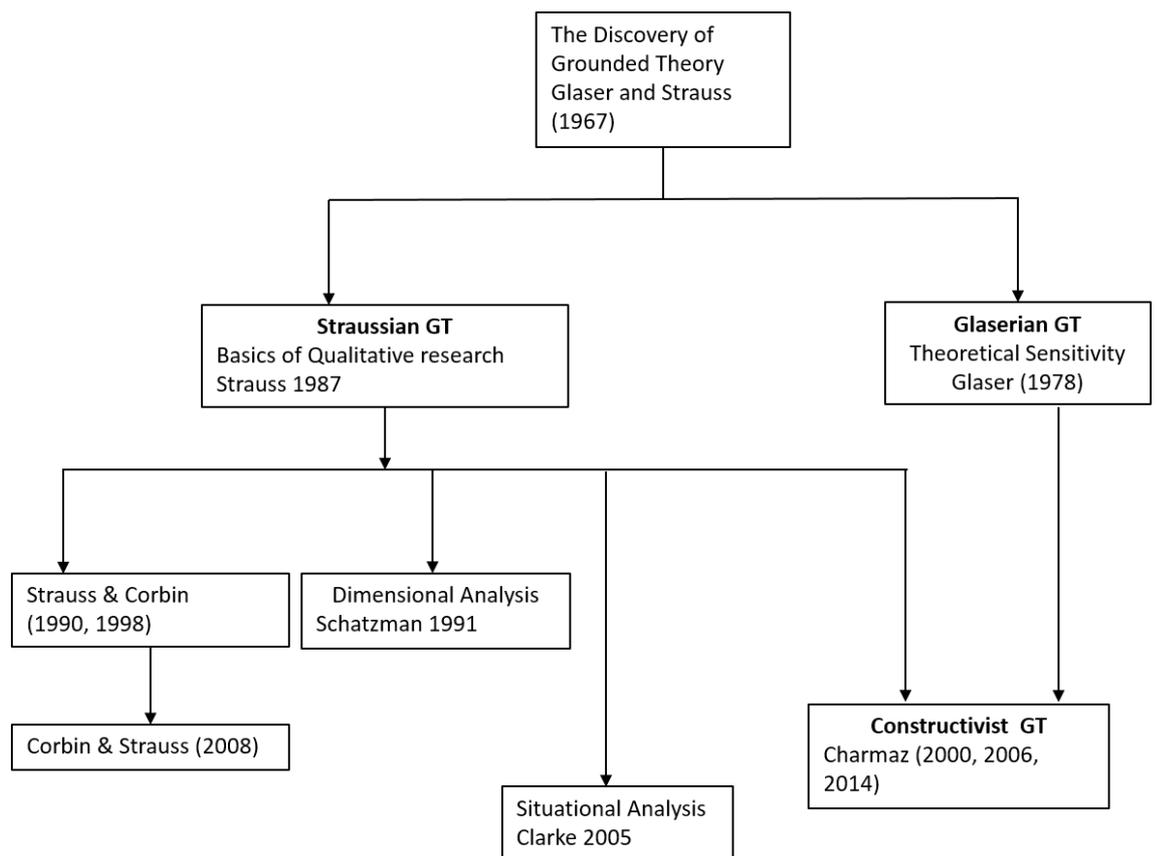


Figure 3-1 Genealogy of grounded theory methods

Glaser became renowned for his skills in analysing data. Glaserian grounded theory was developed primarily by Barney Glaser but latterly with Judith Holton (Glaser and Holton, 2008). Straussian grounded theory developed out of Strauss' work with Juliet Corbin. Their work focused on research into chronic illness from a symbolic interactionist perspective. The approach of Strauss and Corbin, (1990) focusing on verification of theory led to a very public dispute and rebuttal of this approach by Glaser in his 1992 publication *Basics of grounded theory analysis*.

Since this split there has been further development of grounded theory methods with new interpretations reflecting epistemological, theoretical, and methodological developments and movement over the past twenty years (Babchuk, 2011). This has taken grounded theory in a spiral of methodological development rather than binary opposition (McCann and Clark, 2004), and has resulted in a number of iterations of grounded theory. Creswell, (2012) classifies GTM into three approaches, Denzin, (2007) identifies seven different variants, and Babchuk, (2011) lists five major approaches based on their epistemological and theoretical orientations.

The approaches offered by Babchuk, (2011) – Glaserian, Straussian, Constructivist, Dimensional Analysis and Situational Analysis – are positioned in Figure 3-1. The latter three are often referred to as second generation grounded theorists, the authors having studied under and taken their lead from Glaser and Strauss (Morse, 2009)

Dimensional and Situational analysis have been heavily influenced by the Straussian variant. Constructivist grounded theory developed by Kathy Charmaz was influenced by both founders retaining the pragmatic and symbolic interactionist underpinnings of Straussian theory and Glaser's focus on emergence through the promotion of abductive reasoning during theory development.

The differences between Glaserian, Straussian and Constructivist grounded theory have been the focus of dissent within both grounded

theory and in the wider qualitative research arena (Cutcliffe ,2005; Melia, 1996; Heath and Cowley, 2004; Kenny and Fourie, 2015). The similarities and differences between the major grounded theory variants – Glaserian, Straussian and Constructivist grounded theory – are listed in Table 3-1. The differences between the variants will now be discussed and the variant of grounded theory selected for this study justified. The similarities between the variants will be discussed as part of the elements of a grounded theory study in Section 3.2.3

Differences	Similarities
Philosophical positioning	Theoretical sampling
Coding strategies	Theoretical saturation / sufficiency
Use of the literature	Constant comparative method of analysis
Emergence of the grounded theory	Memo writing

Table 3-1 Application of methodological techniques across Glaserian, Straussian and Constructivist grounded theory methodologies

Bryant and Charmaz, (2007) have suggested that the diversity found within the grounded theory method ‘*needs to be seen as basis for the discussion and exchange of ideas and not as an excuse to erect barriers between one ‘true’ version of GTM and all others*’ (Bryant and Charmaz, 2007, p48). There is a common acceptance that understanding the methodological differences between the variants was important in ensuring the most appropriate version was selected for this study (Birks and Mills, 2011) and these differences are summarised in Table 3-2

On an initial review Charmaz’s constructivist grounded theory appeared to sit well with my ontological and epistemological standpoint. Justifying why constructivist grounded theory was the best ‘fit’ was an important part of the research process for this study. Increasing my understanding of the differences and similarities between Glaserian, Straussian and Constructivist grounded theories informed the selection of the appropriate variant.

	<b>Glaserian Grounded Theory (Glaser, 1978, 1992,1998,2011)</b>	<b>Straussian Grounded Theory (Corbin and Strauss, 2008))</b>	<b>Constructivist Grounded Theory (Charmaz, 2006a,2014)</b>
<b>Philosophical position</b>	Glaser perceives GT to be method and as such divorced from philosophical consideration. Positioned by others in a positivist or post positivist critical realist paradigm. Role of Symbolic Interactionism not clearly articulated.	Authors claim relativist ontology and pragmatic symbolic interactionist underpinnings Symbolic interactionist roots explicit.	Author locates to relativist ontology and epistemology lies in social constructionism. Symbolic interactionism is theoretical perspective aligned with Constructivist GT.
<b>Coding procedures</b>	Substantive to theoretical coding. Trusts in the <b>emergence</b> of theory during theoretical coding. Objectivity within coding can be reached if sufficient data is collected	Systematic and rigorous coding structure to <b>create</b> an explanatory theory corresponding to the data.	Move from initial to focused coding. Highly adaptable coding guidelines to encourage imaginative engagement with the data to <b>construct</b> a grounded theory.
<b>Emergence of the grounded theory</b>	Definitive property of grounded theory. Emergent categories are objective, general and abstract with abstraction removing subjectivity. Views emergence of abstract categories as devoid of interpretation.	Less reliant on emergence and permit previous experience and ideas to play a part in the developing theory. This has led to claims that theory is forced.	Agrees with the original idea of emergence but views research as an emergent product of the time, condition and situation.
<b>Use of the Literature</b>	Restricted to a constant comparison with the data at the end of the study.	Encouraged use of appropriate literature at every stage of the research process to guide questions and direction of the study.	Literature viewed as part of the context of the study and is interspersed throughout the study. Extensive literature review should have its own chapter.

Table 3-2 Comparison of the major differences between Glaserian, Straussian and Constructivist grounded theory methodologies.

### 3.2.1.1 Philosophical positioning of grounded theory

When developing grounded theory in the 1960s, Glaser and Strauss were working in a positivist era of scientific endeavour. There was no requirement to demonstrate the congruence between the underpinning philosophy, methodology and methods of their research study required in current qualitative studies.

Glaser has never cited the philosophical position of Glaserian grounded theory. He cites grounded theory as a method and as such divorced from philosophical consideration. Glaser also believes that such an approach reduces the potential of grounded theory (Glaser and Holton, 2004). Those using Glaserian grounded theory had to position his methodology. Glaserian grounded theory has been considered as being that of a critical realist within the post-positivist paradigm (Annells, 1996).

Even Strauss and Corbin did not clarify the philosophical position of Straussian grounded theory in their joint work. Corbin acknowledged the relativist ontology and pragmatic symbolic interactionist underpinnings of their iteration twelve years after the death of Strauss (Corbin and Strauss, 2008).

All of the second generation grounded theorists justify their methodological and philosophical positions. This enabled the reader to identify the position of the researcher within the study, the approach to analysis and different levels of conceptual and theoretical abstraction sought (Birks and Mills, 2011).

Dimensional analysis with its grounding in symbolic interactionism and Schatzman's sociological roots has a similar foundation to Straussian theory. This was as a result of the close working relationship between Strauss and Leonard Schatzman, the original developer (Bowers and Schatzman, 2009). Situation analysis also developed from Straussian root stock but Adele Clarke has since developed a grounded theory

methodology which is underpinned by post-structuralist and feminist assumptions (Clarke, 2005; 2009).

Initially a student of both Glaser and Strauss, Charmaz, (2006a) developed constructivist grounded theory from the original format. This was at a time when constructivist thinking and the position of the researcher in the research process were influential (Birks and Mills, 2011). In constructivist grounded theory, Charmaz, (2006a, 2014) identifies the researcher as the author of the reconstructed meaning and experience of the research participants (Mills, et al., 2007).

Within this study the relativist underpinnings of both Straussian and Constructivist grounded theory could have been appropriate choices. However, the explicit constructivist epistemology of Charmaz grounded theory iteration made it the more appropriate for a study in which the role of both participant and researcher would impact on the outcome.

The role of symbolic interactionism in this study is more fully explained in Section 3.3, but the historical links between symbolic interactionism and grounded theory will be considered here. Anselm Strauss was a member of the influential sociology department at the University of Chicago. The Chicago School was the origin of symbolic interactionism, (Blumer, 1969) and Strauss brought those influences to grounded theory methodology. These links are clearly articulated in the 16 assumptions of grounded theory proposed by Corbin and Strauss (2008) which clarify the position of symbolic interactionism within Straussian grounded theory. The role of symbolic interactionism is not so clearly articulated in Glaser's emergent model of grounded theory.

Charmaz, (2014) acknowledges the benefits of a partnership between symbolic interactionism in offering a world view and language for conducting grounded theory studies (Charmaz, 2014, p284). The theoretical perspective of symbolic interactionism viewing humans as active, interactive and interpretive beings is congruent with constructivist grounded theory. This theory method link strengthens the position of

grounded theory as a method of choice when considering a study such as the one proposed here to look at the meaning of an event from a social perspective (Chamberlain-Salaun, Mills and Usher, 2013).

#### 3.2.1.2 Coding procedures

Coding of data is viewed as the first stage of analysis in all iterations of grounded theory but there are differences in the ways it is approached by the three variants. Glaser, (1992) identified two stages in which coding progressed from a substantive to a theoretical state with codes being saturated and objectified as increasing amounts of data support the codes. Through coding and the analysis arising from the process, Glaser trusts in the *emergence of a theory* from the data. This was a relatively unstructured process.

Strauss and Corbin,(1990; 1998) developed a complex coding structure within a narrower field of coding families than that supported by Glaser. The coding matrix moves the researcher through a meticulous and specified process in a step-wise fashion with the goal of *creating an explanatory theory*. The original aim of this was to provide guidance to novice grounded theory researchers struggling with a method taught in the oral tradition.

However, it is claimed this approach led to a focus on validation and description rather than generation of theory (Annells,1996; Glaser, 1992). In his open disagreement with the direction taken by Strauss, Glaser, (1987) claimed the use of the matrix forced theory development rather than allowing it to emerge from the data.

Charmaz takes constructivist grounded theory back to a more flexible coding framework to encourage engagement with the data. She supports Glaser's approach to questioning the data but in the use of gerunds and in vivo codes promotes a much more interpretive and intuitive analysis of the data to *construct a theory*.

This study used Charmaz's approach, particularly with regard to the use of gerunds. This approach was clearly articulated in the core text for the method (Charmaz, 2014). It supported engagement with the data which seemed to prevent early abstraction in an unsupported direction.

#### 3.2.1.3 Development of the grounded theory

In Glaserian grounded theory the *emergence* of the theory from the data is the definitive property of the method (Glaser 1978). The theory results from developing codes and categories considered to be objective as a result of the coding process. The codes are then abstracted out of the data to remove the subjectivity of the data. The theory that emerges is derived from the data viewed as devoid of interpretation.

Straussian grounded theory is much less reliant on emergence as it acknowledges that experience and therefore a degree of subjectivity is a part of the theory being *created*. Charmaz agrees with Glaser's original concept of the theory emerging from the data but sees the theory as being a product *constructed* out of the time, conditions and situation of the researcher and researched.

In this study the theory was constructed from the data and context of the study.

#### 3.2.1.4 Use of the literature

The use of literature also varies across the three primary variants of grounded theory. Glaser restricts the use of literature to a review undertaken as part of a constant comparison of the data with the emergent theory at the end of the analytical process.

Straussian theory supports use of the literature to guide both the question and direction of the study at every stage of the process. Charmaz views the literature as part of the context of the study whose use is interspersed

throughout the study. Charmaz also accepts that an extensive (contextual) literature should be a part of the completed study.

As a social constructionist in this research setting I believe that the knowledge created was an interpretation of the information exchange that occurred between researcher and participants. The grounded theory methodology selected needed to be congruent with this position.

Glaser's, (1992, 2007) version of grounded theory with its positivist underpinnings considers the researcher to be neutral to the study, able to collect and analyse data objectively. This approach was not compatible with my social constructionist ontology and was discounted as being inappropriate for this study. Strauss working with Juliet Corbin, (1990; 1998; 2008) moved from this approach to a more relativist ontology (Bryant and Charmaz, 2007; Anells, 1996), as they acknowledged that the researcher and participant create the theory that is interpreted and can never be fully objective (Strauss and Corbin, 1990; Corbin and Strauss, 2008). This move towards a relativist approach retained a positivist position in not acknowledging the impact the researcher has on every aspect of the study, reducing its compatibility with this study.

Within a constructivist approach, the way in which the researcher influences the whole research process is acknowledged (Charmaz 2006a, 2014). This differs from the original standpoint where the researcher as a neutral tool creates a theory from their perspective (Glaser, 2011). Charmaz's constructivist<sup>12</sup> grounded theory with its emphasis on the individual's engagement in a process provided further fit with this study. This made it an appropriate selection for a study placing the perspective of the participants as the key component.

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<sup>12</sup> Constructivism focuses on how the individual cognitively engages in the construction of knowledge. Social constructionism is the knowledge and meaning that are historically and culturally constructed through social processes and action.

### **3.2.2 Constructivist grounded theory**

Charmazian grounded theory set within the constructivist paradigm with its relativist ontology was selected for this study as being the best 'fit' for the question being asked. The constructivist grounded theory method can be used in a situation the researcher is familiar with and when the researcher wishes to understand more of what is happening in a specific situation, offering further 'fit' with this study (Charmaz 2006a, 2014).

Charmaz developed this variant of grounded theory over many years (1991, 2002, 2006a, 2014). The resultant grounded theory is constructed from the researcher's experiences and interactions with people, perspectives and research practice. Underpinned by symbolic interactionism, Charmaz (2006a, 2014) has retained the traditions of grounded theory in her constructivist method through the use of the constant comparative method of analysis and memos to raise codes through concepts to theory.

This constructivist grounded theory method has congruence with my social constructionist epistemological stance, which acknowledges that the outcome of any research will be an interpretation of the interaction between researcher and participants. As a novice researcher, Charmaz's (2014) encouragement to retain the participants' words in all aspects of data analysis aided in hearing the voice and perspective of the participants in the resultant theory (Mills, et al., 2007).

### **3.2.3 The elements of a grounded theory study**

Irrespective of the grounded theory method selected, there are a set of essential elements which should be undertaken as part of a grounded theory study. As discussed in Section 3.2.1 the review of the differing philosophical positions or approaches to analysis supported the selection of constructivist grounded theory for this study.

The essential elements of the grounded theory method, incorporating the similarities between the methods previously listed in Table 3-1 will now be

discussed. The essential elements are theoretical sampling, theoretical sufficiency / saturation, the constant comparative method of analysis and memo writing.

The essential elements of a grounded theory study and the principal works which guided how they were applied in this study are shown in Table 3-3.

<b>Essential grounded theory methods</b>	<b>Principal works for this study</b>
Coding and categorisation of data	Charmaz 2006a, 2014
Concurrent data collection and analysis	Charmaz 2006a, 2014
Memo writing	Glaser ,1978; 1998 Charmaz 2006a, 2014
Theoretical sampling	Glaser, 1998 Charmaz 2006a, 2014
Constant comparative method of analysis (CCMA)	Glaser and Strauss, 1968 Charmaz 2006a, 2014
Theoretical sensitivity	Glaser,1978
Theoretical sufficiency (saturation)	Charmaz 2006a, 2014
Theoretical integration	Glaser, 2011 Charmaz 2006a, 2014

Table 3-3 Essential elements of a grounded theory study and principal works guiding their application in this study

The texts used to support the study are not all based in the constructivist arena. The work of Glaser was studied to aid understanding and use of the ‘troublesome trinity’ (Hood, 2007): theoretical sampling, constant comparative method of analysis, and theoretical saturation.

A diagrammatic representation, based on the works of Birks and Mills, (2011), of the iterative way in which the essential elements were applied in this constructivist grounded theory study is shown in Figure 3-2 Elements of a constructivist grounded theory study. (Adapted from Birks and Mills, 2011, p13). The general principles of these elements will be discussed now, and the specific ways in which each element was applied in this study will be discussed in Chapter 4.

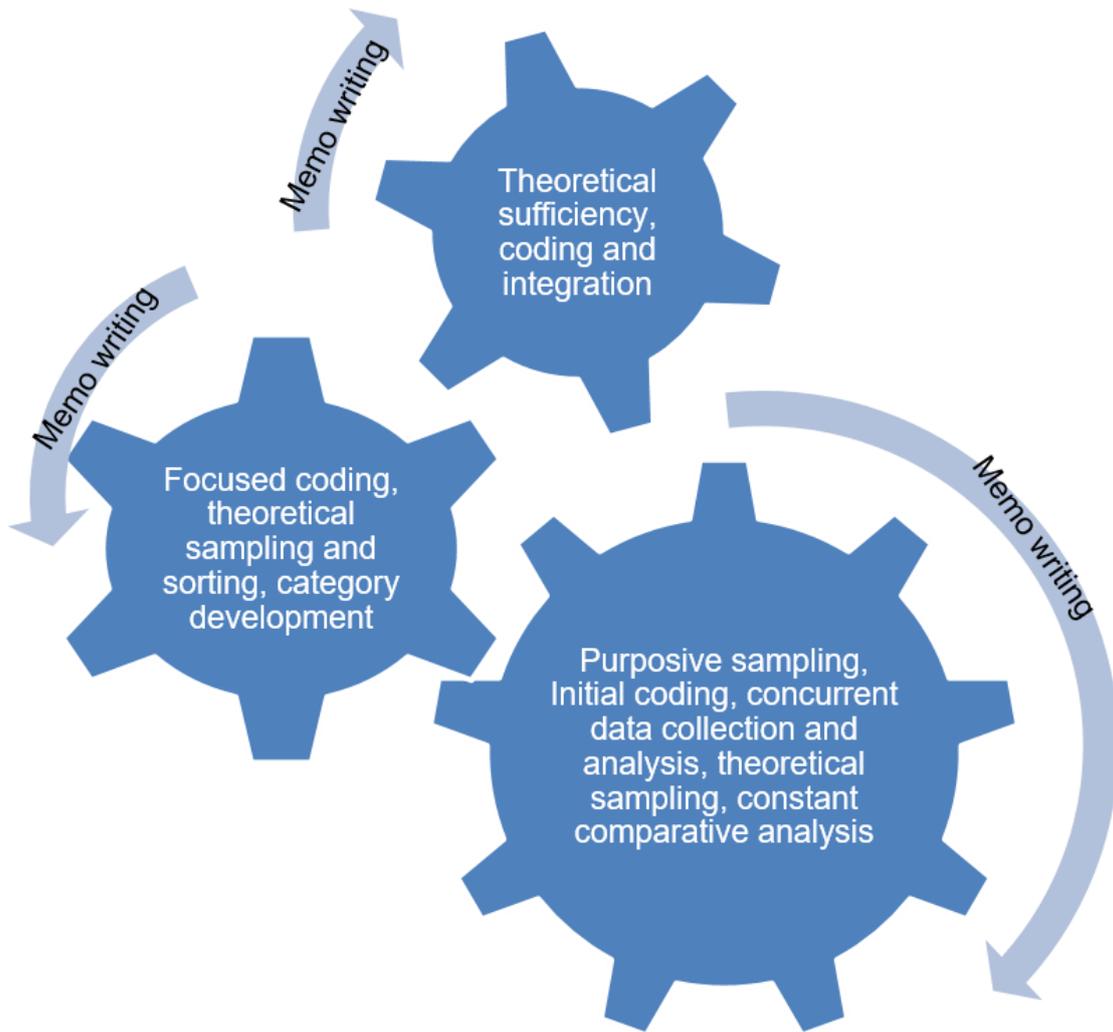


Figure 3-2 Elements of a constructivist grounded theory study. (Adapted from Birks and Mills, 2011, p13)

Charmaz's methodology for coding and categorisation follows two phases, initial and focused coding. The use of gerunds and in vivo codes retained the voice of the participants which helped ensure the study remained true to its constructivist epistemology.

### 3.2.3.1 Constant comparative method of analysis

Adherence to the constant comparative method of analysis (CCMA) is a core concept in the original iteration of grounded theory. This required the comparison of incident to incident, incident to concept through to the comparing of concepts with hypotheses as the theory developed (Glaser and Strauss 1968). Constructivist grounded theory advocates this iterative

and comparative process in that both data collection and analysis proceed simultaneously using inductive, deductive and abductive<sup>13</sup> forms of reasoning, to explore all the possible explanations for the findings.

Data collection becomes progressively more focused and analysis more theoretical as the theory is constructed by the researcher. Through this continuous process of induction, deduction and abduction ideas are generated and then taken back to the data for testing. This cycle carries on until there is sufficient data and ideas to develop a substantive theory.

### 3.2.3.2 Memo writing

Within the grounded theory method, memos capture the thoughts of the researcher and provide an audit trail of the development of the theory. They are the notes made by the researcher at every point in the study process.

Within the constructivist grounded theory method memos are viewed as personal, provisional and correctable notes. Conjectures can be made and then checked back with the data before developing or discarding the ideas contained within them (Charmaz, 2014). Critical re-examination of memos can identify the assumptions and standpoints of the researcher which may be subconsciously influencing the direction of the study.

### 3.2.3.3 Theoretical sampling

Theoretical sampling is one of the hallmarks of a grounded theory study. The researcher samples for data on the strength of the codes and categories emerging during the constant comparative method of analysis. It is not about the sampling for representativeness or generalisability

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<sup>13</sup> Inductive reasoning extrapolates trends or patterns from a range of individual examples, while deduction applies generalised or abstract concepts to specific cases. Abductive reasoning “entertains all possible explanations from the observed data, and then forms hypotheses to confirm or disconfirm them until the researcher arrives at the most plausible interpretation of the observed data” (Charmaz, 2006).

required in quantitative studies. This tool is used systematically and strategically to actively seek participants who will provide data to support or refute the current direction of the study (Charmaz, 2014). This is in contrast to a more purposive sampling approach in which data is gathered until the same patterns recur.

#### 3.2.3.4 Theoretical sufficiency or saturation

Theoretical saturation is the point at which theoretical sampling and analysis of that data is not leading to new properties or insights about the aspect of the study being developed (Charmaz, 2014). This is not a one-time check but a continual critical review at all levels of the study, coding, categories and theory construction, to explore for additional properties of the concept under scrutiny. Critics of this term suggest that saturation of categories is not achievable in a study that does not explore all of the data collected, preferring to use the term theoretical sufficiency (Dey, 2007). Charmaz, (2014) in response to this suggests that these claims support her concerns that concepts are considered saturated prematurely if analysis has been superficial or uncritical. The principle of theoretical sufficiency was used in this study.

#### 3.2.3.5 Theoretical integration

Theoretical integration is the sorting of memos to construct a coherent and plausible theory of what is happening on the data. Theoretical sorting facilitates comparison of the categories and concepts at an abstract level. Charmaz, (2014) promotes the use of drawing and diagrams to aid this integration as a visual representation of the scope, direction and connections between categories.

#### 3.2.3.6 The iterative nature of grounded theory

These elements have been discussed individually but the iterative nature of grounded theory became apparent from the early stages of data

collection. All of the elements were all applied at all stages of the research process. In a few hours of analysis during this study it became the norm to interrupt coding to write a quick memo or add depth and understanding to a current memo. This could provide direction for further theoretical sampling or back into the data to follow up a lead suggested by the memo.

This continual flow between the elements is emphasised in the texts but this did not fully prepare me for the reality of undertaking a grounded theory study. The Birks and Mills, (2011) diagram illustrating the process using interlocking cogs (Figure 3-2) helped me adjust to the lack of linearity in this process.

#### 3.2.3.7 Additional elements of a constructivist grounded theory

In addition to these essential elements, the reflexive stance, the position of the researcher, and the theoretical framework also need to be addressed when justifying the use of a constructivist grounded theory methodology (McCann and Clark, 2004).

Whilst retaining the essential elements of the grounded theory method, constructivist grounded theory takes a reflexive stance towards actions, situations and participants and the analytic constructions emerging from the data (Charmaz, 2006a; 2014). The impact of those involved in the process is openly acknowledged in the final outcome of the research. A critical reflexivity was applied throughout the process but particularly during analytical constructions to identify areas where a positivist stance may have crept in as a consequence of any assumptions I held as a consequence of working in the positivist biomedical arena.

Constructivist grounded theory is built on the symbolic interactionist theoretical perspective of Straussian grounded theory. Grounded theories in a constructivist study are constructed from the interaction of researcher, participants and their world views. Constructivist grounded theory uses a symbolic interactionist theoretical framework to locate the argument and present the researcher's interpretation of reality (Charmaz, 2006a; 2014).

Given that the aim of this study was to consider meaning making in the context of action and social interaction, the symbolic interactionist perspective of constructive grounded theory was influential in the choice of grounded theory method.

The constructivist grounded theory method and its application are described by Kathy Charmaz in her original textbook (Charmaz, 2006a) and developed in the second edition (Charmaz, 2014) and these texts provided the majority of the guidance for this study.

### **3.3 Symbolic interactionism**

Symbolic interactionism is a sociological perspective for understanding the complexity of human social life. It proposes that a human being acts towards and within the environment in contrast with deterministic sociological theories where the human being is a product of and controlled by society (Charon 2010). Symbolic interactionism originated in the work of the philosopher and social psychologist George Herbert Mead but the theory is attributed to his student Herbert Blumer who drew on the works of John Dewey, Charles Pierce and Charles Cooley to develop the theory in the 1950s and 60s.

Since then, the growth in the use of qualitative research methodologies and the work of others in the field (Goffman, 1990; Warriner, 1970; Shibutani, 1955; Charon, 2010) have seen the integration of symbolic interactionism, as a perspective for understanding the socially constructed world, into mainstream sociology. Anselm Strauss, who left the Chicago School to work with Glaser in California during the late 1960s, is credited with bringing symbolic interactionism as a theoretical perspective to grounded theory.

#### **3.3.1 Key concepts of symbolic interactionism**

Symbolic interactionism (Blumer, 1969) assumes society, reality and self are constructed through an interaction which is interpretive, and relies on language and communication. It addresses how individuals create, enact

and change meanings and actions and how collective meaning is constructed (Sandstrom and Fine, 2003). These three premises are based on the key concepts underpinning symbolic interactionism theory defined by Mead, namely mind, self and society.

#### 3.3.1.1 Human mind

Symbolic interactionism gives the label of 'mind' to the process of thinking, a process dependent on both self and symbols that we engage in all of the time (Blumer, 1969). It is the constant process of giving messages to yourself as you move through your daily activities and can be a very conscious deliberate action, such as when we have to problem solve, or less so if we are undertaking very familiar activities such as cleaning our teeth.

Within the human mind we have the ability to take on the role of others, to consider the effects of our actions on them, their response and our subsequent adaptation of activities. This is core to being human; in any situation we interpret and react both to our own and others' perspectives and so adapt how we manage the situation as it progresses. As participants were admitted to hospital with their heart attack, they interpreted from their previous experience, other patients and health care professionals the way in which they were expected to act as a patient.

Human action arising from the messages of mind is complex and involves other people. Humans engage in a continuous stream of actions which are influenced by social interaction and interaction with self. These actions can be either covert or overt and they take us in a certain direction which is changed by the decisions and actions we take. Behaviour change such as increasing levels of physical activity after experiencing a heart attack could be viewed not as a response to the heart attack but as a result of interpreting that, via a process of self-indication, one feels more energised after undertaking physical activity. (Blumer, 1969).

### 3.3.1.2 Nature of self

Self is a highly complex concept which has a specific meaning within symbolic interactionism; the self is an object of an individual's own action (Charon 2010). Self arises and is maintained or changes through interaction. Self develops from putting oneself in the position of others and viewing our self from there. The participants in this study now view themselves as someone who has had a heart attack in addition to their previous perception of self, for example as father or plumber.

As individuals, we become objects of our own self. We talk to ourselves, we look back on ourselves in situations, we imagine and see ourselves in situations and we recognise who we are in relation to others. We then interpret and act on these actions. The result is a reinterpreting of self which emerges out of interaction and via ongoing interpretive processes (Kivisto, 2005). If, as someone who has had a heart attack, we are constantly being informed by others that we must 'take things easy' then we may be cautious about undertaking certain activities as a consequence of our interpretation of these messages.

However, having a self also means we are active in relation to the world. We have self-control and self-direction and as individuals with the ability to enact change our sense of agency is empowered. Those who have had a heart attack will interpret the message of 'taking it easy' differently and may restrict their activities, while others may reject the message and undertake more physically demanding activity as an act of defiance of the message.

### 3.3.1.3 Society

Human society is created, defined, altered and used by active beings who possess self and engage in mind action. From a symbolic interactionist perspective everything is seen in the context of social interaction which creates society (Charon 2010). What a person does is constructed through interaction with others and themselves which leads to a new construction

and line of action. This cyclical and ongoing process (Blumer, 1969) requires individual interpretation and self-reflection (Sandstrom and Fine, 2003).

Within a symbolic interactionist perspective, symbols are social objects which are used intentionally to communicate and represent something. Words, as symbols, are understood by the person speaking them and by the listener who is interpreting them. The words 'heart attack', for example, symbolise a serious health-related event. Words are acknowledged as the most important symbols; they make human thinking possible (Charon 2010).

Almost all acts which take place between humans are symbols and in conjunction with words allow humans to respond actively to their environment. Humans remember, categorise, perceive, think, deliberate, solve problems, transcend space and time, create new ideas and direct themselves.

Meaning involves human beings interpreting the meaning of things based on their previous experience and understanding. This is a continuous process through which meaning is formed, learned and transmitted through social interaction. This changes over time as humans create and recreate the world around them (Blumer, 1969). Public health campaigns encourage us all to increase our levels of physical activity for the benefit of our long-term health. However, this message can become more personal after a heart attack if the message is now that increasing your level of physical activity will reduce the risk of suffering another heart attack.

### **3.3.2 Key premises of symbolic interactionism**

Blumer (1969) identified three main premises of symbolic interactionism, listed in Table 3-4. The main tenets of these principles and their bearing to this study will now be detailed.

Premises of symbolic interactionism
1. Human beings act toward things on the basis of the meaning those things have for them.
2. Meaning is derived from the social interaction one has with other human beings.
3. Meaning is handled in and modified through interpretation.

Table 3-4 Premises of symbolic interactionism (Blumer, 1969)

### 3.3.2.1 Human beings act toward things on the basis of the meaning those things have for them

Symbolic interactionism considers human beings to be actors. As actors humans notice and act on things according to their context and their relevance to them as individuals at that specific time. The situation is defined and a course of action decided upon as a result of what is occurring in their present thinking and present situation. In deciding to seek medical support for their initial symptoms it is possible that participants acted as a consequence of being unable to find meaning and cause for their present symptoms in their past experience (Charon 2010).

From a symbolic interactionist perspective individuals who experience a myocardial infarction will be trying to understand the meaning this event has for them. It may include assimilating information and making decisions which could inform their recovery and any health-related behaviour changes they make. If an individual does not perceive that his heart attack could be prevented, he may be less likely to change his behaviour than another who conceives some actions do reduce the risk of a further heart attack in the future. It was the process of gathering and interpreting information with the subsequent action that this study aimed to capture.

### 3.3.2.2 Meaning is derived from the social interaction one has with other human beings

Social interaction is a key concept in symbolic interactionist theory. A core assumption of symbolic interactionism and this study is that everything is seen in the context of social interaction. What a person does is constructed through interaction with others and then themselves which leads to a new construction and line of action. This is a cyclical and ongoing process in which change rather than stability is the norm.

Human beings act in response to their interaction with others. They react to a situation with a reinterpretation of their behaviour and an acceptance or rejection of that behaviour (Blumer, 1969). The meaning of a heart attack will vary between individuals and for some it may confer a future of invalidism if that is their previous experience. However, if interaction with others, for example health care professionals, offers a different outcome then the individual may change their perspective. This reinterpretation and any health-related behaviour change arising from it are the areas which were explored in this study.

The perceptions myocardial infarction patients develop both prior to and after their event come from this interaction. Their everyday world can be changed over time but only if the individual perceives this as important within the context of their own life (Leventhal, Meyer and Nerenz, 1980) and is flexible enough to learn and/or construct new meanings (Sandstrom and Fine, 2003). Within this study the social interaction I was trying to understand is that which shapes the meaning of a heart attack for the participants. This included interactions with family, friends, health care professionals and other patients, but also television, the internet and books.

### 3.3.2.3 Meaning is handled in and modified through interpretation.

Blumer (1969) proposes that this reinterpretation is achieved through social interaction where the capacities of 'mind' and 'self' are developed

allowing a human to see and respond to their self as objects (Sandstrom and Fine, 2003). A symbolic interactionist perspective would assume that the beliefs which heart attack patients develop prior to their event come from this interaction with their everyday world.

Leading from this assumption is another that these meanings can be changed over time but only if the individual perceives this as important within the context of their own life. An individual who has recently had a heart attack may or may not adapt these beliefs depending upon their interpretation of its importance and impact on their future.

From a symbolic interactionist perspective this group of patients have to absorb information about coronary heart disease, interpret it within the context of their current beliefs and then decide on the action they will take, for instance, to change their behaviour or not. The individual participants will have different interpretations of concepts such as health as being either a feeling of wellness or the absence of disease.

### **3.3.3 Relevance of symbolic interactionism to the research question**

The underpinning of constructivist grounded theory by symbolic interactionism required that I review it for its congruence with the method and the research question I was asking, which centred on why individuals react to a heart attack in the way they do and what influences these reactions. Symbolic interactionism as a perspective offered a way of dealing with these questions.

Symbolic interactionism's focus on interaction and interpretation is central to this study. The individual participants had interpreted the experience of having a heart attack in a way that was meaningful to them. These participants then interpreted the questions I asked at interview and provided a response based on their experience. I as researcher interpreted their words and immersed them in the research process.

Participants may have reinterpreted their meaning if the research questions provoked different ways of thinking about their experience. Every stage involved an interpretation and construction of meaning from the words spoken, read and written. The iterative nature of the grounded theory method resulted in reinterpretation of meaning as new information was added. Thus symbolic interactionism as a perspective for understanding the complexity of human life is relevant for this study on a range of levels.

### **3.4 The role of narrative theory in this study**

Narrative research and specifically illness narrative has informed this study. The recognition that the participants were recounting their story of life after a heart attack instigated a review of the relevance of narrative inquiry to this study. This review occurred after data commenced and influenced subsequent data collection and analysis. The stories told by participants were analysed but re-presenting the data whilst retaining a narrative element in the retelling was a means of hearing the participant voice throughout the study.

The postmodern epistemological shift away from the science as the dominant perspective has benefitted the narrative paradigm in which subjective human experience is pre-eminent. This shift in what is now referred to as the 'narrative turn' took place in social science research during the late 20<sup>th</sup> century (Bochner, 2001). As a result, illness narratives which tell of the suffering of those who are ill within the context of their everyday lives are challenging medicine as the dominant discourse in disease and illness, particularly chronic illness (Charmaz, 2002; Frank, 2010).

Narrative inquiry is a qualitative approach for making sense of the lives we lead within social science research (Jones and Tansey, 2015). Initially perceived by the medical profession as improving patient–doctor communication (Kleinman and Kleinman, 1994), the work of authors such as Arthur Frank, (2010; 2013), Arthur Bochner, (2001) and Catherine

Reismann, (2005) has broadened our understanding of illness narrative. It is now seen as a legitimate means of articulating the impact illness has on the daily lives of those experiencing it (Mazurek, 2015).

The subjective nature and potential lack of adequate analysis, when compared against modernist criteria, led to early criticism of narrative inquiry (Atkinson, 1997; Atkinson and Silverman, 1997). This has been rebutted by the suggestion of different criteria for the validation of narrative research by authors such as Gabriel, (2004), and a robust defence of the legitimacy of narrative research (Bochner, 2001). Gabriel, (2004) also argues that the juxtaposition of the voice of first-hand personal experience and the scientific voice of expertise has privileged the voice of medicine over accounts of the lived experience.

An underlying assumption in narrative theory is that life itself has an implicit narrative structure and that we all lead storied lives. These stories tell us what is happening in our lives and tell us what it is to be human (Plummer, 2013). Illness disrupts our stories and admission to hospital further disrupts them. The way in which medical personnel fragment our story when taking a medical history also disrupts the way we tell our stories (Frank, 2013; Lucius-Hoene, et al., 2012).

If narratives provide us all with a way of making sense of an experience, identifying its significance and if necessary learning to live with it (Gabriel, 2004), then within medicine illness narratives offer an opportunity to increase our understanding of the meaning of disease in the lives of our patients. Thus the role of narrative inquiry in offering meaning to an experience is in keeping with the research question.

Narrative inquiry fits with the selected constructivist methodology (Charmaz, 2014) as it recognises that the meaning of the narrative is co-constructed by researcher and participant. Further, both narrative inquiry and constructive grounded theory look for the voice of the storyteller in the final analysis of the work (Frank, 2010; Charmaz, 2014).

The role of narrative within this study emerged with a realisation that the data gathered was being offered by participants as a story of recovery from a heart attack. The longitudinal element of the research highlighted this when the second interview commenced with a resumé of the story by participants progressing to a telling of the next chapter in their story. Once the participants were viewed as storytellers the data took on a new life-form (Bochner, 2001). The ways in which individuals made sense of the heart attack in the minutiae of their daily life became apparent (Bleakley, 2005).

Narrative inquiry can either use a story and analyse it or the product of data analysis can be the story (Bleakley, 2005). This study merged the stories of the individual participants during data analysis and from this process different narratives which told of life after a heart attack were constructed as the theory developed.

The very different ways participants experienced the same event was also highlighted when the data was viewed as a narrative. Two elements of narrative methodology have added guidance to this study: the use of narrative typologies and the ethical principles in narrative inquiry. The illness typologies developed by those such as Frank, (1997; 2013) and to a lesser degree Hawkins, (1999) were useful when developing the potential theories suggested by the data. In 'thinking with' my stories I had gathered an awareness of typologies such as Frank's quest, chaos and restitutive narratives and these provided a structure for data and facilitated the development of categories during theory development.

Narrative inquiry makes explicit the responsibility which comes with the 'narrative privilege', (Nelson, 2001 cited in Adams, 2008, p190.), we are afforded as researchers. In applying the 'So what?' (meaning) and 'Did it really?' (verisimilitude) questions to both the data being collected and the analysis, the eventual theory is more likely to have meaning and be representative of the participants' reality (Gabriel, 2004). This added to the credibility, usefulness and resonance of the grounded theory.

### **3.5 Reflexivity**

Reflexivity is utilised as a tool in qualitative research. However, its role and definition vary across the methodologies (Doyle, 2013; Pillow, 2003). In broad terms, reflexivity within qualitative research involves making clear the ways in which the researcher's assumptions, actions and decisions have impacted on all aspects of the research process. This required an active, critical self-evaluation on my part as researcher (Bradbury-Jones, 2007; Guillemin and Gillam, 2004; Pillow, 2003; Stronach, et al., 2007).

Reflexivity is most frequently used within qualitative research to enhance the credibility and trustworthiness of the research (Buckner, 2005; Cutcliffe, 2003) through 'recognition of the other' (Pillow, 2003, p184). However, there are limits to our ability to make both our researcher role transparent and represent our participants' voices within qualitative research. While reflexivity will support these aspirations of transparency and voice it needs to be undertaken in the acknowledgement that it will never be perfect. In undertaking critical self-reflection of our work a lingering discomfort that we could have represented our participants better or differently may be the reality of qualitative research (Pillow, 2003).

#### **3.5.1 Reflexivity within a grounded theory study**

Glaser, (1978) implies that a degree of reflexivity is undertaken in all grounded theory studies when he refers to the role of the researcher's knowledge, understanding and skills within theoretical sensitivity. He further maintains that the role of the researcher during constant comparative analysis in ensuring codes and categories remain grounded in the data will highlight any researcher impact. He has subsequently stated reflexivity is unnecessary (Glaser and Holton, 2004). Mallory, (2001) and McGhee, Marland and Atkinson, (2007) have posited that the over-use of reflexivity in constant comparative analysis can lead to a descriptive theory. However, Neill (2006), a Glaserian grounded theorist, does view reflexivity as an appropriate part of the process which should be acknowledged.

In her original text, Charmaz, (2006a) did not address reflexivity within the context of constructivist grounded theory, but in the recent second edition (2014) she explicitly discusses the role for reflexivity. The relativist ontological positioning of constructivist grounded theory with its understanding of humans as complex, unknowable beings and the emphasis on knowledge as being socially constructed supports a reflexive approach. As a reflexive researcher, I was required to question the underlying meaning and ideologies of participants to increase understanding of the underlying social structures and discourses influencing their perspectives (Charmaz, 2014). The symbolic interactionism underpinning the methodology, with its tenet of interpretation of human interaction, implicitly promotes the use of reflexivity to acknowledge the relationship between researcher and researched in constructing data (Neill, 2006; Mruck and Mey, 2007).

A reflexive approach was used through this study and the manner in which this was undertaken within specific components of the method will now be discussed. The area of study is one which is underpinned by the biomedical model and the evidence supporting practice is almost exclusively positivist as was the literature I selected to support the specific question for the study.

The original study aim reflected this and has shifted as a consequence of a reflexive review during the design period. The use of a reflective journal has tracked my changing ontological and epistemological positions and exposed these underlying positivist assumptions. Summarised in the chapter on reflection (Section □) the reflective journal was the tool which provided an understanding of the constructivist grounded theory analytical lens that was used (Mills, Bonner and Francis, 2006a; Charmaz, 2014).

Symbolic interactionist underpinning of this study is built on an assumption that data is constructed from a constant process of interaction between researcher and participant. This interaction involves a bi-directional interpretation and ascribing of meaning to questions,

responses and the non-verbal elements of the interaction. The participant's responses to my questions afforded an in-built reflexivity during the interviews. My performance as researcher during interviews impacted on the data collected. The audio recordings of interviews were reviewed to critically examine my own performance in pursuing or overlooking topics (Kvale and Brinkmann, 2009; Roulston, 2010). An example of the outcome recorded in my reflective diary is illustrated in Table 3-5.

Post Interview 1

I was too concerned with his story and not sufficiently aware of responses that mentioned he was gaining and processing knowledge. Examples are when he talked about pain and how he interpreted the nurse continually asking if he had pain. Also link between searching internet for health issues related to brother but not yet himself.

I need to be aware of this and put researcher not nurse hat on.

Post interviews 3 and 4

These were undertaken within 2 days of each other and analysis and transcription was slow – too slow. My ability to pick up cues is getting better but it still needs to focus more on information sources and how this is used.

Table 3-5 Excerpt from reflective diary

There is an accepted view amongst grounded theorists that reflexivity is implicit in the constant comparative method of analysis. A rigorous application of the method of iteration between data and analysis during the coding process was a means of examining any preconceptions influencing coding and categorisation. This ensured coding was derived from the data and not solely my view (Birks and Mills, 2011; Saldana, 2012). The audit trail of memos illustrating decision making and meaning

making (Charmaz, 2014) is deemed to provide the study with an in-built reflexivity addressing issues of rigour or 'truth' (Pillow, 2003, p185).

The rigour of the constant comparative method of analysis within the context of a constructivist study does facilitate a reflexive stance. However, as a novice researcher new to the grounded theory method, I was not confident that a reliance solely on the reflexivity implicit in constant comparative analysis would ensure a reflexive approach to this study. An awareness of different reflexive strategies such as those suggested by Pillow, (2003) enabled me to identify that one role of my research was to represent the participants and raised an awareness of the ways in which this could occur.

The reflexivity inherent in the way data and theorising remain close within the constant comparative method of analysis guarded against their position being misrepresented. The voice of the participants, as co-constructors of the theory, was represented in a meaningful way by ensuring that their transcribed data was used appropriately to help explain and illustrate the theory (Lather, 1995; Pillow, 2003; Charmaz, 2006a).

The iterative nature of a grounded theory study presented challenges when writing an academic thesis. The thesis required a sequential format, but the use of reflective and analytical memos to provide a timeline (Mruck and Mey, 2007) facilitated this process. Mruck and Mey, (2007) argued that concerns for the audience can influence the writing up of the research.

The thesis I have produced is a document that follows a prescribed format for an academic audience. However, in disseminating the findings through specialist conferences and journals in the future, I will have to attend to the message of the presentation as some of my findings may make uncomfortable reading for colleagues, and sensitivity will be required. Reminding myself that my epistemological positioning has

shifted during this prolonged period of study, a luxury not afforded many of my colleagues, will aid in considering the position to adopt each time.

### **3.5.2 Position of the researcher**

The positioning of the researcher within a grounded theory study is the only component that all the key authors will accept requires the use of reflexivity – if only implicitly. Glaser and Strauss, (1968) did not explicitly identify a role for reflexivity. However, memos as the medium for ‘recording ideas’ (p108) were likely to include a reflection element. In this study, early memos were often free-writing sessions triggered by a code in which a wide range of ideas and thoughts were tested out.

Strauss and Corbin, (1998) began acknowledging that the interplay between researcher and researched influences the data generated. The second generation grounded theorists (Morse, 2009) all acknowledge a role for reflexivity although its meaning and function differs according to the specific grounded theory methodology used (Mruck and Mey, 2007).

Constructivist grounded theory restructures the traditional grounded theory interaction between researcher and participants. There has been a move from the role of the positivist objective researcher as a ‘distant expert’ (Charmaz, 2000, p13) to one in which I as researcher am cast in the role of author (Mills, et al., 2007). The interaction between me and the participants produced data which I interpreted and presented in a manner which described their experiences in the most faithful way possible (Munhall, 2007).

Entering the research arena with a pre-existing passion for the area of study, and in addition personally developing the research question can, and did, blind me to aspects of the data (Blumer, 1969). This was particularly true in the early stages of the study. I entered the study on a mission to find a means of engaging all patients who had had a heart attack in a cardiac rehabilitation programme, adhering to positivist ideals, to encourage them to undertake health behaviour change. The acknowledgement of this standpoint over time, through the adoption of a

reflexive stance, increased my awareness of the way in which I approached all aspects of the study. This included how I used medical language in the interview structure and what I 'saw' in the data, enabling me to address it.

Discussions with others who operated from a standpoint outside the discourse of medicine yet understood the area of study, such as experienced qualitative researchers, aided in identifying some of these hidden assumptions and world view (Birks and Mills, 2011). This acknowledgement of inherent standpoints and the shifting of these standpoints during the study resulted in a tension between the research and the clinical worlds in which I functioned. In the research world, I had the power to influence these tensions through the ways in which I used and presented the data. I had to learn how to be non-judgemental about both the participants and my clinical world during data collection and avoid being seen to support or disparage either discourse.

In the clinical world, my influence was reduced as I have to negotiate changes in the way care is delivered with colleagues whose source of knowledge is the discourse of medicine. The emotional and intellectual tussles involved in undertaking a constructivist study from a location within a positivist discourse were recorded in the reflective journal which was maintained throughout the period of the study (Birks and Mills, 2011). As co-creator I was responsible for ensuring the participant voice was heard in the final outcome of the research (Charmaz, 2002). Through my immersion in the data and the selection of codes and categories which related closely to the participants' words and stories, the contribution of the participants to the final grounded theory model was visible.

Grounded theory does not aim to provide full individual accounts as evidence. Rather, it seeks to move a theoretically sensitive analysis of participants' stories onto a higher plane while still retaining a clear connection to the data from which it was derived. Representation of the participant voice has become a criterion for evaluating the quality and validity of qualitative research (Pillay, 2003). Careful selection of the data

to ensure it was used in the context provided and remained respectful of the participants was important in achieving this.

In relinquishing the role of objective analyst of experiences for that of partner in the construction of knowledge of that experience, I included the use of their voice in acknowledging their role as author of the shared experience. The language and writing style helped render the collective story of the researcher and participants into a useful account that hopefully has meaning for those who have an interest in the outcome.

A constructivist grounded theory approach to the interviews, which was the primary data collection tool, was considered to be contextual to the time and place for both researcher and participant (Kvale and Brinkmann, 2009). The data that came out of the conversation was a shared set of meanings and understanding about the subject, as opposed to objective data. The value of the data lay in its contribution, to the development of the theory about the ways in which participants managed one aspect of their lives following their heart attack (Kvale and Brinkmann, 2009; Roulston, 2010).

The relationship that developed between me and the participant involved co-operation from both parties to develop an atmosphere intimate enough to allow the participant to converse openly. This open atmosphere provided rich data but was structured enough to ensure that concepts and assumptions were explored rather than accepted as understood by either party (Mruck and Mey, 2007). As the researcher I needed to be attendant to my thought processes and non-verbal behaviour to ensure I was not being judgemental or assigning value to the participant's responses. This was particularly important if they were discussing my area of clinical expertise and offering a perspective of the speciality which was different from mine.

An important part of the reflexive process was undertaking preparation ahead of the interview, in particular the subsequent interviews in this longitudinal study. I familiarised myself with details as to how the previous

interview had gone, and identified if there were any difficult moments I should plan for on this occasion. This also included any information participant had provided in the previous interview that would help re-establish the relationship and situate both researcher and participant for the interview itself.

As an experienced clinician in the area under study I was concerned that my experience and inherent assumptions would prevent me from capturing the participant's perspective. I frequently probed further on certain points to ensure I captured the participant's understanding (Holloway and Wheeler, 2010).

### **3.5.3 The asymmetry of power**

Power imbalance is an inherent part of all human conversation, but within a research interview it needs to be acknowledged. In the semi-structured interviews undertaken for this study I held the balance of power as initiator, director and interpreter of the event (Kvale and Brinkmann, 2009). As participants talked about their experiences and perceptions of their heart attacks I requested verification through further probing and questioning.

Although I was seeking the participant's story, theoretical sampling and the desire to strengthen or refute potential theories meant I did guide the direction of the story and the type of data which was collected. Although this gave me as researcher the balance of power, the participant retained a degree of control through the amount and depth of the information they gave in their responses.

Measures taken to establish a position of reciprocity between me and the participant included conducting interviews at the time and venue preferred by the participant and ensuring there was an opportunity for the participant to ask questions (Birks and Mills, 2011). Every participant was specifically asked if there was anything else they had expected me to ask, if they

could think of any other information they felt would be of benefit to the study and what they felt about their experience as a participant (Swanson, 1986). At this point most participants, acknowledging that I also held a current clinical position, asked a question with regard to their clinical situation. Responding to this offered an opportunity to bring an element of reciprocity to the research process as information was received (Anderson, 1991; Corbin and Morse, 2003).

Achieving a relaxed atmosphere within a semi-structured interview format supported a situation in which participants felt they were taking part in a conversation, albeit a conversation which had certain themes running through it as I sought information for later interpretation (Kvale, 1999; Warren, 2002; Charmaz, 2006b). Achieving this balance is important in hearing the participant's views as opposed to having them agree with my views. This was important within the social constructionist belief that researched and researchers co-construct knowledge during these interactions (Mills, et al., 2007).

Alongside the power imbalance in the conversation was the power imbalance between the discourse of medicine and the discourse of the participants' lifeworld's (Mischler 1984, cited in Barry, et al., 2001). The participants afforded a respect to the information provided by doctors, reflecting medicine's dominant position within society.

The participants linked me with the discourse of medicine. This required me to establish my role as a researcher who perceived them as the expert owners of the knowledge I was seeking and that this was complementary to the knowledge I had from medicine. This was addressed to a degree during the opening to the interview when I explained that within the world of medicine we did not sufficiently appreciate the patient perspective and expertise in living with illness and that the aim of this study was to increase our understanding of that.

### **3.6 Ethical considerations**

Consideration of the ethical issues associated with this study was undertaken as required under the Research Governance Framework (Department of Health, 2005). As a nurse I must comply first and foremost with the Nursing and Midwifery Council Code of Conduct (Nursing and Midwifery Council (NMC) 2015) requiring me to obtain consent and ensure the confidentiality of participant information. Ethical approval for this study was sought and obtained from the University of Brighton Faculty of Health and Social Science Research Ethics and Governance Committee in January 2012 and by the NRES in November 2012.

#### **3.6.1 Respect for autonomy and informed consent issues**

Informed consent requires that the potential participants in any study are 'carefully and truthfully informed about all aspects of the research' (Denzin and Lincoln, 2005, p89). This is underpinned by the ethical principles of autonomy and veracity (Beauchamp and Childress, 2001). Autonomy is the ability to make decisions independently and free of the control of others. Within the context of a research study it is the ability to make an informed decision regarding participation. In order to make an informed decision, information is required and the application of veracity requires that this information provides detail on all aspects of the study.

The information sheet (Appendix 9.2) provided information on the purpose of the study, the commitment required for participants, and the risks and benefits of participation. It also provided information on the duration and governance of the study and was given to all potential participants by nursing staff unconnected with the research study. In asking ward staff to distribute the information sheet, there was a risk that patients might agree to participate out of a desire to help the nursing staff or a concern that declining to participate would be detrimental to the care they received.

During the discussion with potential participants I discussed both those scenarios to ensure this was not a factor in their decision. Nursing staff did not promote the study after distributing the information sheet to ensure

there was no perception of pressure to participate. When patients expressed an interest in joining the study, I visited them in hospital or telephoned them at home if they were discharged, to discuss the study in greater detail.

Once a participant had agreed to take part in the study, a date was set for the interview and the participant was reminded they could withdraw at any time. The consent form was not signed until the first interview, up to three weeks after agreement to participate. This was considered sufficient time for the participant to make an informed choice. Informed consent requires that the individual has the capacity to understand the information provided and this was assessed by me based on the ability of the patient to take part in the discussion regarding participation. As researcher I had no access to translators and this led to the exclusion of those who did not have sufficient command of the English language to make an informed decision to participate.

### **3.6.2 Assuring non-maleficence and beneficence**

Non-maleficence, or the ethical principle 'to do no harm', is perhaps the over-riding ethical consideration in research (Beauchamp and Childress, 2001). The potential for harm must be minimised and any risks made clear to participants. In distributing the information sheets, ward staff occasionally made the decision to exclude patients who were very unwell or those with acute mental health issues where discussions around sensitive topics were likely to cause distress. An exclusion criteria based on the principle of non-maleficence was that those with a history of mental health issues were excluded from the study. This was on the grounds that I did not have the skills to provide specialist care and support should the participant experience an acute episode of their illness as a consequence of their heart attack.

The most likely risk identified was emotional distress necessitating the termination of an interview. One female participant became upset briefly

during her second interview but after a pause for a drink she decided to continue and completed the interview without further incident.

Related to non-maleficence is the ethical principle of beneficence, or 'doing good'. It was explained in writing in the participant information letter that there was likely to be no direct benefit to the participant by taking part in the research. Participants appeared relaxed and comfortable during the interviews with a proportion expressing that their involvement allowed them to feel they were giving 'something back to the NHS'. However, as suggested by Silverman, (2010) one participant, who lived alone, did report that participating in the study gave him an opportunity to tell his story 'out loud'. He reported this helped him realise that he was making progress after his heart attack.

As this was a longitudinal study and I was involving participants on more than one occasion, I used an ongoing process of consent in which I renegotiated consent at every meeting (Polit and Beck, 2004). Prior to the second interview, contact was made with participants to ensure they wished to maintain their involvement with the study. I also ensured there were no changes to their situation which might preclude their continued participation. In recognition of the mortality rate in the early months following a heart attack, NHS information systems were accessed prior to each contact with a participant to ensure they had not died as this would have been distressing for relatives were I to contact them in this situation.

At two interviews family members were present; on both occasions the participant asked if there was an issue with their partner remaining in the room. I assured them their presence would not affect the research and that so long as the participant was comfortable answering questions with their partner present we could proceed. The assumption was made that as they were present with the participant's agreement, privacy and confidentiality of data provided by either party would be maintained.

A small, potential risk to me was identified in visiting participants in their homes. This risk was either from the individuals themselves or, more

likely, from the environment or neighbourhood. To minimise this, in accordance with the Trust lone worker policy, NHS colleagues were made aware of the time and location of the scheduled visits. I contacted these colleagues by telephone when going into and leaving the participants' homes.

### **3.6.3 Measures to ensure confidentiality, privacy and data security**

The regulations governing confidentiality require that information and data relating to an individual will not be used for any reason other than the research study they have consented to join. The information must not be shared with a third party without the expressed signed consent of the participant.

Participants were informed that the formal interviews were being audio recorded, and that data collected would be transcribed and electronically stored. Interviews were recorded on a small device used only during research interviews. The data which was uploaded and sent to a transcriber did not contain any personal details and participants were identified only by the pseudonym chosen by me. All audio recordings were destroyed by the transcriber following transcription and my audio recordings will be destroyed on successful completion of the thesis.

In accordance with the 2005 Data Protection Act, Research Governance Framework Legislation and the Code of Practice for MPhil, PhD and Professional Doctorates (University of Brighton Doctoral College, 2015–16), all data was kept in a safe place, accessible only to me. No data was stored on either University or NHS computers and no patient-identifiable data was stored electronically.

The pseudonym allocated to each participant was recorded on their consent form and this was kept separate from data in a further attempt to maintain confidentiality. The participants were not informed of their

pseudonym to protect their identity in the final thesis, and in any publications or conference proceedings arising from this study.

### **3.7 Issues of rigour**

Rigour is the 'use of logical systems that are shared and accepted by relevant scientists to ensure agreement on the predictions and explanations of the theory' (Davidson Reynolds, 1971). There are no set criteria for assessing the quality of qualitative research (Munhall, 2007). Although Ryan-Nicholls and Wills, (2009) identified that those who believe the same criteria can be applied to both methodologies, the texts offered as evidence were all from the 1980s. This was a time when the evaluation criteria suggested by Guba and Lincoln, (1985) was not widely known. The evaluation criteria offered by Guba and Lincoln remain widely used by current qualitative researchers. However, concerns have been expressed that in attempting to develop criteria for assessing qualitative studies, additional concepts such as reflexivity, a tool linked to validity in many qualitative methodologies, has been raised 'inappropriately to the status of scientific rigor' (Trihn 1991, p46, cited in Pillow, 2003).

There remains a suggestion that qualitative research is no more than a relaxation of scientific rules and as such is not rigorous (Rolfe, 2006). In response to this view, founded on an alleged lack of rigour, qualitative researchers have developed criteria for general application (Lincoln and Guba, 2005) and application for specific methodologies as described in Munhall, (2007).

#### **3.7.1 Criteria for evaluating grounded theory research**

The ongoing debate around the quality and perceived lack of rigour in qualitative research was part of the impetus for developing grounded theory (Birks and Mills, 2011) with Glaser and Strauss, (1968) advocating the application of rigorous approaches to research outside the positivist paradigm. The original criteria for evaluating grounded theory have been modified over the years by the key authors as they have evolved grounded theory methods. Charmaz, (2014) identifies four criteria for evaluating a

constructivist grounded theory and Table 3-6 suggests how the criteria of the key developers of grounded theory relate to those suggested by Charmaz.

Charmaz (2014)	Glaser & Strauss (1967)	Glaser (1978, 1992)	Strauss & Corbin (1990, 1998) Corbin & Strauss (2008)
Credibility	Fit Understandable Control	Fit Work	Data quality Empirical grounding Research process
Originality		Relevant Work	Data quality Theory quality Research process
Resonance			Theory quality Research process
Usefulness	General	Scope Modifiable	

Table 3-6 Approaches to evaluating classic variants of grounded theory.

These four criteria were applied to this study as the subjectivity and co-construction of the data, a key construct of a constructivist grounded theory study, is specifically addressed when considering the resonance of the study. According to Charmaz, (2006a), a strong combination of credibility and originality increases resonance and usefulness; however, further enhancement of the theory is dependent on the articulation and presentation of the final theory.

### 3.7.2 Credibility

In assessing the credibility of a constructivist grounded theory study you are looking for evidence of logical progression and conceptual grounding of the study (Birks and Mills, 2011). Credibility remains in-built in grounded theories where the process of data collection and analysis have been rigorously applied (Cutcliffe, 2000) and as such will be evidenced in Chapter 4. Familiarity with the data and analysis made an objective assessment of the credibility of this study challenging. It is others who will

confirm the credibility of my grounded theory through their ability to follow my links between the data, analysis and theory and decide if they support or refute the claims I have made (Charmaz, 2014). The following brief summary offers a glimpse of the ways in which data was used. I obtained sufficient data within this longitudinal study to explain the process by which an individual's perspective of their illness beliefs related to experiencing a heart attack adapts. In identifying that participants were telling their story, a link with narrative and biographical theory was suggested. A literature review was undertaken to sensitise me to the topic and this provided a breakthrough in the development of the theory.

In this study, credibility was addressed by providing an audit trail of the development of codes, categories and theory as the constant comparative method of analysis was undertaken. Memos were used to demonstrate the application of inductive, deductive and abductive thinking to develop the theory from the data and demonstrate to the reader the ways in which all of these components fitted together to produce the grounded theory (Glaser 1978).

### **3.7.3 Originality**

Originality considers the ways in which the theory generated offers new insights into the area studied. The literature review undertaken at the start of this study identified gaps in the knowledge around the social processes involved in health-related behaviour change following a heart attack. Specifically, it identified that the patient perspective of the factors influencing the development and adaptation of illness beliefs was missing. Regular searches of the literature throughout the study period suggested the gap remained despite ongoing research in the area studied (Astin, Horrocks and Closs, 2014; Fors, Dudas and Ekman, 2014; McKinley, et al., 2012). This suggested the theory generated would make an original contribution to practice.

### 3.7.4 Resonance

The longitudinal element of this study and increasingly purposive sampling provided the opportunities for ensuring the developing theory made sense to participants (Cooney, 2011). However, the challenge lay in balancing the need for new data to substantiate theory and ensuring resonance within the same interview. Structuring and timing of open questions in the later interviews was important in encouraging participants to provide data to help substantiate and saturate categories prior to checking with the participant that this data fitted the theory. The original study design involved a user group<sup>14</sup> who assisted in the development of the initial semi-structured questionnaire. I have taken the findings back to this group to enquire if the interpretations I have made of the data makes sense to them despite their distance from their original event. This group could identify with the theory and provided personal examples of this in the discussion suggesting there is both resonance and usefulness in the theory (Charmaz, 2014).

During data collection, requests to participants to elaborate, clarify and give examples of their experiences helped to expose taken-for-granted meanings which reduced the risk of misinterpretation of the intended meaning or the participant experience (Charmaz, 2014).

Undertaking a reflexive stance has encouraged the scrutiny of my own personal views and assumptions and an acknowledgement of their impact on the study (Chiovitti and Piran, 2003). This included gathering information on professional background and experience, making reflective memos during analysis throughout the study, and revisiting them from a critical perspective to understand their impact on this process. Additionally, a reflexive journal was used to track the personal journey of a novice researcher (Birks and Mills, 2011).

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<sup>14</sup> User group is a group of former patients who had an MI between 1 and 10 years previously. They attend a fitness programme run by the local authority aimed at delivering lifelong exercise for cardiac patients.

### **3.7.5 Usefulness**

In determining the usefulness of the study, the applicability of the study and knowledge gained are considered (Birks and Mills, 2011).

In qualitative studies where numbers are usually small, the repeating of studies is one way of adding to the credibility of the theory. The finding of similar outcomes in a different population can confirm applicability. This is facilitated through the provision of accurate information on both the population studied (for example, demographic descriptors and geographic boundaries) and the research process followed, if the comparison of the findings across studies is to be made possible.

The conclusions also suggest ways in which the study could be of use to clinicians, patients and future researchers.



## **4 Research Methods**

This chapter presents the ways in which the constructivist grounded theory method described in Chapter 3 was applied to the present study. The research setting, the process by which participants were recruited, and the timeframe of data collection in this longitudinal study are all described. The rationale for the selected data collection method and its application in this study is presented. The sampling strategy is described with detail on the progression from purposive to theoretical sampling to the achievement of theoretical sufficiency. Data analysis is discussed using examples of coding and categorisation techniques and memos to illustrate how the constant comparative method of analysis was applied.

### **4.1 The participants**

#### **4.1.1 Research setting**

The study centre is a University teaching hospital with over 1100 beds serving as a district general hospital for a rural and urban population of around 500,000. The centre provides some specialist services for the regional population of just under 6 million people. However, cardiac specialist services are provided in the cardiothoracic tertiary centre 15 miles away.

Around 500 patients are admitted to the hospital following a heart attack each year under the care of either general physicians, care of the elderly physicians or a cardiologist. Hospital data from the year 2013/14 identified that 55% of these patients were admitted under the care of a cardiologist. One of the criteria for inclusion in the study was admission under the care of the cardiologist therefore almost half of those admitted with a heart attack were immediately excluded from participation.

There were no set criteria for referral to cardiology within the Trust. Following admission and senior consultant review, patients were accepted

by the medical team considered most appropriate for their care needs. There was subjective evidence to suggest there was a degree of variation between the eight consultant cardiologists in the Trust as to which patients were accepted under their care. Clinical decisions over which I had no control therefore influenced the numbers of potential participants. An assumption has been made that the lack of defined criteria for acceptance and the individual variation reported to occur between cardiologists regarding acceptance for cardiology care will mean that no specific group of patients has been excluded from potential participation in the study.

An additional 200 (approximately) patients per year who were experiencing a heart attack and lived within the geographical area covered by the Trust were admitted directly to the tertiary cardiothoracic centre. The patients admitted to the tertiary centre were experiencing a different type of heart attack (STEMI) from the population admitted to the Trust (NSTEMI).<sup>15</sup>

The pathway of care followed by the group admitted to the tertiary centre is an evidence-based pathway in which early treatment is associated with improved outcomes (Hartwell, et al., 2005). Research considering the experiences of this group was emerging as the study commenced (Astin, et al., 2009). A potential future study could be to replicate this study in that population to examine if the care pathways influence the development and adaptation of illness perceptions and health-related behaviour change.

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<sup>15</sup> ST segment elevation myocardial infarction (STEMI) is the most serious type of heart attack: this is caused by a total blockage of the coronary artery, which can cause extensive damage to a large area of the heart. A non ST segment elevation myocardial infarction (NSTEMI) can be less serious than a STEMI. This is because the supply of blood is only partially rather than completely blocked. As a result, a smaller section of the heart is damaged. However NSTEMI is still regarded as a serious medical emergency. Primary PCI (percutaneous coronary intervention) in a tertiary centre is the treatment of choice for STEMI. There is no difference between NSTEMI and STEMI in clinical presentation. Short-term (in-hospital or one month) mortality is lower in NSTEMI (3–5%) compared with STEMI (10–15%). Re-infarction rate (further heart attack) is higher in NSTEMI (15–25%) after hospital discharge compared with STEMI (5–8%). Long-term mortality is similar or higher in NSTEMI compared with STEMI (two-year mortality is approximately 30% in both cases).

#### **4.1.2 Access to participants**

In line with grounded theory methodology (Charmaz, 2006a; Morse, 2010), initial purposive sampling of the population who are likely to have the information required for the study was undertaken. In this study those who have had a heart attack were the individuals likely to have the information.

Prior to commencing data collection, ethical approval had been obtained from the University of Brighton's Faculty of Health and Social Science Research Ethics and Governance Committee in January 2012 and from the NRES in November 2012. In order to approach patients, approval for the study was obtained from the Research and Governance Service within the Trust.

Patients admitted with a diagnosis of myocardial infarction were considered potential participants for inclusion in this study. Participation was limited to patients under the care of the cardiologist on the cardiology and coronary care wards. In a large teaching Trust, there are numerous research projects taking place, and it is time consuming for staff to remain updated on all the research opportunities available to patients.

As is normal with doctoral research projects I was principal, and only, researcher. Therefore, I was solely responsible for ensuring that those caring for patients, to whom they would be offering participant information leaflets, understood the purpose of the study. I was also required to be accessible to provide support and meet with those interested in participating in a timely fashion. Restricting the participation to those under the care of the cardiologist limited both the numbers of staff and geographical locations I had to support during the data collection phase whilst still undertaking a full-time clinical post within the Trust.

The exclusion criteria for the study are shown in Criteria for exclusion from the study. Only those with cardiovascular instability, those requiring the use of an interpreter to converse with health care professionals, and those with acute exacerbation or a new diagnosis of mental health issues were excluded for ethical reasons. The difficulties in obtaining informed consent

to participate were the prime reason for excluding those groups but secondary reasons for exclusion were also present.

**Exclusion Criteria**

1. Cardiovascular instability.
2. English as a second language requiring the use of an interpreter.
3. Acute exacerbation or new diagnosis of mental health illness

Table 4-1 Criteria for exclusion from the study

For those with cardiovascular instability the intensity of care required from clinical staff is higher and takes priority over all other potential interventions by health care professionals. Night time sleep is disturbed by the need for clinical care resulting in patients napping when possible. Both of these situations reduce the time available to fully discuss the study and gain informed consent.

There were no resources for translation services to gain either consent or support data collection. This necessitated the exclusion of those for whom English was not a first language. The risk of experiencing emotional stress during data collection and my own limited skills in caring for those with mental health problems should issues arise led to a decision to exclude this group.

In designing the study to look at adaptations to illness perceptions it was considered important to interview participants as soon after their heart attack occurred as possible in order to explore initial perceptions. The first interviews were planned for two to three weeks after discharge from hospital. This required that the invitation to participate in the study was made during the period of hospitalisation.

Experiencing a heart attack can be an emotionally and physically challenging period for some patients. Gaining ethical approval required that I would not exacerbate these challenges by seeking their participation in the study. This concern was addressed by ensuring that patients

assessed by ward nursing staff as being in obvious distress were not approached to join the study.<sup>16</sup>

Patients admitted to the study centre with a myocardial infarction who met the criteria for inclusion were offered a patient information leaflet (Appendix 9.2) and invited to consider participating in the study by cardiology nurses. The nurses could be either ward-based nursing staff or specialist nurses from the cardiology nurse practitioner or cardiac rehabilitation teams.

No record was kept of whether one section of the nursing team distributed more leaflets than another or if every patient meeting the inclusion criteria was given an information leaflet. This is a potential limitation of the study as a systematic method of distributing leaflets might have ensured every eligible patient was offered an information leaflet. However, distribution of leaflets was an additional task taken on by those staff and was not always a priority. As a researcher holding a clinical position of authority on the cardiology unit, being seen to monitor information leaflet distribution could have been perceived as putting unacceptable pressure on staff to assist in recruitment.

The patient information leaflet provided information on the aims and purpose of the research. It detailed who could be involved and the commitment they would be making in consenting to participate. Details about me, the sponsors of the study, and how to raise a concern about the study were also included.

Before distributing the information leaflet, the cardiology nurses had to make an initial decision as to whether an individual had the capacity to understand the information and give informed consent. There is an

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<sup>16</sup> This was a subjective assessment and may have denied some patients the opportunity to participate but in trying to ensure that the ethical principle of beneficence was adhered to, the decision of those providing care for the patient was respected.

assumption in the study that they worked within the Nursing and Midwifery Council Code of Conduct (NMC 2015) when distributing the leaflets.

The cardiology specialist nurses informed me of the names of all patients who expressed an interest. I then visited the individuals during their in-patient episode. The study was discussed, questions answered and if the individual agreed, verbal consent for participation was obtained. Full signed consent was not requested at this time. The consent forms can be viewed in Appendix 9.3. This delay gave potential participants time to think about involvement and discuss the study with family members if they wished.

There was no assessment of their potential as an 'excellent informant' on the basis of ability to articulate or reflect on their experience (Spradley, 1980), and all were interviewed.

All participants were advised that participation was voluntary and withdrawal at any time would not in any way jeopardise their care. Three potential participants requested further time to consider their participation. On telephoning these individuals after discharge, two agreed to participate and one declined.

In some instances potential participants expressed their interest in participating but were transferred to the tertiary centre within 48 hours for further treatment before my visit to provide information could take place. Cardiology specialist nurses informed me of the date of discharge from the tertiary centre and the initial contact for this group was through a telephone call from me in the following forty-eight hours.

#### **4.1.3 Timing of recruitment and data generation**

This was a longitudinal study with two interviews planned for each participant. The first interview took place in the first few weeks following their discharge from hospital and the second at least 6 months later.

Undertaking the first interview as soon as possible after the patient's admission facilitated recollection of their illness beliefs prior to their

myocardial infarction. The second interview at least six months later was after completion of any cardiac rehabilitation programmes accessed by the participants and beyond the three-month time frame it takes a health-related behaviour change to be considered a habit and part of an individual's normal behaviour (Lally, et al., 2010). The timeframe available for completion of the Doctorate also precluded a follow-up beyond 6 months.

Recruitment was undertaken in phases as a consequence of both study design and situational factors. The emergency nature of admission to hospital following a heart attack made it impossible to predict the timing of initial interviews to allow an even spread over time. The date line of the recruitment and data generation process is shown in Table 4-24-3.

The reduced number of interviews in the spring and summer of 2014 was caused by a decision to transfer from the Professional Doctorate to PhD programme. As a part-time student I did not have the time to both prepare the transfer document and continue with data generation and analysis.

	2013				2014				2015	
	Spring	Summer	Autumn	Winter	Spring	Summer	Autumn	Winter	Spring	Summer
Lost 1	Interview 1									
Andrew	Interview 1			Interview 2						
Barbara		Interview 1		Interview 2						
Lost 2	Interview 1									
Charles		Interview 1		Interview 2						
David			Interview 1			Interview 2				
Edward			Interview 1		Interview 2					
Frank				Interview 1		Interview 2				
Lost 3				Interview 1						
George										
Helen							Interview 1		Interview 2	
Isobel								Interview 1		Interview 2
James								Interview 1		Interview 2
Kenneth								Interview 1		Interview 2
					Pause in data collection and analysis to prepare for transfer to PhD.					

Table 4-24-3 Timing of data collection

The initial five interviews took place in late spring and early summer of 2013. However, I lost the first and fourth participants to follow-up and another participant having to delay their second interview meant I had lost

half of my participants to follow-up and was struggling to complete second interviews by early winter of 2013.

The two participants who were lost to follow-up did not respond to written and telephone requests to arrange the second interview. Their medical records indicated they were still alive and I was left with the assumption they no longer wished to continue with the study or were unable to do so.

In autumn 2013 I also realised that the data collected in the second interviews was likely to lead to a search for specific data with future new participants. In recognition of this, recruitment of new participants was paused until late winter when initial coding and analysis of early second interviews had taken place. In autumn of 2015 recruitment commenced again with the aim of recruiting female participants as there was only one lady in my seven participants who had completed both interviews. This was successful and the final participant was recruited at the end of 2014 with completion of data in 2015.

The early challenges of completing second interviews associated with a loss to follow-up of two of the first four participants did affect my confidence as a novice researcher. On reviewing my reflexive diary accounts from that time, I was questioning my interview technique amid a concern that I had been too assertive or had unknowingly upset participants who were at an emotionally vulnerable time in their lives.

I listened to the transcripts and reviewed my field notes again, looking to see if I was responsible for the loss to follow-up. I came to the conclusion that my interview technique could be improved by fewer affirmative sounds but that I had not caused the participants any noticeable distress. I had to put this setback down to experience.

## **4.2 Data generation**

Within a grounded theory study, data collection, sampling and analysis is an iterative process (Birks and Mills, 2011). In this thesis, it is presented in

a linear manner with cross referencing where the iterative nature of the process is important for context and understanding.

Within grounded theory there is an arbitrary move to distinguish between the terms 'data generation' and 'data collection' based on the relationship the researcher has with the data source (Birks and Mills, 2011). In undertaking interviews, I had direct engagement with the participants who were the source of my data. The interaction resulting from this engagement generated data and for reasons of consistency the term data generation was used in this study.

#### **4.2.1 Rationale for the use of semi-structured interviews**

An intensive interview was selected as the most appropriate method of generating data in a study which aimed to increase understanding of the social processes informing health-related behaviour change following a heart attack (Charmaz, 2014). The semi-structured approach adopted in intensive interviewing fits with constructionist grounded theory method. Both method and interview proceed from the general to the specific in their handling of data generation and analysis respectively.

Concerns over the accuracy of the data obtained during an interview have been raised over the years most notably by Atkinson and Silverman, (1997). However, the constructivist approach to this theory acknowledges that the information gained during interviews (and the resultant theory) is a product of a research process generating a reconstruction of the participant's reality (Charmaz, 2014).

This reality is constructed by both researcher and participant during the ebb and flow of the interview. Responses to questions triggered further thoughts with questions probing for deeper meaning and clarification in a bid to ensure the outcome is a recognisable reality.

The format of open-ended questions appeared to encourage the participants to converse without restraint about their experience. The participants seemed enabled to tell their story even in the second

interviews when the conversation had certain themes running through it (Kvale, 1999; Warren, 2002). The flexibility also incorporated in-depth questioning on areas introduced by the participants who had insight, experience and expert knowledge of the impact of experiencing a heart attack (Charmaz, 2014; Mills, et al., 2007). From these experiences came the words which formed early codes and informed the structure and content of later interviews as sampling became more purposeful and sought to refute or support tentative potential ideas.

The flexible structure of the intensive interview makes it responsive to the twists and turns of the patient's story (Swanson, 1986; Birks and Mills, 2011). Participants would spontaneously refer back to our initial interview and progress certain elements of their story from six months previously. This supported the grounded theory ethos of iterative data collection and analysis (Charmaz, 2014).

I discovered early in the interview process that participants do not tell their story in a chronological fashion. Having a flexible structure enabled me to let participants set the pace and some of the direction of the interview. If I had redirected participants' conversations to the order I had planned, then I would have disturbed the flow of their story and potentially missed out on alternative directions for the study. In early interviews it was difficult to let participants set the direction as I was worried that I would not get the information I perceived I 'needed'.

I had to learn that my ideas which had the best 'fit' with any potential theories I might be working on would be covered during the conversation if they were relevant to the participant's individual story. An advantage of letting the participant tell their story as opposed to only answering my questions was that the data generated was participant driven. When this data seemed to support my current ideas, probing questions at that point in the interview generated detailed knowledge and a deeper understanding of that participant's experience of the idea. I was able to enquire about any specific ideas not covered towards the end of interviews when necessary.

There was a tension between adopting a loose interview structure designed to hear the participant story and entering the interview with more focused questions designed to support or refute developing categories. I did not wish to miss out on new concepts but I did require to obtain data to support the previous data.

This balancing of progressing analysis and ensuring there is an opportunity to hear new stories is a necessary part of constructing a grounded theory from interview data (Charmaz, 2014). This was a skill which I had to learn. Later interviews tended to last longer as I provided time to ensure this was undertaken. The times of the individual interviews are shown in Table 4-4.

<b>Participant</b>	<b>Gender</b>	<b>Interview 1</b>	<b>Interview 2</b>
Andrew	Male	43	61
Barbara	Female	40	72
Charles	Male	38	46
David	Male	42	58
Edward	Male	53	54
Frank	Male	45	66
George	Male	42	55
Helen	Female	48	58
Isobel	Female	42	57
James	Male	51	48
Kenneth	Male	41	61

Table 4-4 Interview times in minutes for individual participants

Participants were offered a choice of settings for their interview. The suggested venues were a clinic room in the hospital, a small private room in a local community centre or the participant's own home. The participants were encouraged to select the environment in which they would feel comfortable (Dearnley, 2005). All participants chose to have the interviews undertaken in their own homes explaining this was the most practical option for them.

In the first interview, soon after their heart attack, many remained unable to drive for legal reasons and this saved them having to organise transport to another venue. In selecting their own home, the familiar surroundings

would enable the participant to feel more comfortable than the more formal setting associated with meeting rooms in public venues.

All participants had prepared a quiet room for the interview to take place. This enabled both of us to remain fully immersed in the interview as we were not interrupted during this time. Two participants requested that their partner remain in the room during the interviews but for all other interviews there was only me and the participant present. Participants were very welcoming and in some cases had prepared tea or coffee in advance of my arrival. I always accepted these offers of hospitality perceiving it as the participant's way of welcoming me into their home and providing a means of enabling both of us to 'feel at home' in the environment.

#### **4.2.2 Structure and content of the interviews**

I sought to gain an understanding of how participants gathered and used knowledge in deciding whether or not to make a health-related behaviour change following their heart attack. This required a range of questions general enough to cover their experience but narrow enough to explore in detail the specific parts of that story relevant to the study (Charmaz, 2006a). Each interview started with a 'warm-up' period in which informal non-specific questions were asked. This was in an effort to build a relaxed atmosphere and create a rapport with the participant (Kvale and Brinkmann, 2009).

In meeting for the first interview, the consent form for the study needed to be discussed. This was to ensure the participant understood the process and how the information being provided would be used. This made for a formal start to the interview and two participants asked for further details about the way in which their anonymity would be protected in the report. However, at the second interview this was a much less intrusive process probably because of familiarity with the form and research interview process.

Preparing a structure for the interview was daunting; as a novice researcher I had concerns about my performance. The interview guide

needed to be sufficiently detailed to support me as a novice researcher with open questions and some hints for probing. However, it needed to be flexible enough to enable me to pick up themes participants mentioned which I had not considered.

Charmaz, (2014) offers a range of interview questions and Blumer's (1969) notion of using sensitising concepts to give initial ideas was helpful. I utilised these ideas to generate a structure based on the five illness belief domains in the common-sense model. These are: identity; perceived cause of the illness; timeline; consequences of the illness; and curability and controllability (Leventhal, Meyer and Nerenz 1980; Leventhal, Brissette and Leventhal 2003). They provided the framework for the interview guide in the initial interviews. I had to select guiding questions (Table 4-5) which I hoped would encourage participants to discuss rather than give me the one-word responses I was dreading. The first column in Table 4-5 is the research question and the second column is a list of questions for participants designed to generate data to answer the research question.

<p>In what ways do illness beliefs adapt following a myocardial infarction?</p>	<p>Can I take you back to the time before you had your heart attack what if anything did you know about heart attacks at that time? Where did this information come from?</p> <p>Tell me about your thoughts and feelings when you learned you had had a heart attack?</p> <p>What do you now know about heart attacks? And where did this information come from?</p> <p>How, if at all have your thoughts and feelings about having a heart attack changed in the few weeks since that day?</p> <p>Who or what has been important in supporting you since you came out of hospital? In what way?</p>

Table 4-5 Guiding questions for the initial interview

This provided a range of questions and as I ascertained their usefulness in stimulating responses from the participant these questions developed over subsequent interviews. The questions became more open and there were two specific factors in this change. The first was that my understanding of open and closed questions altered. Experience of working with them in interviews suggested that the questions in Table 4-5 were relatively narrow in their focus. The second factor was the realisation that with open questions I required fewer questions to generate expansive data.

The ways in which guiding questions developed between the first and subsequent interviews is shown in Table 4-6. A similar process was undertaken for the second question. The manner in which the guidance sheets developed over time can be seen in detail in Appendix 9.4,9.5 and 9.6. The initial interviews did provide the general overview being sought (Birks and Mills, 2011). The data sensitised me to the participant perspective of a heart attack, a perspective which was different from the one I knew (Glaser and Strauss, 1968; Duffy, Ferguson and Watson, 2004).

<p><b>May 2013 – Initial interview</b></p> <p>Who first told you, you had had a heart attack?</p> <p>How did this relate to what you knew or what you thought was happening?</p> <p>To whom did you direct any questions about your diagnosis or its consequences for you whilst in hospital?</p> <p>What did this information make you think?</p> <p>Have you changed any aspect of your life as a result of this?</p>
<p><b>August 2013 – after 4 interviews</b></p> <p>Tell me about your thoughts and feelings when you learned you had had a heart attack?</p> <p>What changes have occurred in your life since that day? (This question will explore both positive and negative changes and why the changes have occurred)</p>

Table 4-6 Adaptations to the guiding questions used in interviews.

The guiding structure changed and questions were replaced with key words as the study progressed. The key words came from developing categories and as theoretical sampling entered the process and I became more focused on information to support or refute developing ideas. The guide for a first interview half way through data collection is shown in Table 4-7.

At this stage in the process I was developing a theory around biographical fracture and it illustrates the move away from prepared questions. I began to use phrases such as ‘Tell me about’ and ‘Could you describe’ to start conversation in these areas within the interview.

**Interview prompts: Nov 2013 First interview with G  
Biographical Fracture**

Meaning making

Pre admission / early symptoms

Medical story

Place

Hospital routine of CCU / loss of independence

Witnessing death

Impact of readmission

Time

Witnessing death – impact on own biographical timeline

Life in limbo

Dialogical self

Thoughts, impressions, meaning making in hospital

Disturbance to previous life on discharge

Table 4-7 Interview guidance notes for later participants.

As data collection progressed, the interviews become more structured as I theoretically sampled and asked more open but targeted questions. These questions focused in on the thoughts and the meaning of the experience for the participants. The aim was to augment the general story of their experience. This strategy assisted the process of clarifying and substantiating what had been generated from the coding and constant comparative analysis of data (Charmaz, 2006a; 2014). This same strategy assisted in the verifying of early conceptualisations and ideas (Morse, 2010).

Probing comments were used when a response was unclear or more depth was wanted (Charmaz, 2005). The issue of balancing probing and intruding diminished as I gained confidence in the interview process and techniques. General questions about aspects of their recovery progressed to more specific probing for aspects relevant to the study using a 'funnelling' technique suggested by Swanson, (1986). An example of a funnelled approach is shown in Table 4-8.

Participant responses were summarised and rephrased at regular points of the interview. The participants were invited to confirm that my understanding reflected what the participant was trying to express.

Nature of Question	Question	Participant response
General	Family and friends, do they talk much about your heart attack with you?	I had given him (my son) quite a lot of rein (with the family business) so he could do what he wanted to do which suited me at the time because I was getting a little bit stale and fed up with it and then luckily enough after I'd had this heart attack it didn't sort of affect any of the businesses but they just stepped up to the plate and to be fair they just said 'Have a nice lot of time off dad and we'll deal with it' and I actually haven't... I am here for them and I do little bits of pieces and some pricing and stuff, but they have just let me recoup for a couple of months really, so I have been very, very lucky.
More specific	Do they voice worries or fears or anything?	They drive me nuts to be fair because they are always asking how I am (LAUGHS), especially my daughter. My son, he attacks it in a very abrupt and matter-of-fact way, whereas my daughter ... I have only got to look a little bit flushed in the cheeks and she'll think something is wrong. She will say 'Are you feeling all right and are you a bit under...?' And she says, you know, 'If you don't feel right go to the doctor's and

Table 4-8 Example of a funnelling question.

### 4.2.3 Transcribing the data

Converting the spoken word into a written format is the first interpretation of the data which becomes the evidence to support my theory. This is a part of the process which receives minimal critical appraisal (McCracken, 1988; Kvale and Brinkmann, 2009).

Within the process of consent I obtained permission to audio tape all of the interviews. This ensured that a record of everything said during the interview was secured (Whyte, 1982). I used two devices to record: a small digital audio recorder which was placed on a table between me and the participant and a digital pen with audio capacity. As neither device was obtrusive this reduced any self-consciousness participants may have experienced from having their words recorded (Erlandson, et al., 1993).

In addition two devices offered a fail-safe should one of the devices fail to record (Kvale and Brinkmann, 2009). The audio pen was digitally linked to a notebook and I would jot down key words during the interview. Again, permission was granted by participants. These comments were linked to the audio recording of the moment I had written the words allowing notes to be located within the audio recording. This enhanced my ability to capture the participant's non-verbal cues, the contextual aspects of the interview, and my immediate impressions about what the participant was saying and link it to the transcription (Birks and Mills, 2011).

The same notebook was used to record field notes immediately after the interview. These notes were a personal perception of how the interview had gone. They might include views on the participant's demeanour, the manner in which participants opened up during the interview and any other thoughts which might be important later. The notes informed post-interview memos which were written later in the day.

As the study progressed, the comments began to include analytical and theoretical prompts. This was invaluable immediately after the interview when I expanded on the notes containing first impressions of the interview. I also generated more memos based on the initial analytical and theoretical thoughts immediately after the later interviews (Birks and Mills, 2011).

I personally transcribed the first four interviews. This helped me get to know the data and capture the meanings which participants were attributing to specific words. In linking back to my notes during

transcription I found I paid closer attention to feelings that were coming through in the conversation (Charmaz, 2005).

However, my limited typing skills slowed down my progress significantly so with later interviews I used a professional transcriber. The data was then transcribed according to a pre-agreed format with the use of symbols to denote events such as silences. The use of a professional transcriber ensured that I had a standardised script format from which quotes could be extracted for inclusion in the analysis. My own transcriptions lacked this consistency and I reformatted the sections I used to match the professional transcription.

Kvale and Brinkmann, (2009) promote undertaking your own transcription as it enables a greater understanding of the final text. I listened to the audio recordings on a number of occasions to ensure this important facet of interpretation was not missed. This increased my awareness of the context of silences, irony and other nuances of language that were part of the conversations but differed between participants. In an attempt to stay close to the data I did use the audio recordings in conjunction with the text during analysis and theory generation. This ensured the data was used in the correct context as I began to abstract and conceptualise out of the data.

As a means of improving my interview technique I reviewed my contribution to the conversations on the audio recordings. I considered how I established a rapport, where I missed opportunities for following up, and how I used silence and affirmatory sounds, to alert me to those opportunities when they next arose (Birks and Mills, 2011; Kvale and Brinkmann, 2009; Pezalla, Pettigrew and Miller-Day, 2012). This was particularly useful in the early phase of data collection as I lost participants to follow-up and considered my interview technique as a contributory factor in this loss.

As analysis progressed listening to transcripts helped identify opportunities I had missed in following up on participant responses. This critical review

of my technique was useful in improving my ability to hear such cues in the interview situation.

### **4.3 Sampling, saturation and sufficiency**

Grounded theory sampling commences with purposive sampling of initial participants to obtain an understanding of the phenomenon under study. This proceeds to theoretical sampling in which participant selection is guided by the emerging theory (Birks and Mills, 2011; Charmaz, 2014; McCann and Clark, 2004).

#### **4.3.1 Sampling**

In accordance with the grounded theory method, initial selection of participants for this study was based on the assumption that having had a heart attack they would provide data which would give a general understanding of the phenomenon under study (Birks and Mills, 2011). The demographic range of the participants is annotated in Table 4-9 below.

The pseudonyms were given alphabetically to correspond with the order in which participants completed the second interview thus Andrew was the first participant and Kenneth the last. The participants who were lost to the study were given the pseudonyms Linda, Martin and Nigel and their data was used where it was congruent with the analysis. This was limited as it became apparent that the comparison of data provided at different time intervals was instrumental in theory generation.

Participant	Gender	Age	Occupation	Family and social support
Andrew	Male	56	Hotelier	Married with teenage child
Barbara	Female	79	Retired	Lived as part of extended family unit
Charles	Male	67	Retired	Married with adult children nearby
David	Male	67	Retired	Married, no local family
Edward	Male	85	Retired	Widowed, adult children nearby
Frank	Male	58	Self-employed builder	Married, adult children nearby
George	Male	57	Engineer	Married with teenage children
Helen	Female	64	Administrator	Divorced, friends nearby
Isobel	Female	71	Retired	Married, adult children nearby
James	Male	64	Managing Director	Married, no local family
Kenneth	Male	63	Gardener	Married, adult children nearby
Linda	Female	62	Housewife	Married, no local family
Martin	Male	71	Retired	Married, adult children nearby
Nigel	Male	68	Retired	Widowed, no local children

Table 4-9 Participant demographic information.

Sampling progressed to theoretical sampling as categories began to emerge and in line with the iterative nature of grounded theory. Theoretical sampling commenced early: after the first three interviews as data to support a focused code 'Something not quite right' was sought. This in vivo code was taken from the words used by Charles to describe the feeling he had when first experiencing symptoms. This term encapsulated and summarised what the other participants were articulating.

Subsequent theoretical sampling identified that this inability to pinpoint the exact nature of the symptoms was common, supporting the elevation of the code to a potential category (Morse, 2009; Birks and Mills, 2011; Charmaz, 2014). At the same time, other questions within the same interview were focused on initial coding to gain general understanding of the ways in which social processes influenced lifestyle change following a heart attack. In practice there were elements of both purposive and theoretical sampling occurring from a very early stage of data collection but as the study progressed sampling became increasingly theoretical in two ways.

In this longitudinal study the progression from initial to purposeful sampling was not linear. During the second interviews, I was interviewing

participants with both initial and purposeful sampling goals to fulfil. There was purposeful sampling in that specific data to support developing categories and ideas was also being sought. Additionally, there was new knowledge from the time between interviews to obtain for analysis.

At times during the study I was undertaking initial and second interviews concurrently. On occasions data pertinent to categories arising from a second interview would be generated by a participant in their initial interview. However, analysis of this data identified that these initial interview participants were responding to the questions differently from the participants who were participating in their second interview.

The participants on the second interview seemed to articulate and explain their responses with greater ease than the initial interview participants group. This difference was attributed to the time frame from their event facilitating greater experience of the topics under discussion. This enabled them to speak with more confidence about the reality of their experience.

As sampling became increasingly purposeful the memos for potential categories and theories included notes about sampling strategies (Holton, 2007). The contribution of the sampling strategy to substantiating the information already known about the subject was incorporated into these memos (Charmaz, 2014). This included whether data was generated in a participant's first or second interview.

The demographic profile of the early participants is annotated in Table 4-9 and of the first seven participants only one was female. This participant's view on her level of confidence instigated a memo around a sustained loss of confidence. A section of that memo presented in Table 4-10 pertained to the sampling strategy. This resulted in theoretical sampling for female participants to look for these differences and similarities. Confidence lost remained an important theme but it was not solely gender based.

Potential direction for sampling

Initial analysis of participant 2 (Barbara) identified the code 'confidence lost'. All of the other participants to date have reported a regaining of confidence. Barbara is both the only female participant to date and the only participant with seemingly significant ill-health as a consequence of her MI. Was this a gender specific issue or was there another explanation? What other differences might be attributable to gender? My other female participant to date has been lost to follow up. Purposeful sampling will need to consider the recruitment of more ladies to the study.

Table 4-10 Theoretical memo pertaining to purposeful sampling.

### **4.3.2 Theoretical saturation and sufficiency**

Sample size in a grounded theory study cannot be predetermined and 'relates to judging the extent to which issues of saturation have been adequately considered' (Bowen, 2008). Sampling continued until the data was not generating anything new about the categories and theory which were developing (Glaser and Strauss 1968; Charmaz, 2006a; 2014). There was also a high level of 'fit' between the new data and the theory being developed from data previously analysed.

At this point I considered the categories to be theoretically sufficient and made the decision to stop seeking further participants (Dey, 2007). A much more pragmatic influence on sample size and theoretical sufficiency are practical issues such as time and financial limitations (Wiener, 2010). However, I believe I have sufficient data to present and defend the findings of this study.

### **4.4 Data analysis: Constant comparative method of analysis**

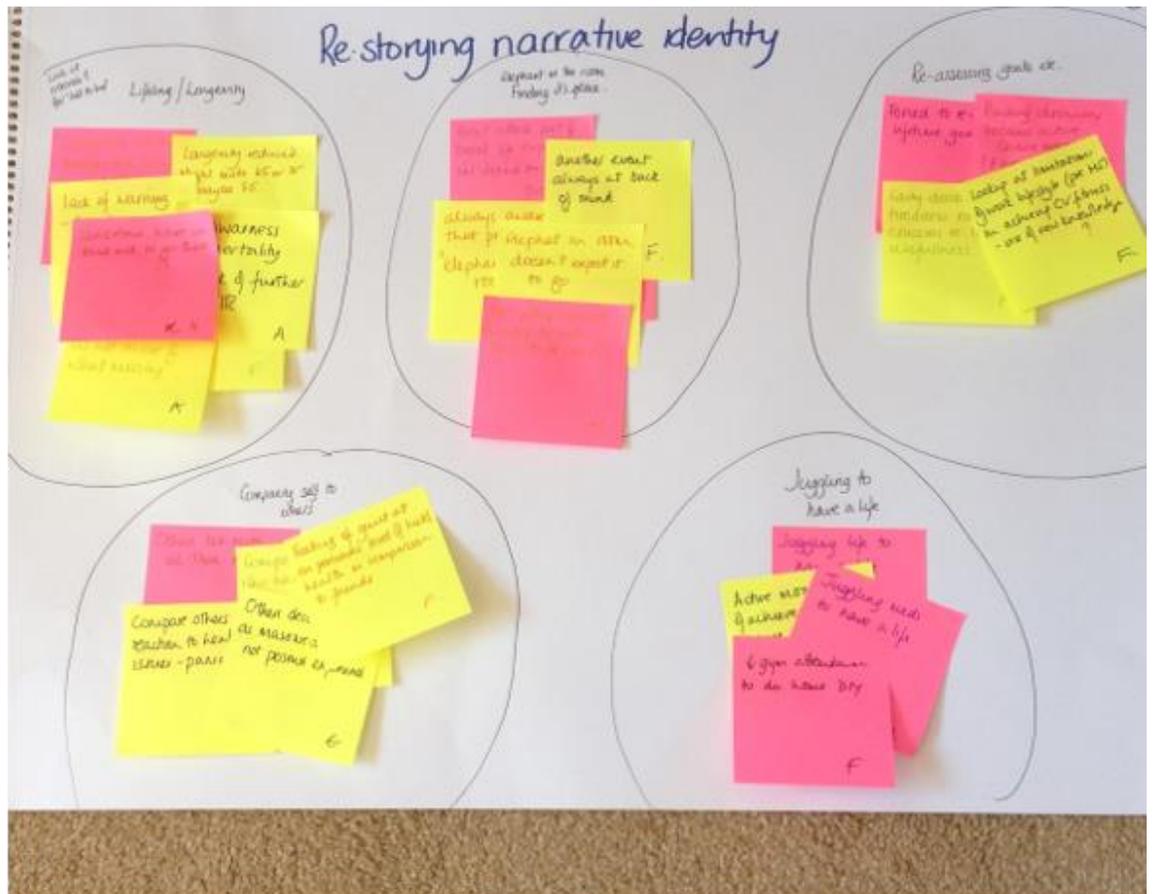
Central to the development of a grounded theory is the constant comparative method of analysis developed by Glaser and Strauss, (1968). This is a technique in which data collection and analysis are simultaneous acts occurring at and across every level of the study (Charmaz, 2014).

The individual activities involved in this process are coding data, memo writing and theory development. The way they were used in this study is described in the following sections. Given the iterative nature of the constant comparative method of analysis it has been a challenge to fully articulate and evidence the manner in which these individual activities were used in a linear fashion.

The volume of data accumulated rapidly during the study. A combination of manual and electronic methods of storing and organising data were employed. Any material generated using traditional pen and paper methods was then uploaded through digital transfer or scanning to have one reservoir of data.

This simplified what could have been a cumbersome cross-referencing and storage system. The use of a digital camera to record every change followed by uploading to the computer (see Figure 4-1) and attaching it to a memo aided in ensuring the rationale for adapting the relationship between categories was recorded.

I used NVIVO, a software programme designed for use in qualitative studies, during early coding and category development. I found that traditional paper and sticky notes were much more useful during later analysis as I was moving categories around and exploring relationships between categories to confirm the theory. The physical act of moving sticky notes around and associated focused free writing injected a life into the theory that 'dragging and dropping' in a software programme did not achieve (Charmaz, 2014).



## June 2014: Restorying narrative identity

This is what begins to happen after discharge from hospital. The categories currently sitting here are: juggling to have a life, re-assessing goals, comparing self to others, longevity and the elephant in the room (fear of another event).

Figure 4-1 Linking written and electronic analysis in analytical memos

Charmaz, (2006a; 2014) defines the constant comparative method of analysis as a process which uses inductive, deductive and abductive reasoning skills to begin to generate a theory explaining what is happening in the data. The constant comparative method of analysis drove the sampling strategies described in Section 4.3.1. Initial sampling generated

data, which was analysed through constant comparative analysis with subsequent data being gathered through theoretical sampling (Birks and Mills, 2011).

The constant comparative method of analysis enabled some aspects of the theory to progress faster than others as the fit between codes and categories developed within different time frames. The sub-category 'seeking help and support' within the category 'Identifying a cause for symptoms' (Section 5.4.2 ) became saturated as there was a similar account of this across the participants. However, 'symptoms not experienced' was originally linked to a 'reinterpreting knowledge' category where I was struggling achieve a 'fit' with the category.

Going back to the data and reviewing the context of the statements relocated 'symptoms not experienced' to the category 'Identifying a cause for symptoms'. This relocation triggered memos around the potential links between 'seeking help and support' and 'symptoms not experienced' and the discrediting of knowledge. This led me to Bury's, (1982) literature on biographical disruption and the introduction of narrative inquiry to the study.

#### **4.4.1 Coding**

A code is a 'researcher generated construct that symbolises and thus attributes interpreted meaning to each individual datum' (Saldana, 2012, p4). Charmaz, (2014) encourages the use of initial and then focused coding to account for the data, emphasising that until the data is taken apart through the coding process analysis will not be possible.

In early initial coding I became very focused with coding in particular the use of *gerunds* to define some of the meaning and action of the participants (Glaser 1978; Charmaz, 2014). However, I became so embedded in the minutiae of coding, generating large numbers of codes, that I was not looking **at** the data in context. I was pulling the data apart as if assuming that would trigger analysis automatically.

Attributing a name to a code is a subjective decision situated in context at that point in time. As I developed the initial codes, a descriptor was developed for each code to clarify its attributes (Table 4-11). This was accessible as a prompt to ensure that new data I was coding fitted the criteria. This also aided decision making when reviewing codes for their ongoing usefulness or potential merging with other codes having similar attributes but created at a different point in the study.

<b>Code:</b>	<b>Explaining self-management:</b>
Descriptor	in which the participant describes actions they are taking to take care of health issues
<b>Code:</b>	<b>Not associating risk factors with heart disease:</b>
Descriptor:	in which the participant discusses how they address risk factors for chd as stand-alone events and do not link improving those risk factors with a reduction on their risk of having a heart attack.

Table 4-11 Example of descriptors developed for codes within NVIVO

The code ‘staff walking on eggshells’ (Table 4-12) was one example of a code which attracted only one piece of data. After seven interviews and having similar properties to ‘this is serious’ code, they were merged together (Bazeley and Jackson, 2013). The record of the merging and splitting of nodes was all retained within the software package NVIVO. This ensured there was an audit trail of how data was moved around in a much more disciplined way than I believe I could have maintained with a paper trail.

Such is the flexibility of the constant comparative method that by progressing to a mixture of incident and focused coding I was able to begin to abstract out of the data. An example of initial and focused coding applied to the same piece of data is shown in Table 4-12. A full transcript with initial coding can be viewed in Appendix 9.7. During focused coding I utilised in vivo codes which conjured a specific incident in my mind. This seemed to help begin comparing data between participants as I could look

for comparable incidents an example of the use of an in vivo code ‘walking on eggshells’ can be found in Table 4-11. I then returned to line-by-line coding and was able to see across the data. Returning to line-by-line coding also enabled the merging of codes. I reduced the total from over 60, which was unmanageable, to 40 as I had generated codes with very similar attributes and little data attached to them which were identified during the early stages.

George Interview 1	Initial Coding	Focused Code
<p>Yeah, I'd think <i>What's all the fuss about</i> I really thought <i>Yeah, what's all the fuss about, I've just had a bit of discomfort in my chest, but why is everyone running around sort of....? Yeah, walking on eggshells.</i> And it's not until you learn a little bit more down the line as to why they have got certain protocols that they follow and that's what they do when this is ... when you have had a heart attack.</p> <p>Yeah, because at that time they don't know if it's stabilised or... they just have no idea what's going on there and you don't either, so that kind of rocks me a bit, yeah.</p>	<p>Wondering what the fuss was about</p> <p>Minimising seriousness of symptoms</p> <p>Everyone running around</p> <p>Staff walking on eggshells</p> <p>Unknowing was worrying</p> <p>Following protocols</p> <p>Not knowing if condition had stabilised</p> <p>No one knowing outcome</p> <p>Feeling scared</p> <p>In the safest place</p> <p>Staff being too overprotective</p>	<p>Minimising seriousness of symptoms</p> <p>Living in limbo</p> <p>Acknowledging fear</p>

<p>Yeah I was a bit scared I felt safe, I felt as though that was the best... I felt as though I was in the best place to be. I kind of felt that they were being a bit too overprotective but then again I'd felt like that... you know, like <i>what am I doing here? I am only young, I shouldn't be here</i> sort of thing. I was a bit detached from reality – I am thinking <i>well why are you behaving the way you are, why are you saying I have got to have complete bed rest, I can't go to the toilet and that? Because I am quite independent, I am used to doing it, I am a big boy now, I can do those things on my own</i>, so that time was a bit difficult to kind of accept.</p> <p>And at no time, touch wood, have any pains reoccurred or anything like that – no time at all. I get a bit breathless now sometimes although that is easing off, but I have had no discomfort whatsoever since. I feel a bit of a fraud to be perfectly honest.</p>	<p>Too young to be here</p> <p>Feeling detached from reality</p> <p>Restricted to bed</p> <p>Questioning management</p> <p>Relating back to childhood</p> <p>Losing independence</p> <p>Difficult to accept restrictions</p> <p>Superstitious touch</p> <p>No recurrence of pain</p> <p>Getting breathless at times</p> <p>No discomfort</p> <p>Feeling like a fraud</p>	<p>Reasoning why the MI should not have happened</p> <p>Independence lost</p> <p>Feeling like a fraud</p>
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Table 4-12 Example of initial and focused coding applied to the same segment of data

As data accumulated and initial coding was completed, some codes became more prominent in the study than others. This was either in terms of the volume of data attributed to them or due to the significance attached to them by me as they triggered analytical or theoretical thoughts (Charmaz, 2006a; 2014; Saldana, 2012). These codes became the focus

of attention as the content of them was compared with all the previous data to see if anything could be added. This generated further thoughts, and therefore memos, about the potential significance of this code to the findings.

Occasionally a comment in an interview would illuminate what had been said by previous participants providing a light bulb moment for me and generating a more focused code (Charmaz, 2014). As an exemplar one participant described as 'cherry picking' his attempts at living healthily prior to his heart attack in that he would undertake elements of healthy eating but ignore others. This phrase summarised what previous participants had described and 'cherry picking at healthy living' became a focused code and ultimately a category.

Another tool which helped me progress from coding was starting to write memos about individual codes. The code 'seeking support' was initially coded as the decision to ask family members advice on early symptoms. This was expanded to focus on the decision to seek support at the next level of escalation and triggered analytical comparisons with the theory of help-seeking behaviours. This developed further and remained a category 'Seeking help and support' in the final theory. Focused coding drove new data collection as theoretical sampling was employed to obtain additional data to support or refute these prominent codes.

At an early stage there was some conceptualisation and consideration as to whether theory and knowledge from my previous experience might help explain what was going on in the data. The memo in Table 4-13 relating to self-interpretation of medical information in which participants described their thoughts in response to aspects of the care they received was written after three initial interviews.

**Code: Self-interpretation of medical information**

In this situation participants are interpreting information in a way that would not always make sense to health care professionals. This interpretation often occurs around technical information and less often around lifestyle information. The participants all kept this interpretation to themselves and did not share their thoughts with health care professionals at the time. These interpretations often caused the participant to worry further about the seriousness of their condition.

Potential areas of further reading and sampling:

- Meaning making for patients under stress as opposed to being in 'normal' situation. Is it different?
- Impact of worry and issues around not 'bothering' health care professionals.
- Information and pain theory – is there anything in the theory for this section?
- Lay knowledge.
- Power of medical staff and not 'daring' to question or ask for clarification; also medics not seeking / offering patient understanding.

Frank:

*I did notice there was a defib bag on the end of the bed (LAUGHS) which I thought 'Oh Christ, you know, something might kick off'.*

Andrew:

*And all the time, I remember thinking all the time, because they kept saying to me when they came round to do the pills to me 'have you got any pain? Have you had any more pain? Have you got any pain? Do you feel any pain?' I kept thinking why do they keep asking me? Does it mean I am more than likely to have another heart attack when I am here and that was bothering me a lot. Although I was in the right place but the thought it would happen. And I kind of got the impression from the nurses that they were expecting it to happen again the way they kept asking me.*

Table 4-13 Excerpt from memo relating to self-interpretation of medical information

This memo was written as a result of the coding of data provided in an interview. The code had been in existence but the addition of this latest

data generated new analytical thoughts about the data as it was compared with data already attached. In this way coding and analysis were linked in the iterative process.

#### **4.4.2 Memo writing**

Theoretical memos relating to the development of the theory, analytical memos relating to all aspects of coding and a reflective journal where many entries were then converted into memos have been the threads linking this study together. The writing of memos frequently interrupted data analysis and writing as another potential comparison or direction for the study was captured (Glaser, 1978; Charmaz, 2014).

The decision to separate memos by type arose out of a pragmatic need to organise the numbers I was accumulating. Writing memos during coding was undertaken through the NVIVO software package. Adding to a memo about a specific code, linked the memo and code electronically. This had two advantages: breaking off from coding however briefly to record fleeting analytical thoughts was quick and easy (Glaser, 1978) and there was an audit trail of decision making. The audit trail became increasingly important as more data was added and early thoughts were developed (Cooney, 2010).

As the study progressed and categories were forming then it made sense to link memos to the categories rather than their initial grouping by type (Charmaz, 2014). The memos being generated at this stage had elements of both analytical and theoretical significance and this retained all of the information in one place in a chronological order. This provided an audit trail particularly during the theory generation stage. In this stage there was a large amount of moving in and out of memos as I checked back on previous notes to ensure there was data to support the claims I was making.

The extract from an analytical memo in Table 4-14 explains the naming of a code. The memo also includes other thoughts and actions associated with this code. Colour coding of text was a personal prompt to

undertake further coding and theoretical sampling in relation to the current memo (Holton, 2007). This memo also contained questions I had asked of the data. These were fleeting thoughts associated with the memo which may be developed if subsequent data and its underlying meaning is generated.

Living in limbo

This was a term used by Frank discussing how he feels he cannot make any long-term plans until he knows the outcome of a test. The appointment to discuss this is 3 months away at the end of the summer and he does not feel able to go on holiday whilst awaiting the result. He perceives this test will class him as sick or well and is some strange place between the two at the moment. He feels well but cannot believe he is well until this test confirms it.

Others have also discussed this feeling of waiting for further tests and treatment and a focused code around this will be started.

Is it only waiting for tests and treatment which gives this feeling? F feels well - has he lost faith in his own perceptions of how he feels?

Does this demonstrate the hold medicine as power and expert has over people's lives? Have they no confidence in their bodies and need the medical expert to pronounce?

Table 4-14 Exemplar of an analytical memo

Theoretical memos tracked methodological adaptations such as changes to the interview structure as theoretical sampling occurred. An example of this was discussed in Section 4.3.1 with the memo extract being illustrated in Table 4-10.

Reflexive memos demonstrated how I reflected on my choice of the word 'recovery' used in the interview question to which the participants and I attribute different meanings. Memos were the place where assumptions and positivist thinking surfaced most frequently, supporting the claim that

reflexivity is built into the grounded theory method. Reflexive memos were used to help prevent the preconceiving of ideas and forcing theory (Birks and Mills, 2011; Charmaz, 2014) and I often transferred information into a reflexive memo to aid in locating these thoughts should I need to revisit them.

#### **4.4.3 Accessing the literature**

Charmaz, (2014) supports the use of literature during the comparison and analysis phases of a constructivist grounded theory study. In this study, I accessed literature on the major categories as they were developing during the analysis and a timeline demonstrating this access is shown in Table 4-15.

Certain topics, such as self-management within the broader concept of self, proved to be less relevant and do not feature in the final theory. Exploring the literature within the context of the data gathered established that the concept of self was not a major category. Other major topics such as illness perceptions required regular forays into the literature. This was necessary to explore potential connections with earlier studies as this study generated potential new information in an area that has been widely studied through a quantitative lens.

During analysis, I noted similar patterns of behaviour and interaction developing between the participants; however, one of the participants did not fit into any of the three patterns that were emerging. In looking for a possible explanation for this outlying participant, I explored the literature on chronic illness. This included the work of Charmaz on loss of self (Charmaz, 1991; 2002; 2006b). This literature echoed the story my participant had recounted and provided in part a plausible explanation as to why her story was so different from all the other participants.

Further interrogation of the literature on the role of narrative led to narrative inquiry and illness narratives. The literature from the narrative arena then supported the development of a theory built from data which had been provided in the form of a story.

Once my theory was finalised the literature most relevant to the areas was reviewed again to inform the discussion chapter. There was a substantial volume of literature reporting quantitative research with substantially less from the qualitative domain. The literature review focused on identifying where the theory generated in this qualitative study suggested complementary or divergent findings from other studies from either paradigm.

	2009			2012/13	2014	2015 2015/16			
	Planning study and developing question			Data collection and analysis		Data analysis and writing			
General illness perception works									
Focus on cause and identity beliefs									
Biographical disruption / Illness trajectory									
Focus on control and consequence beliefs									
Concept of self: self management									
Lay and professional knowledge									
Concept of self: self efficacy / self									
Narrative in chronic illness									
Narrative inquiry									
Health illness continuum									

Table 4-15 Timeline indicating accessing of the literature for potential categories during the study period.

#### 4.4.4 Constructing theory

Theoretical integration and construction of the theory was the most difficult part of the study (Strauss and Corbin, 1997). Identifying a core category from the major categories was the main reason for this difficulty. Birks and Mills, (2011) identify a clear central category as one of the essentials of a successful grounded theory, the other two being theoretical saturation and a substantial bank of analytical memos.

In considering how else I might look at the data in search of the core category I turned to the principles of dimensional analysis (Bowers and Schatzman, 2009; Kools, et al., 1996) and created a matrix on an Excel spreadsheet. This revisualisation of the data, an excerpt of which is shown in Table 4-16, highlighted similarities and differences between participants and codes which I had not perceived before. The matrix facilitated the development of categories as I linked codes together and the category illustrated in the table 'Perceiving the cause of the heart attack' was considered a potential core category in an early emerging theory. This early theory was heavily informed by the common-sense model (Leventhal, Brissette and Leventhal, 2003). However, working with the data it became obvious I was forcing data into the domains of the model (Glaser, 1992). The matrix proved useful in identifying that I was looking for data that fitted a preconceived idea of what my data would tell me. I needed to find a means of looking through another lens and to have the confidence that my data would tell me what was happening if I stuck with the iterative process (Glaser, 1992).

Constructivist grounded theory emphasises the importance of memos and saturated categories but does not state that a specific core category needs to be identified. In this constructivist study a core category 'responding to physical sensations' **was** identified as able to explain the ways in which illness beliefs adapt following a heart attack. This category became more central to everything that was occurring in the data; it seemed to be

Category	Contributing codes	Andrew	Barbara	Charles	David	Edward	Frank	George
Perceiving the cause of the illness: in respect of heart disease this may be believed to be genetic, biological or psychosocial and many patients believe a combination of factors are involved (e.g. 'I had a heart attack because my father had one and I have been very stressed at work recently')	reasoning why the MI should not have happened	X	X			X	X	X
	previous self-knowledge as a way of knowing		X	x	x	X	X	X
	seeking a cause	X	X					X
	not associating risk factors with heart disease	X		x	x		X	X
	symptoms experienced prior to MI				x		X	X
	medical staff information as a way of knowing	X	X	x	x		X	X

Table 4-16 Example of early category development 'Perceiving the cause of the heart attack'

'everywhere' (Glaser, 1978). It allowed the other categories to slot into place fulfilling the criteria of being the 'central phenomenon around which all other categories are integrated' (Strauss and Corbin, 1990, p116). In identifying the core category and the manner in which it fitted with behaviour change, my 'negative case' also had a place within the developing theory (Charmaz, 2014).

In this study my negative case had arisen from maintaining a positivist stance around behaviour change. In a memo I had considered this group as 'deviant' in their behaviour as they did not undertake behaviour change after their heart attack. After considering behaviour change in the context of the core category 'responding to physical sensations' their maintenance of previous behaviour could be explained.

The range of thought processes used when making decisions have modified with the iteration of grounded theory over the years. The original iteration claimed to be an inductive methodology (Glaser and Strauss, 1968). More recently Reichertz, (2007) and Charmaz, (2014) have reviewed the constructivist method and identified that inductive and abductive reasoning are the decision-making processes used in this iteration.<sup>17</sup>

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<sup>17</sup> Inductive reasoning: 'a type of reasoning that begins with a study of individual cases and extrapolates patterns from them to form a conceptual category' (Bryant and Charmaz, 2007, p94).

Abductive reasoning: 'a type of reasoning that begins by examining data and after scrutiny of these data, entertains all possible explanations for the observed data and then forms hypotheses to confirm or disconfirm until the researcher arrives at the most plausible interpretation of the observed data' (Bryant and Charmaz, 2007, p94).

I could identify elements of both types of reasoning in this study and Figure 4-2 illustrates, in a very simplified way, the route I took to understanding that my data was being recounted to me as a story.

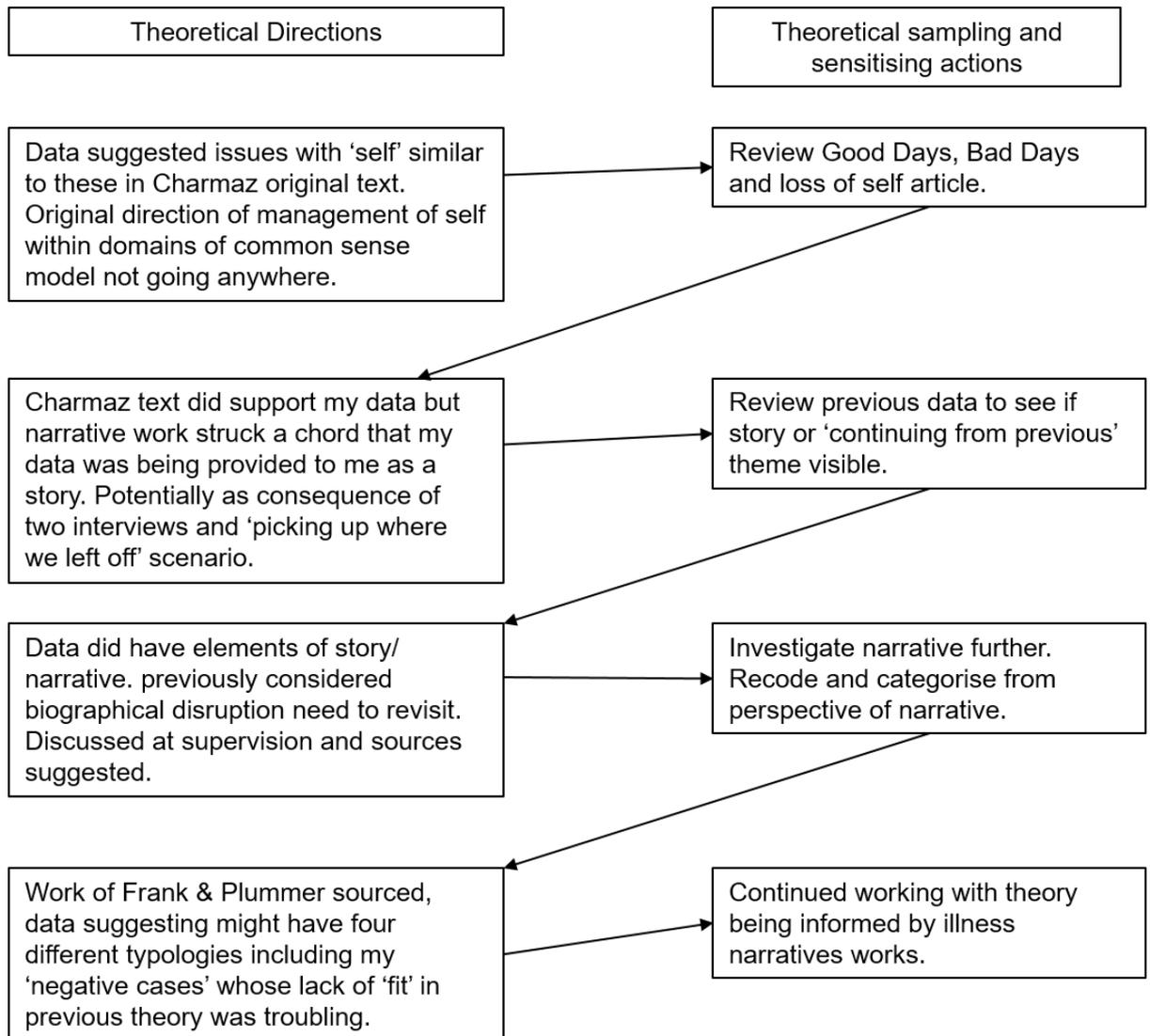


Figure 4-2 Audit trail of an aspect of theory generation

The diagram, using excerpts from memos, tracks the way in which the data suggested a change of direction in my analysis and my subsequent action. In beginning to look at the data from a narrative perspective I undertook further theoretical sampling, analysis and sensitising in conjunction with a literature review. This led to a stage in the process where the illness narrative work of authors such as Frank,

(2013) and Plummer, (2013) provided a framework for generating a theory. Within this framework, the participants' contribution was heard through the stories told by the data.

In the illustration I consider that abductive reasoning was involved in the decision-making process at the level where I reviewed Charmaz's work on chronic illness. This sensitised me to a range of possible explanations of why some participants were able to self-manage whilst others struggled. Although it is not in the diagram I also considered Bandura's work on self-efficacy (Bandura, 1977), as I sought the most plausible explanation for what was occurring in the data.

In this chapter I have explained how I have applied the concepts of grounded theory in this study giving examples of the ways in which I have used the data from my participants in the constant comparative method of analysis to generate my theory. The findings and theory will be presented in the next chapter.



## 5 Findings

### 5.1 Introduction

This chapter proposes a theoretical explanation for the factors which influenced the development and adaptation of illness beliefs following a heart attack.

The findings are presented around a conceptual framework demonstrating the trajectory of biographical restorying following a heart attack. This trajectory is presented in Figure 5-1. An episode of acute biographical disruption associated with hospitalisation at the time of their heart attack is discussed in Section 5.4.1. This disruption required individuals to restory their lives.



Figure 5-1 Conceptual trajectory of biographical restorying after a heart attack.

Four different narratives of lives which were continuing, a struggle, limited or enhanced emerged. Section 5.5 presents the ways in which participants' lives adapted following their heart attack as they create a different narrative. Interpretation of the physical sensations participants experienced was central to the stories of change within the theory of biographical restorying after a heart attack and is discussed in Section 5.5.1.1. The relationship to other categories, as evidence of its centrality, being provided throughout the chapter. Figure 5.2 depicts this centrality to the theory of biographical restorying.

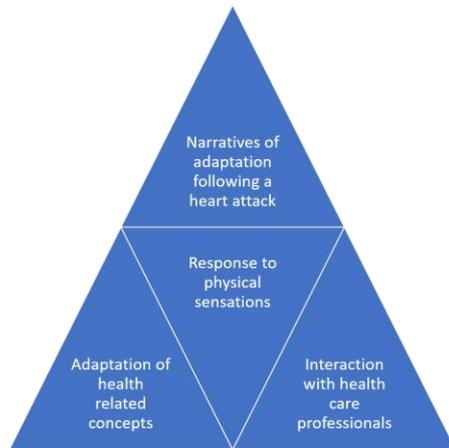


Figure 5-2 Responses to physical sensation as a central phenomenon in the theory of biographical restorying.

The four different narratives of biographical restorying, created over time, are explained in Section 5.6. They told of lives which were continuing, a struggle, limited or enhanced. The first group who did not realign their concept of a heart attack attributed on-going symptoms to the process of ageing and told a story of life continuing unchanged.

Others recounted how they controlled the occurrence of physical sensations through limiting activities and pacing themselves. With forward planning, his group were able to lead a life which was limited but minimised the intrusion of the impact of the heart attack into their lives. The third group experienced on-going sensations associated with illness. These sensations were out with the control of the individual and told of a struggling life increasingly dominated by ill-health. A final group reported their lives had been enhanced following their heart attack. They described positive physical sensations which encouraged further activity. This group were unlimited in the activities they could undertake.

Illness beliefs adapted along the post event trajectory with differences in these interpretations and adaptations apparent across the four narratives. Beliefs around the identity and cause of their illness were influenced and became fixed early in the journey, during the period of disruption, as

participants sought to make sense of the physical sensations that had led to their hospitalisation.

Interpretation of their physical sensations, as a new narrative was created in the weeks and months after their heart attack, led to the adaptation of illness beliefs in the spheres of consequence and control. Beliefs in the consequence and control domains were more fluid, influenced by the allocation of meaning to changing physical sensations. These adapting beliefs also informed concepts such as feelings of self-confidence, positioning on a health-illness continuum and the physical limitations participants believed the heart attack had placed on their lives.

The ways in which health related concepts of self-confidence, perceptions of health and illness and the impact of living with physical limitations varies across the narratives is discussed in Section 5.5.3 to 5.5.5. as a new narrative is created (Figure 5-3).

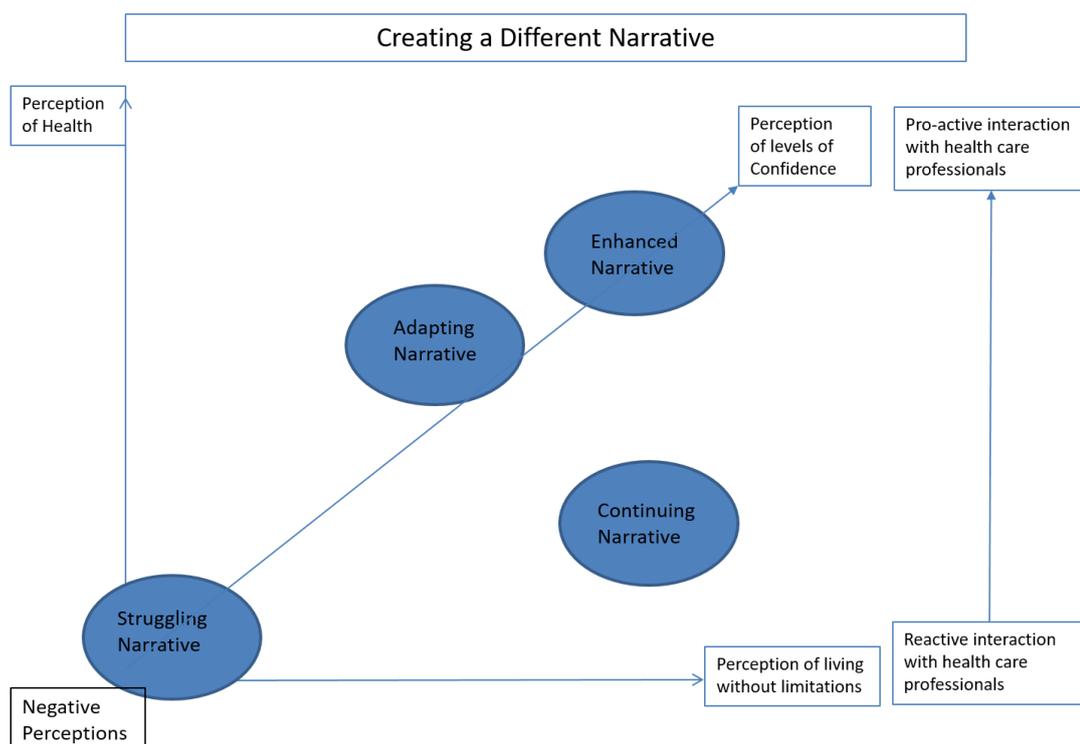


Figure 5-3 Creating a different narrative

Section 5.5.6 describes the ways in which knowledge is sought and used by those who have experienced a heart attack. The theory of biographical

restorying explains the different ways in which individuals engage with health care professionals (Figure 5-4). Medical staff remain central figures in the provision of information to patients and for the most part doctors retain their privileged respected position with patients. However, their failure to discuss the patient's understanding of the information they have provided did lead to later concerns. Participants interpretations were challenged as they increased their own knowledge giving rise to conflict with other health care professionals they encountered in their journey.

Specifically, individuals increased their lay-knowledge to find meaning and create a narrative around the identity, causes, consequences and controllability of their condition. Interpretation and labelling of illness perceptions of those experiencing a heart attack were different to those of medicine. They interpreted this information and developed lay beliefs incorporating it into the biographical restorying undertaken after their heart attack.

The substantive theory of biographical restorying after a heart attack (Figure 5-4) proposes that there are four narrative typologies depicting life after a heart attack. The theory of biographical restorying after a heart attack proposes the physical sensations experienced, the behaviour change undertaken and interaction with health care professionals as being key factors in the development of these four narratives. Illness beliefs and health related concepts are informed, adapted and reinforced in response to physical sensations experienced during and after a heart attack.

This substantive theory provides insight into the means by which illness beliefs are adapted through the process of biographical restorying following a heart attack. It provides an explanation for some of illness behaviours and adds insight into the strategies adopted by people recovering from a heart attack and the meaning they make of that experience.

	<b>Narrative Typology</b>	<b>Associated physical sensations</b>	<b>Behaviour change undertaken</b>	<b>Interaction with health care professionals</b>
<b>Antecedents</b> Previous experience of heart attack. Prior knowledge about heart attacks.	<b>Continuing narrative</b>	Nil attributed to heart attack	Minimal adaptation	Reactive contact for routine monitoring
	<b>Struggling narrative</b>	Restricting daily activities	Enforced change in response to ill-health	Frequent contact with preferred health care professionals.
	<b>Adapting narrative</b>	Absence is contingent on controlling levels of activity.	Maintenance of behaviour limiting intrusion of negative physical sensations	Proactive contact with preferred health professionals to support self management
	<b>Enhanced narrative</b>	No intrusion on increasing levels of activity.	Continuation of positive health related behaviour change	Proactive contact to support self-management
<b>Biographical Restorying following a heart attack.</b>				

Figure 5-4 The theory of biographical restorying following a heart attack

The substantive theory is supported by data segments selected for their being representative of the participants' stories. However, atypical data was included where it illustrated variation relevant to the theory being presented. Data segments are presented in italics to differentiate between the data and my concurrent analysis. In some instances, larger segments of data are included to illustrate a specific aspect of the theory and they are presented in a tabulated format. The analytical commentary is supported by diagrams to provide a visual representation of the relationship between the categories and to locate the commentary to a specific group of participants.

The chapter begins with an overview of the usual care those experiencing a heart attack would expect in the Trust where data was collected, in order to contextualise the findings. A profile of the participants is then presented before the main findings are presented.

## 5.2 Provision of care for a patient admitted with a heart attack

Patients admitted to a district general hospital in the United Kingdom with a heart attack have generally experienced a heart attack classified as a non ST elevation myocardial infarction (NSTEMI). In a NSTEMI the patient history and symptoms suggest the potential for a heart attack but the electrocardiogram (ECG)<sup>18</sup> does not show any of the classic changes associated with a heart attack. An NSTEMI is confirmed by a rise in the enzyme troponin.<sup>19</sup>

The troponin levels rise over the 6–12 hours after the initial chest discomfort commences. This creates a delay between the onset of symptoms and confirmation of the diagnosis of heart attack. Following diagnosis, patients can expect to remain in hospital for 4–5 days. The first 48 hours are typically spent in a coronary care unit (CCU),<sup>20</sup> under constant monitoring with restricted movement until the risk of complications such as dangerous heart rhythms are reduced.

The remainder of the time is spent on a general cardiology or medical ward. A series of investigations will take place to determine if any invasive intervention is required and new medication will be commenced. A range of health care professionals such as cardiac rehabilitation staff, physiotherapists and dietitians will provide discharge advice.

Some patients will require transfer to a specialist cardiac centre for procedures to improve blood supply to the heart muscle such as the insertion of a stent, or surgical bypass of their coronary arteries. These procedures relieve symptoms such as chest discomfort. However, all patients require

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<sup>18</sup> An ECG is a simple, non-invasive procedure. Electrodes are placed on the skin of the chest and connected in a specific order to a machine that, when turned on, measures electrical activity all over the heart. Output usually appears on a long scroll of paper that displays a printed graph of activity on a computer screen.

<sup>19</sup> The troponin test is used to help diagnose a heart attack, to detect and evaluate mild to severe heart injury, and to distinguish chest pain that may be due to other causes. In those who experience heart-related chest pain, discomfort, or other symptoms and do not seek medical attention for a day or more, the troponin test will still be positive if the symptoms are due to heart damage. Peak troponin levels are a good estimate of infarct size and are used by consultant cardiologists to quantify the potential size of the heart attack for individual patients in the early period. Actual infarct size will be determined by echocardiography at around three months after the heart attack.

<sup>20</sup> Coronary care unit (CCU) is a hospital ward specialising in the care of patients with heart attacks, unstable angina, cardiac dysrhythmia and various other cardiac conditions that require continuous monitoring and treatment.

lifelong medication to manage the underlying disease process and reduce the risk of further heart attacks.

All patients are reviewed on at least one occasion by cardiac rehabilitation specialist nurses during their in-patient stay. The timing of this review is negotiated with the patient and usually occurs during the last few days of their hospitalisation. If ward nursing or medical staff perceive patients to be particularly anxious before this, multiple consultations can be undertaken.

A cardiac rehabilitation programme lasting three to six months is offered to all patients during the in-patient cardiac rehabilitation review. This can commence two weeks after discharge. The decision to accept a place on the programme and a specific starting date is agreed at the in-patient review or during a telephone review following discharge.

The cardiac rehabilitation programme is offered at four venues in the Trust's geographical catchment area. It aims to provide education and activity to support patients in their recovery. It facilitates and supports individual lifestyle changes which the evidence suggests reduce the risk of future heart attacks (Section 1.2.2).

All patients will be reviewed in a nurse-led cardiology clinic three months after discharge. The focus of this clinic is on ensuring symptoms have resolved or are being optimally managed, treatment pathways are completed and secondary prevention medication has been prescribed.

### **5.3 The participants**

Fourteen people were recruited to the study, of which eleven completed the two interviews. The eight men and three women who completed the study were aged 56 to 85 years at the time of recruitment to the study. Six of the participants remained in employment in a range of occupations from manual to senior management positions; all were planning to remain in their current occupations after their heart attack.

Two of the participants lived alone but all described themselves as having social support in the form of either family or friends available on a daily basis.

Those providing this support lived within an area that formed a part of the participant's local environment such as an area of the city or the neighbouring village in the case of those living in a rural area.

The timing of the data collection interviews in relation to contact with health care professionals at cardiology follow-up and attending a cardiac rehabilitation programme is shown in Table 5-1. This is provided to illustrate opportunities for participants to seek knowledge from health care professionals which might influence their illness beliefs and approach to health-related behaviour change. All participants had attended their cardiology follow-up prior to the second interview and for those attending cardiac rehabilitation they had either finished or were due to complete within 3 weeks of the second interview.

<b>Participant</b>	<b>Interview 1</b>	<b>Interview 2</b>	<b>Cardiology Follow-up</b>	<b>Attended Cardiac Rehabilitation</b>
Andrew	April 2013	November 2013	September 2013	No
Barbara	June 2013	November 2013	November 2013	No
Charles	June 2013	December 2013	November 2013	No
David	October 2013	June 2014	January 2014	Yes
Edward	October 2013	May 2014	January 2014	No
Frank	November 2013	May 2014	March 2014	Yes
George	November 2013	June 2014	March 2014	Yes
Helen	September 2014	April 2015	January 2015	Yes
Isobel	November 2014	June 2015	Spring 2015	Yes
James	December 2014	July 2015	Spring 2015	Yes
Kenneth	January 2015	July 2015	Spring 2015	Yes

Table 5-1 Chronological relationship between data collection interviews and contact with health care professionals

## 5.4 Narrative identity transition following a heart attack

The findings are presented around a conceptual framework of restoring narrative identity following a heart attack. A broad overview of this framework is presented in Figure 5-5 below. The framework flows from left to right and is chronological.



Figure 5-5 Conceptual trajectory of biographical restorying after a heart attack.

### 5.4.1 Disrupted narrative identity

Admission to hospital with a heart attack was an alarming experience for the participants. The future they had envisaged was brought into question as the potential implications of their diagnosis were considered.

### 5.4.2 Identifying a cause for the symptoms

Two distinct stories were told of the ways in which participants were first alerted to the onset of their heart attack. The first story was one of symptoms which began during everyday physical activity. The second story, in contrast, was of a range of symptoms, which came on suddenly with no obvious precipitating cause and which did not settle.

The participants (n=3) whose symptoms started during activity described what they experienced.

*...went on a walk around Wickambrook and I had a bit of a tight feeling across me chest which felt just like indigestion but higher up. And I thought I Oh well I'll get past it. Carried on, finished the walk had lunch came home and it was fine.*

*David*

*...first noticed shortness of breath walking up the hill to home, I have always been a fast walker but I was slower and having to stop halfway*

*James*

*...I was getting a tightening across the top of the chest that I was obviously noticing, but I thought it was... I don't know, I just thought that it was a minor ailment that sometimes you shrug off. Now if you stopped... if every time you got a bit of a niggles when you went out running you wouldn't do anything, so I just sort of ran through it and after thinking Cor, that's got me again, I would just carry on and it would be fine.*

*George*

This group of participants recalled how observing that the starting and resolution of their symptoms were linked to undertaking and then ceasing activity. This offered them a potential reason for their symptoms. This resolution of their symptoms enabled participants to think the situation was of minor concern which did not require any more consideration at that time.

The most frequently recounted story (n=9) was of a range of symptoms unrelated to physical activity. These symptoms commenced with no obvious precipitating cause and did not settle. It was described as a feeling that something was amiss, which came upon the participants relatively suddenly.

*...I had a bit of a tight feeling across me chest*

*Frank*

*...I am used to living with pain so I know pain but this was very different this time*

*Helen*

*...I knew it wasn't normal I was sweating a little bit and I was walking around and I could breathe ok but I just didn't feel ...I said 'I don't feel well, I really don't feel well'. I didn't feel desperately ill but I didn't feel right so I knew something was going on.*

*Andrew*

The participants described symptoms which developed over a period of a few hours. The symptoms were associated with a nonspecific feeling of being unwell which did not resolve. Participants tried to clarify what might be happening to them. They recalled comparing what was normal and what was abnormal, such as identifying pain as different from that pain usually experienced or recalling that breathing was not a problem.

All participants (n = 11), irrespective of the manner in which they recounted their symptoms starting, tried to piece together information to identify a cause for the feelings they were experiencing.

#### 5.4.2.1 Attributing a cause to the symptoms.

Participants looked to the feelings and symptoms associated with previous experiences of ill-health to explain their current situation. Of the participants whose symptoms developed suddenly, three had some previous knowledge of the potential symptoms of heart problems and rationalised why their heart might, or not, be the cause:

*...Kept thinking it was indigestion as there was no pain in chest, arms or neck to make it my heart*

*Kenneth*

This participant concluded it was indigestion. This was not only because of what he had eaten. His prior knowledge of the symptoms associated with a heart attack, gleaned from first aid training, were not the symptoms he was experiencing. This led him to exclude the possibility that he was having a heart attack.

Two participants had suffered a heart attack in the past. They described how they dealt with the symptoms they were experiencing.

*...Really I did think, because I had one 10 years ago (a heart attack), and it was a similar sort of pain and underneath I really thought that it might be but I was hoping it wasn't. So I tried things like Gaviscon to see if it made a difference which it didn't and there was all sorts of things went through my mind because it went into my shoulder blade and I thought*

*maybe I have got a gallstone or something but I think that underneath it all I think I did realise it might be a heart attack.*  
*Barbara*

*...No I thought it was another angina attack. So I just didn't worry too much but when I went to go to bed on the Saturday night it was there a little bit but then I couldn't sleep.*

*Charles*

Both participants recognised that their symptoms could be related to their previous cardiac condition but differed in the way they accepted this. In identifying that the symptoms were slightly different from her previous experience, Barbara was able to hope they had another cause. This led her to use remedies for other potential causes in trying to fulfil this hope.

The other participant, Charles, who had experienced angina for a few years after his first heart attack, recalled this past experience. His last experience of angina was nine years ago. He linked his current symptoms to that experience and immediately assigned the symptoms to angina.

Those with previous experiences of heart problems or knowledge learned from first aid courses considered their heart as the potential source of their symptoms. However, only the participant with prior and repeated experience of the exact symptoms immediately related these feelings to a problem with their heart.

The other participants (n=5) whose symptoms developed suddenly also sought an explanation for their symptoms. Unlike those with previous experience or knowledge, or the group associating symptoms with activity, they did not have any immediately obvious triggers with which to associate their symptoms.

*...Thought it was indigestion as it started after eating, came and went a couple of times*

*Kenneth*

*...realised that I had got a pain sort of high up in my chest and to be fair I actually thought it was indigestion because I had got a bit peckish about 9 o'clock and I'd come out into the kitchen and had a banana and you know what bananas.... You know, so I just thought I have got indigestion.*

*Frank*

*...I had had a rather spicy curry that night and thought that maybe that was a bit dodgy but it turned out not to be that. I thought I had indigestion just a strange feeling of being... across here (rubs hand across chest) being emm.... Something odd was going on.*

*Andrew*

*...I thought I don't feel very good, in fact I don't feel terribly well, and I started eating the blancmange and I thought, 'No, I am really going funny'*

*Edward*

In seeking a cause for their symptoms, participants looked for a potential trigger. They recalled recent events such as consuming food and the consideration of indigestion as a potential cause for their symptoms. These potential reasons however, did not explain all of their symptoms and so did not provide a satisfactory cause for them.

Some of the participants struggled to articulate their experience when recalling these early symptoms. They physically located the area of the discomfort by placing their hands on their chest to convey more expressively the vague symptoms and sensations they had experienced. The symptoms described by this group have all been identified as potential signs of a heart attack in the literature. However, like the group who associated symptoms with activity, the lack of prior experience or knowledge was a reason for the links not to have been made.

The participants (n=3) who had recurrent symptoms associated with physical activity continued to work through their symptoms as they sought an explanation.

*...I did start getting a bit of a pain down my left arm and I thought it was my jersey, my t-shirt was a bit tight for me so I had to loosen it off a bit but it was having no effect and again, I just sort of ran through it. So I thought Um, that's a bit concerning, I might have something like... you know, I might have pulled a muscle or something like that.*

*George*

*...Once or twice in the next week I got this little bit of tightness but mostly it didn't stay all day. I got it gardening on the Sunday and I got a little bit of it and a little bit of indigestion as well and so I wasn't really sure what I had got.*

*David*

They sought to further explain the situation by trying to pin down more precisely the link between activity and their symptoms. They considered it might be a pulled muscle, enabling them to identify a possible cause—potentially resting it or working through it – which might resolve their discomfort. Creating an explanation such as this allowed the participants to continue with their activity. However, when the situation continued to recur they were again questioning their reasoning. This group were experiencing symptoms classically associated with angina<sup>21</sup> in the weeks leading up to their diagnosis but, with no prior experience or knowledge of this condition, did not associate the feelings they were experiencing to their heart.

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<sup>21</sup> Angina is chest pain due in general to obstruction or spasm of the coronary arteries. A typical presentation of angina is that of chest discomfort and associated symptoms precipitated by some activity (running, walking, etc.); symptoms typically abate several minutes after activity and recur when activity resumes. Worsening angina attacks, sudden-onset angina at rest, and angina lasting more than 15 minutes are symptoms of unstable angina and herald myocardial infarction (a heart attack); they require urgent medical attention and are, in general, treated as a presumed heart attack.

All of the participants described a situation in which they instinctively felt there was something wrong. Only one participant immediately identified the cause as being related to his heart and this was based on previous experience of the same symptoms. The remainder of the participants could not be specific in their feelings but the symptoms they were experiencing added up to more than they felt comfortable ignoring or waiting to resolve spontaneously.

All participants located their discomfort to the chest area of the body. However, there was a hesitation in speech when describing these symptoms as participants sought to find the best word to describe what they had experienced. Overall, they struggled to clearly articulate the sensations they had experienced. All participants then spoke to family members telling the story of their symptoms and seeking their support and opinion on what might be happening.

#### 5.4.2.2 Seeking help and support

In order to seek support and advice on the action they should take, participants spoke to family members, either spouses or adult children, recounting the story of their symptoms.

*...So I woke my wife up and she was up like a shot and said she was calling the ambulance, not because I looked ill but she probably thought straight away something's going on here.*

*Andrew*

*...my wife said 'We're going to have to ring someone about this because it doesn't sound right' and we rung the helpline.*  
*Frank*

*...she said 'For goodness sake,' she said 'I am fed up with this, you know, every time you go out... will you go and see the doctor please?'*

*George*

*...It was really my daughter who nagged me and said 'come on I am going to take you to casualty'.*

*Barbara*

The time taken to involve others was dependent on the way their symptoms first arose. Those in whom symptoms started during activity took a matter of days or weeks to discuss this. However, those in whom symptoms developed suddenly and who could find no precipitating cause for their symptoms sought help within a few hours. There was a brief discussion around the symptoms and the possible causes participants had considered, but no further self-administered treatments were attempted. A decision, driven by the family member consulted, was made to seek help from health care professionals.

Ultimately in both groups the physical feeling of something not being right was the driver to seek help from health care professionals. The family members having quickly explored their own previous knowledge and experience were unable to identify a satisfactory reason for the symptoms. The family member wanted support from a person who they felt would be able to deal with a health problem. This escalated support from lay-knowledge sources to knowledge from professional sources.

The participants whose symptoms started during activity discussed this with family members at a time when they did not have any symptoms. There was no perceived need to access health care immediately. This group sought support by arranging an appointment to see their general practitioner.

*...He (GP) looked at it (ECG) and said there is something not quite right there, you had better go to hospital.*

*David*

*...I went to the GP on the Monday who said do not pass go, do not collect £200, go straight to hospital and that was it.*

*George*

The reaction of the GP was to have the patients admitted to hospital

immediately. All were advised that their ECG,<sup>22</sup> undertaken during the consultation, was suggesting that something was occurring with their heart. They were advised that confirmation of the exact diagnosis would be undertaken at the hospital.

The participants for whom symptoms developed suddenly with no obvious precipitating cause instigated an emergency call. In all cases this resulted in the arrival of a paramedic crew.

*...Well he wasn't quite sure was he, he done an ECG and he said my heart was fine but then when we got into the ambulance they done another one and it was different they then thought it might be a heart attack.*

*Charles*

*...The paramedics did the ECG test said something was wrong and took me to Hospital*

*Isobel*

*...They said the ECG showed something unusual, they were not sure it was a heart attack but they wanted to take me to Hospital for more tests.*

*Helen*

The paramedics<sup>23</sup> were the first people to suggest that the source of their symptoms could be their heart. This is the point at which participants first came to realise that a problem with their heart might be the cause of their symptoms. In order to confirm this, the need to move participants from their home environment to hospital was expressed by health care professionals.

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<sup>23</sup> Paramedics are health care professionals who are based in the field in ambulances or emergency response vehicles providing care in emergency medical situations. This includes an initial assessment, a diagnosis and a treatment plan to manage the patient's particular health crisis.

*...He (GP) said pack a bag, which I did thinking I won't need this and I drove off to hospital and that was that.*

*David*

*...They were debating whether to take me to Papworth or Hospital and they decided on Hospital. I thought they'd be sending me home.*

*Andrew*

*...thought should go to hospital just to be on the safe side. At this point I am not worried I don't think anything is happening we are just checking.*

*Helen*

The inability of health care professionals to provide an accurate cause for their symptoms led participants to perceive that their symptoms were indicative of a minor complaint. This belief enabled them to suppress any thoughts or feelings that the symptoms may represent a serious illness. Giske and Artinian, (2008) suggest this thought process is a characteristic of the 'rational awaiting' behaviour of patients who believe that nothing has changed until a diagnosis has been confirmed. Despite the expressed belief that a minor ailment was the cause of their symptoms, admission to hospital was acknowledged by all participants as being a stressful time.

#### 5.4.2.3 Visual perceptive mismatching

On arrival at the hospital participants noticed that staff appeared to be taking their condition seriously.

*...as I came out of the ambulance there was a nurse waiting actually at the door ... it's something that you often see on the telly and I thought 'Oh, get this'.*

*Frank*

*...it was like having the old express pass for the Disney – it was like oh right, you know, just whiz through – right, come in, we'll sort that, get that, you've got a chest x-ray, your bloods.*

*George*

The speed with which they were admitted to the emergency department caused participants to perceive that the symptoms they had felt to be minor were being viewed from a different perspective by health care professionals. The participants relied on vicarious experiences from television hospital-based drama or a previous experience to describe how they felt at being the focus of this attention. Participants began to assimilate new information about their situation from the range of visual and auditory cues they noted from the moment of their arrival at hospital.

The emergency department was recalled as a place where a series of investigations and tests were undertaken.

*...I had another ECG and various bits and pieces when I got there, blood tests then they took me to AandE cubicle.*

*David*

*...just wheeled me in through AandE and then they started sticking needles in me and taking samples and that was it.*

*Andrew*

*...they put some more wires on me and I was, (I don't know how long), maybe an hour or two hours while they sorted the ward out.*

*Edward*

There was an awareness of what was going on but in distant uninvolved terms. Everything undertaken was accepted as a part of the necessary examination and assessment but with little active participation required by them as patients.

*...Whether I was in a different sort of state of mind I don't know, because you just... Whether I was sort of shutting it off 'Well it's not me, it's not happening to me'.*

*Frank*

*...it was all happening around me if you like. It didn't seem to be much to do with me because I was sat there perfectly happy.*

*David*

The emotional detachment described by participants suggests that they absolved themselves of responsibility, handing this over to health care professionals going about their duties. The sense of reassuring urgency in health care professionals combined with the speed with which events such as cannulation and repeat ECGs occurred did not match participants' initial perception of suffering a minor ailment such as a muscle injury or indigestion.

The mismatch between their thoughts and the actions taking place in front of them disrupted their ability to make sense of a situation. This led to their temporary withdrawal whilst they tried to adjust to a situation which was outside the realms of their previous experiences. This type of response has been suggested to be characteristic of the cognitive strategies used in those adjusting to illness (Felton, Revenson and Hinrichsen, 1984).

Alongside this detachment from the procedures that were being undertaken there was a reflection that the care they had received had been good.

*...She was lovely she was, we had excellent care.  
Barbara*

*...I wrote a letter to the hospital about it saying how good the  
treatment was.  
Edward*

*...she was reassuring and talking to us all the time.  
Frank*

Participants handed over responsibility for tasks and technical care decisions to health care professionals but remained sufficiently engaged with the process to perceive that they were satisfied with the level of care provided. In making sense of this new situation, participants continued to process some information as the health care professionals continued with their work of confirming that a heart attack had caused their symptoms. However, they

continued to experience difficulty assimilating the potential seriousness of the situation to the symptoms they had considered to be of a minor nature.

#### 5.4.2.4 Receiving the diagnosis

Participants recounted the manner in which they had been informed of the cause for their symptoms.

*...then the consultant when he came round the next morning he said 'yes, it was definitely a heart attack'.*

*Barbara*

*...they were looking for a trace of Troponin and then obviously there was a trace of it, so I am assuming that that is their first signs that yes, I have had a heart attack.*

*Frank*

*...the blood test confirmed my troponin levels up and I had had mild heart attack so I was for admission.*

*Helen*

*...doctor said you have a blood count signifying that had a heart attack and I needed to go to the ward.*

*Kenneth*

The confirmation that a heart attack was the cause of their symptoms was given by a doctor often many hours after their admission, when the troponin level result was available. The participants described a range of emotions when articulating their thoughts on receiving the diagnosis.

*...To be honest all I could think of was the disruption it was going to make to my life.*

*Barbara*

*...I was quite worried at that point particularly as my heart rate was quite low.*

*Helen*

*...that was my first sort of understanding, my first realisation that it was a bit more serious than I first thought.*

*George*

*...That was a shock definitely especially as I didn't feel as if I had had a heart attack.*

*Andrew*

*...it was frustrating waiting for the blood tests to confirm the diagnosis.*

*Kenneth*

*...I wasn't terribly worried and I thought they will sort me out.*

*Edward*

The wait for confirmation of their diagnosis had provided participants with time to absorb the potential cause of their symptoms. The diverse range of emotional responses described illustrated that despite all being given the same diagnosis, the impact of receiving potentially distressing news is a very personal experience.

Elements of the emotions of denial, anger, bargaining, depression and acceptance are recognisable in some of the statements above. However, there was no identifiable pattern of reaction to being told they had had a heart attack. This reflects the later works of Elisabeth Kübler-Ross (Kübler-Ross and Kessler, 2007) who identified that the original five stages of grief model associated with bereavement and personal trauma was a coalition of emotions. Individuals experienced these emotions in a range of ways and order, in contrast with the original thought that it was a staged linear process.

#### 5.4.2.5 Symptoms not experienced

In recalling the difficulties, they had experienced trying to find a cause for their symptoms, participants commented that they had not had 'classic' signs of a heart attack. They believed the presence of these symptoms would have suggested the source of their symptoms was their heart.

*...I didn't feel as if I had had a heart attack. It wasn't the classic pains in the chest and down the arm you know and I couldn't breathe it wasn't anything like that at all.*

*Andrew*

*...basically the heart attack to me meant near death, a sharp pain in your chest and if you are lucky enough to live within travelling distance of the hospital then you might be all right.*

*David*

*...other than what you sort of hear on the telly or see on the telly where someone keels over holding their chest.*

*Frank*

*...I had a pain down my right arm and I always thought it was meant to go down the left but apparently that's an old wives' tale.*

*George*

In discussing their response to being told they had had a heart attack, participants described what they thought a heart attack should have looked and felt like. This included symptoms of severe chest pain or breathlessness. These views on classic symptoms derived from individual beliefs and the portrayal of heart attacks on television. There was surprise and frustration that the symptoms they experienced did not mirror what they had been led to expect.

This was put forward as a reason the participants had not considered a heart attack as a potential cause of their symptoms. This difference between the participants' beliefs and knowledge and reality, in conjunction with their admission to hospital for what had been perceived as a minor health issue,

led to participants losing confidence in their personal knowledge. They turned to health care professionals for advice and guidance.

### 5.4.3 Disruption to place and self

The participants were all admitted to hospital. For most of the participants this physical displacement from the privacy of their own homes to a communal way of living was an additional difficulty with which they had to contend.

#### 5.4.3.1 Losing one's independence

All participants were transferred to a coronary care unit (CCU) for close monitoring and observation of their condition.

*...they were going to move me into CCU because it (intravenous medication to stabilise condition) was more dangerous than the other medications and they needed to keep an eye on me so they moved me there.*

*David*

*...being monitored very closely so I wasn't, you know, I was sort of in the high dependency bit so that's how serious they were taking it.*

*George*

*...I did notice there was a defib bag<sup>24</sup> on the end of the bed (LAUGHS) which I thought 'Oh Christ, you know, something might kick off'.*

*Frank*

The participants acknowledged that this location meant their symptoms were being taken seriously. They were aware of the constant observation both through personal observation by health care professionals and continuous monitoring by machines. Participants talked about 'they' (health care

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<sup>24</sup> A defib or defibrillator is an electrical device that provides a shock to the heart when there is a life-threatening arrhythmia present. This helps re-establish normal contraction rhythms in a heart having dangerous arrhythmia or in cardiac arrest.

professionals) taking the situation seriously as opposed to the more personal 'I' taking the situation seriously. The use of third person narration when telling of these events suggests the participants were conveying the story but did not feel a part of the actual events unfolding before them.

The need for close monitoring in CCU resulted in a restriction to individuals' physical movement. Participants described the very different ways in which they dealt with these restrictions.

*...So I was wired up I couldn't get out to go anywhere. I couldn't even reach the bathroom in my room because the wires were not long enough.*

*Charles*

*...why are you saying I have got to have complete bed rest, I can't go to the toilet and that? Because I am quite independent, I am used to doing it, I am a big boy now, and I can do those things on my own.*

*George*

The restrictions on very private personal care such as washing and going to the toilet were most commonly noted by participants. These activities had to be undertaken by the bedside with only a thin curtain separating patients from each other. These physical restrictions were seen as frustrating for most of the participants (n=9). The individual needs for participants to retain their independence conflicted with health care professionals' needs to ensure their safety.

The ceding of control over their independence to health care professionals for these basic activities disrupted the participants' sense of self as an independent able-bodied person. The impact of these restrictions was limited to these personal physical activities of daily living. The potential lack of privacy during interaction with others, for example at visiting time or during ward rounds when personal aspects of their care may have been discussed within the hearing of other patients, were not recalled as a concern.

Two participants did not find the loss of independence such a concern.

*...Anyway I just stayed in bed and got pampered they were fantastic they really were just brilliant I didn't want to go home I enjoyed the rest.*

*Andrew*

*...they didn't seem to be too dreadful so I settled to it actually.*

*Edward*

These two participants perceived the restrictions as an opportunity to rest. They were accepting of the control health care professionals took of the situation. These participants described themselves as optimistic sort of people.

*...I have an upbeat positive attitude. I believe that when you die that's the end of it. It's not as if I will be looking through a window and still see my wife and son living here and going about their daily lives without me, I don't believe that, no, absolutely not.*

*Andrew*

*...I am an atheist so I have not got much to look forward to!*

*Edward*

Andrew and Edward both self-reported they were atheists and considered death to be the end of life and so they felt they should enjoy life. None of the other participants articulated their beliefs so clearly. This belief system which encompasses living in the moment may have enabled them to better accept the limitations placed on them by the hospital environment.

As they were moved to the step-down bays<sup>25</sup> participants dealt with their hospital stay in a range of ways:

*...After 2–3 days they let me get up but it may have just been me thinking 'Better take it easy, don't stress yourself, don't get your heart working too hard' but I think I was being over cautious to be honest. I was going pretty slowly and I would*

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<sup>25</sup> Step-down bays are four bedded wards adjacent to CCU where patients are closely observed but not continuously monitored and they are free to move about within the ward area.

*get myself back into bed.*

*Andrew*

*...It actually felt better because I could go to the loo when I wanted to and I could go and clean my teeth and wash and do all the things that you can't really do when you're all monitored up. I think it was actually Ward A which is right by the entrance and I thought to myself, a little bit of a mental thing, 'I am getting closer to the door to go home' which is how I felt at the time. Then I realised a little bit more how much of an impact that had had on my body because when I got back I did walk down very, very slowly, ... it was just something that I would normally just have gone skipping down there and skipped back and not a problem, but I did actually feel quite tired after I had done that.*

*Frank*

*...Once I was stable it was quite nice with everyone fussing around but frustrating as I felt quite well and I got quite bossy with everyone once I knew the ropes.*

*Isobel*

*...I cannot stand doing nothing; after two to three days I had typing, knitting etc. brought in to stave off the boredom.*

*Helen*

All participants interpreted this movement as a sign that they were stable and improving. However, there were gender-based differences in their recall of thoughts and experiences at this time.

Male participants appeared focused on their physical functioning. They monitored their body's responses to various activities over the period of their stay in hospital. Progress for male participants was seen as tentative as they reflected on the physical and emotional impact of undertaking activity. This contributed to their disruption of self as they compared their current reduced capacity for activity with their capacity before their heart attack.

Female participants sought out activities to fill their time but did not recall it as a time when they were cautious in their movement around the ward area. They reported resuming sedentary hobbies such as reading during

hospitalisation and this may have served as a means of regaining some sense of self by undertaking familiar activities. It may also have provided a distraction from the heightened self-awareness described by the men who did not report participating in more sedentary hobbies.

The awareness of this aspect of recovery during the hospitalisation stage of their event shows consistencies with studies considering recovery from a heart attack. These identified that men consider a return to physical functioning to be a key indicator that they have recovered (Lacey, 2003; Vaccarino, et al., 2003) and their measuring of walking in the ward may reflect this. For the female participants, those same studies identified the resumption of household activities as a key indicator in recovery. As female participants were unable to monitor this in hospital it may help explain why awareness of physical activity levels in hospital appeared to be gender specific.

#### 5.4.3.2 Internalising fear

Participants spoke about concerns they did not feel able to raise with health care professionals.

*...I wouldn't necessarily just talk to a nurse (about the sudden death of a patient)... because I would think that she would be too busy to sit and listen to that sort of thing when there's other people in more need of serious things and I wouldn't want to sort of burden anybody with just talking about something like that when it... you know, it didn't really enter my head to be fair, I just... I wouldn't just naturally do that, I would sort of keep it all to myself.*

*Frank*

This description of a participant's thoughts following the death of another patient were consistent with those of George (Section 5.4.4.2) who describes his silent fears. The rationale for not voicing these fears to staff was explained as staff being too busy caring for very sick patients to talk through fears and worries. In suppressing their emotional concerns, participants were conforming to the biomedical model of care. This model, prevalent in many

health care settings, prioritises the physical elements of illness over psychological and emotional elements.

Participants also described how actions undertaken by health care professionals contributed to fear and concerns.

*...they (nurses) kept saying to me when they came round to do the pills to me 'have you got any pain? Have you had any more pain? Have you got any pain? Do you feel any pain?' I kept thinking why do they keep asking me? Does it mean I am more than likely to have another heart attack when I am here and that was bothering me a lot. Although I was in the right place but the thought it would happen and I kind of got the impression from the nurses that they were expecting it to happen again the way they kept asking me.*

*Andrew*

*...they put me on a monitor and I could see my heart rate, it was always slightly slow but I could see it dropping on the monitor to 35 and 29 and I was concerned that it was going to stop. So I turned over so could not see monitor and I kind of asked if I was going to die let it be while I am asleep so I don't feel pain or fear. It helped when the nurse came and switched off the monitor volume but she did not explain what was going on and that increased my anxiety. I did some meditation and I went to sleep but that first night was horrific.*

*Helen*

Both these participants experienced increased distress as a consequence of a health care professional undertaking an action without an explanation of the rationale behind it. The action, considered to be a routine task for the health care professionals, was not one with which the participants were familiar and this gave rise to disturbing thoughts in the participants' minds. The inability to ask questions of the health care professionals could not be explained by participants; instead they chose to come up with a private analysis of the actions.

Creating their own rationale for a situation to which they had no prior exposure resulted in an explanation which led to a poor outcome such as death or another heart attack. This served to further increase the level of

anxiety experienced by participants. They began to realise that the way they perceived themselves was shifting to include someone who had experienced a significant life event and may die.

Admission to hospital resulted in a physical displacement from their home environment, together with an enforced relinquishment of individual control over their activities. These factors contributed to a disruption to the participants' sense of agency<sup>26</sup> and of self, as participants tried to make sense of all that was occurring.

#### **5.4.4 Disruption to time**

A consequence of disruption to place was a disruption to the participant's sense of time. This was not time in the horological sense but in relation to their biographical timeline.

##### 5.4.4.1 Envisaging a foreshortened life

*...I don't expect to make old bones.*  
*Isobel*

*...There is a possibility that I might die earlier – having had one heart attack I am more likely to have another.*

*Helen*

*...now I think 'will I get to 80?' and it brings everything forwards, a high proportion of gardeners die within two years of retirement.*

*Kenneth*

*...I am 67 in December, you know, so you can't keep going forever obviously, you are going to slow down of course.*

*Andrew*

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<sup>26</sup> Sense of agency can be summarised as the degree to which we feel in control of our behaviour and thoughts.

*...But then you think to yourself well I am 58 now, you know, a couple of years off 60, you know, you are getting up there, you ain't got as much left as what you have lived.*

*Frank*

Their belief was that they had a future that was more likely to be foreshortened as a consequence of having had a heart attack. The female participants spoke in general terms of not living to as great an age as they might otherwise have done. The male participants put a numerical value to it either through rationalising that their current age suggested they were getting older or suggesting a specific age they might not reach. These differences were examples of how men and women think and talk differently when considering difficult situations. This raises a question as to whether health care professionals should consider issues such as gender when providing patients with information.

This foreshortened longevity was a thought which intruded on their lives to a greater or lesser degree.

*...you are not sitting around thinking I am going to be dead one of these days, no, cause you would go crazy if you thought like that, I don't dwell on it really.*

*Andrew*

*...I don't really dwell on it, however it's always there.*

*Frank*

*...It's not a daily worry.*

*Isobel*

*...So we just carry on living, you have to.*

*David*

No participants found these thoughts overwhelming. However, there was consensus across all participants that it existed and intruded when it was least expected or desired. Those who were able to articulate specific

situations that brought thoughts on longevity to the forefront of their minds all related it to the significant family-centred events they would potentially miss.

*...I look at my grandchildren and consider will I see their partners. Isobel*

*...my concern is that I won't see them (very young grandchildren) grow up and get married.*

*Frank*

The participants did not share their views over their potentially foreshortened longevity with other family members.

*...but I think you learn to scoot around it, be crafty about it. Or if I think sometimes it's getting a little bit ... I would just go and make a cup of tea or get out the way for a little while.*

*Frank*

*...We don't talk about it and I certainly haven't told B (husband) how I feel.*

*Isobel*

Isobel's husband had just completed treatment for cancer at the time of her heart attack, yet, in a situation where both were exposed to the reality of their mortality, there was no discussion around the subject. Frank had developed strategies to enable him to leave a situation where he felt vulnerable to these thoughts. He described it as the ever present '*elephant in the room*'.

Discussing death, or at least the potential for a foreshortened longevity, was a taboo subject for the participants in this study. This is a reflection of our society where we now live longer with an improved standard of living but with a reduction in our personal exposure to death. This, together with the public promotion of behaviours such as eating healthily and being more active to prolong our lives, has created a situation in which it is more difficult to talk about death.

#### 5.4.4.2 Personalising death

Three of the participants witnessed the resuscitation of another patient during their hospital stay and this made them think about their own mortality in a very personal way.

*...there is a little mental thing in your brain that's going 'am I going to be next for this thing?' you know.*

*Frank*

*...So you think; it does bring it home to you how fragile life is, really you think, my God it could have been me.*

*Andrew*

The three men who reported witnessing such events were in their 50s and 60s and as such were younger participants in the study. The effect of this was to make them think that this could happen to them. For all three their main concern was the effect this would have on family members.

*...'Mr So-and-so is poorly, it would be advisable if you could come up, make your way to the hospital' and I thought oh it sounds like he's not going to make it. And that kind of upset me because it was sort of a... this is a bit... I thought this is a bit real. And it's not until you learn a little bit more down the line as to why they have got certain protocols that they follow and that's what they do when this is... when you have had a heart attack.*

*George*

George had overheard a telephone call asking relatives of a patient who had suffered a cardiac arrest to come to the hospital. He perceived this conversation as one delivering bad news to relatives. George had struggled to accept the restrictions constant monitoring had placed on his freedom to move around. However, this event changed his perception of the situation and he acknowledged the rationale for the care being provided.

The others expressed their thoughts of what the impact of death would

have on their families:

*...Just imagine my wife coming in and you know my 15-year-old son, well they would phone her up and tell her your husband had died.*

*Andrew*

*...you have just had a little bit of a brush with death if you like and I have got young grandchildren and I just didn't particularly want to be a picture on a wall.*

*Frank*

For all participants the concern was for relatives, either their own or those of another patient, having to be told of their death. The three participants all reported that their thoughts did not centre on the actual mechanisms around their own death. Rather they centred on the impact this would have on their family members. Although all participants considered they had a foreshortened mortality, only those who had witnessed the death of another patient considered specific aspects of what might happen should they die in hospital.

For these participants, death, which had previously been a remote event, was now being considered as an impending possibility. This threw their current biographical timeline into disarray.

#### 5.4.4.3 Living in limbo

The participants who were waiting further tests described their feelings as they waited for the results of these tests.

*...so that was a bit frustrating because I kind of want to know myself as to right, am I doing the right things, am I on the right road to recovery or is this it, or do I need something extra or what? So I am kind of in limbo.*

*George*

*...I am actually still waiting for the results now...and when I left they said that they would either ring or write to me and I am just thinking as a sort of mental thing, I am thinking if*

*there was anything seriously wrong they would have contacted me by now by phone as opposed to just writing to me – I am assuming that's what they would do.*

*Frank*

A lack of clarity as to when and how the results of tests would be communicated to participants induced a feeling of life being on hold or in limbo. They found it difficult to consider themselves to be recovering as they awaited more information which could potentially be distressing and lead to further treatment or find out there is no further treatment available. A 'no news is good news' thought process was a common means of coping with this situation.

The perception of participants was that the information was available to health care professionals but there was no specific time frame in which to share this with participants. The withholding of this information reduced participants' ability to regain control of their lives. Participants wanted to feel they were making progress both through the health care system and towards a full recovery or having to adjust to an altered health state. In addition to the potential of having their biographical timeline permanently disrupted by an earlier death this group's ability to begin to restore their biographical timeline was delayed by uncertainty and a lack of information.

#### **5.4.5 A disrupted narrative identity**

The initial physical sensations, or symptoms, experienced by participants started a series of events which culminated in admission to hospital and being informed they had had a heart attack. Participants told of an increasing inability to make sense of these events from the tacit knowledge and beliefs which underpinned their everyday lives. This inability to make sense of events disrupted participants' taken-for-granted assumptions about their bodies, their knowledge and beliefs and their plans for the future. The elements contributing to this disruption are listed in Table 5-2.

The struggle to explain their symptoms was the initial factor. Participants sought to find a cause for their symptoms and on failing to do so sought help and support from family members to make sense of their situation. As they were admitted to hospital participants' stories progressed from that concerning a minor health problem to being told they had experienced a heart attack.

<b>Disrupted Narrative Identity</b>
Identifying a cause for the symptoms
<ul style="list-style-type: none"> <li>• Attributing a cause to the symptoms</li> <li>• Seeking help and support</li> <li>• Visual Perceptive Mismatching</li> <li>• Receiving the diagnosis</li> <li>• Symptoms not experienced</li> </ul>
Disruption to place and self
<ul style="list-style-type: none"> <li>• Losing one's independence</li> <li>• Internalising fear</li> </ul>
Disruption to time
<ul style="list-style-type: none"> <li>• Envisaging a foreshortened life</li> <li>• Personalising death</li> <li>• Living in limbo</li> </ul>

Table 5-2 Components of a disrupted narrative identity

It became increasingly challenging for these individuals to make sense of, and story, a situation which was outside the realms of their previous experiences. Their story was further challenged when their expectations of the symptoms associated with a heart attack were invalidated. This increased the disruption to their life story as participants lost confidence in their personal knowledge and relied on health care professionals for advice and guidance.

Admission to hospital resulted in both a physical displacement from their home environment and an enforced relinquishment of individual control over their activities. This disrupted a participant's sense of time, self and place.

Participants ceded control of the situation to health care professionals who functioned from a biomedical narrative of power, superiority and control. The loss of agency associated with hospitalisation led to participants internalising their fears and concerns rather than discussing them with health care professionals.

The theory of disrupted narrative identity is built on an evolving situation. A lack of knowledge in a given situation leads to a disruption of the participant's current narrative. Individuals then look to another narrative, in this case that of health care professionals specialising in the care of those experiencing a heart attack, to provide an explanation. This allowed participants to begin to make sense of their current situation. Elements of the narrative of the health care professionals were then introduced to the individual's narrative knowledge<sup>27</sup> base. This assisted them to articulate and put a name to the events that had occurred.

## 5.5 Creating a different narrative

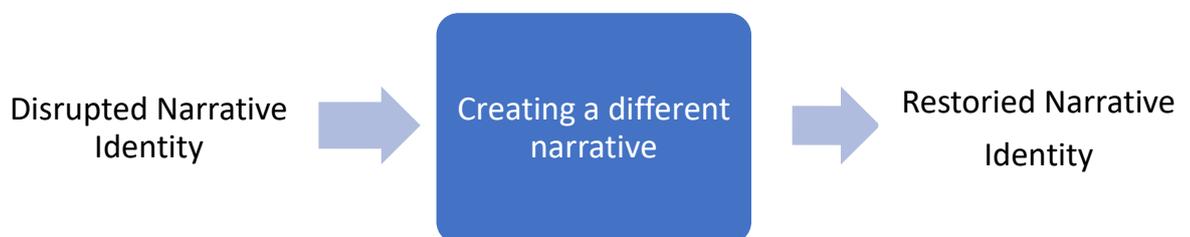


Figure 5-6 Conceptual trajectory of biographical restorying after a heart attack.

This process by which individuals created a different narrative required them to make sense of the situation in which they then found themselves.

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<sup>27</sup> Narrative knowledge is knowledge which is derived from ours and other people's experience and disseminated through stories (Gabriel, 2004).

### 5.5.1 Undertaking and reflecting on action

Participants related how they assessed and scrutinised minor actions and thoughts as they recovered from their heart attack. They reported a continuous process of acting and evaluating the effect of that action.

As an example, they might go for a walk (undertake an action) and then realise they were becoming a bit out of breath during this walk (reflecting on the action). They then drew on their own knowledge and previous experience or looked to other sources for knowledge to help them decide what they were going to do about the situation. For example, they might decide this was because they had gone up a hill or been walking faster, or they might decide they were walking into a headwind which needed more effort. Whatever the reason they had to make a decision regarding how they would approach this action the next time it needed to be undertaken.

This cycle could be influenced by interacting with others. The individual might seek interaction by speaking to a family member or health care professional. Alternatively, the interaction may be initiated by the family member or health care professional providing information which informs the action or reflection of the action in some way.

This process, summarised in Figure 5-7, was one of reflecting on action and undertaking action in a cyclical manner with information from other sources, for example health care professionals, media and family feeding into this cycle.

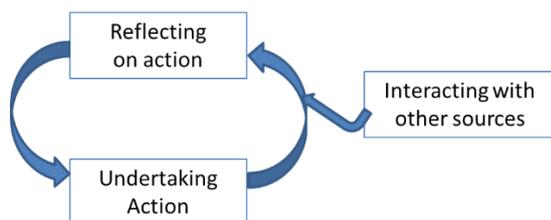


Figure 5-7 Making sense of the situation

This cycle is a continuous process which occurs consciously and unconsciously across all aspects of the participants' everyday lives. It is the manner in which it is applied to making sense of having had a heart attack that will now be explored.

#### 5.5.1.1 Responding to physical sensations

The principal signals participants used when reflecting on the actions they had undertaken were the physical sensations that arose. These physical sensations were frequently the outcome of undertaking a physical act and participants perceived these in a range of ways:

*...I still get this pain between my shoulder blades if I do anything like ironing.*

*Barbara*

*...you get the odd twinge in the chest and things from just doing everyday gardening and stuff like that and you think, you know, have I... what is all that about?*

*Frank*

*...I mean I could set off now and do a brisk walk into town and it's no effort at all. I don't need to stop and think 'I am out of breath, oh I feel tired, I can't go any further'.*

*Andrew*

*...I can't walk uphill and talk as I used to.*

*Isobel*

Participants monitored for both the presence and absence of physical sensations. The reaction to these sensations varied across the range of participants. In considering how these differed, four different reactions to physical sensations emerged and each is now described.

The first group told of a range of causes for their physical sensations:

*...we were up and down hills and so on and it was a bit of an effort, more than it... but I mean I am older, I am 67 in December, you know, so you can't keep going forever obviously, you are going to slow down of course.*

*Andrew, aged 67*

*...I do a great deal of gardening and that, although at my age I am limited now. Where I used to do the garden for five or six hours, about an hour and I think 'Well, I'd better have a rest now.' That's nothing to do with the heart.*

*Edward, aged 86*

*...That's (the weather) what was putting me off in some way but in other ways I am getting exercise which I was told to do. We make it a longer way sometimes; we make it a shorter way sometimes. All depends on what the weather is like ... well I've got to give it a try perhaps surely just to see what it does to me.*

*Charles, aged 67*

The commonality for this first group (n=3) was that any physical sensations they were experiencing were attributed to a factor other than their heart attack, for example the weather or the process of ageing. The age extremes of the participants who attributed physical sensations to ageing were 67 and 86. The age range of all participants was 57 to 86. This would suggest that chronological age was not the only factor which led to this belief.

In considering getting older as the cause for their physical sensations this group associated ageing, a factor beyond their control, with increasing dysfunction. This group did not perceive that these sensations might be attributable to their heart attack.

One of the participants in this group, Charles, did not experience physical sensations associated with his current levels of activity. He did, however, suggest that undertaking more activity might lead to unwanted physical sensations and so linked decisions about the limiting of his activity to weather conditions. In this situation, the weather, as an external cause, becomes the factor which limits activity and reduces the chance of experiencing physical sensations.

This group used external factors to explain both the occurrence and the means for avoiding potential physical sensations. In doing this, these participants reasoned they had no control over the physical signs they experienced after their heart attack. This linking of their experience to an external cause suggests this group have personality traits linked to those with an external locus of control (Rotter, 1966).

The second group (n=1) by contrast experienced frequent physical sensations which impacted on their daily lives.

*...I think that is to do with my heart because if I sit down it goes away. It is a form of sort of angina really.*

*Barbara*

*...I get that now a bit (angina) I did this week, you know, just walking along up the high street which is quite a slope up I think if I am carrying anything, and I stopped which I didn't before I had that (heart attack).*

*Barbara*

In this group, the physical sensations were associated with their heart attack and were viewed as symptoms. These symptoms restricted the participant's ability to undertake or sustain their involvement in everyday activity and were viewed as a sign of ill-health.

*...I don't want to stop going out anywhere just because I am taking the water tablets, you know. But it does limit you a little bit.*

*Barbara*

*...I have had one or two problems and I don't... I am not as well as I was.*

*Barbara*

*...But that is what I have noticed just recently, you know, that it (angina) does limit me for ... where before I could do that without any problem at all, but the last time like yesterday out shopping, I thought oh dear, you know, it's telling me to stop.*

*Barbara*

The symptoms and experiences described by this one participant were very different from the other participants. The symptoms were intruding into all aspects of their life. This participant had been forced to reduce their activities as a response to physical sensations and linked their physical sensations to perceptions of being ill or not well. The situations described by this one individual were of a similar nature to those expressed by the participants who contributed to Charmaz, (1997) study describing their struggles to live with chronic illness.

The third group (n=3) described how they experienced physical sensations which they could control to enable them to carry on with their activities:

*...knowing that I can get breathless but as long as I am aware, I am doing the health walks now and I know that I can pace things and if the breathlessness occurs then I ease off, let it all settle and continue.*

*Isobel*

*...chest pain can stop me walking, but I rest and recover then start more slowly, I judge things and the regular exercise does help, I can swim 40 lengths.*

*Helen*

*...I go to the gym (or have been), since I have been doing the work on my house I haven't been to the gym because I thought well I am not going to overdo it,*

*Frank*

This group also acknowledged there were limits to the amount of activity they could undertake. Unlike the first two groups they undertook definite actions to enable them to continue with a range of activities in their lives. In contrast to the second group who linked their physical sensations to being unwell this group considered their physical sensations to be a sign that they were well if limited in what they could achieve.

This group made decisions about replacing or adapting activities to prevent

limiting physical sensations occurring. In situations in which they did experience sensations they had ways of allowing themselves to continue with their activities. In perceiving these physical sensations to be under their control this group adapted their activity as a means of managing and reducing their impact. This suggests personality traits consistent with those who have an internal locus of control (Rotter, 1966).

The fourth theme that emerged, in a group of four participants, were those who described what they were now able to do:

*...I can now walk unlimited distance and at a good pace.*  
*James*

*...I am working physically harder over time.*

*Kenneth*

*...We have a fairly healthy diet and we walk three times a week usually, sometimes more.*

*David*

This group did not identify specific sensations or symptoms; rather they described the activities they were able to undertake. In the early stages of their recovery this group had experienced some physical sensations.

*...I did run out of puff, so I would just stop a little bit and just catch my breath and then carry on but I must say that it has eased.*

*George*

*...I started playing golf again at 10 days (after the heart attack) and initially had to use a buggy till my breathing got better but now I am back to walking.*

*James*

For this group these sensations had been short-lived. They were now in a situation where they talked about undertaking activity unlimited by any

physical sensations. Their observation of individual elements, such as breathing, muscle aches, or how they were feeling during activity, had reduced over time. This group had reached a state in which self-surveillance of their activity was no longer undertaken at a conscious level. This group assessed this as a sign that their health had improved.

The experiencing of physical sensations and the reaction to those sensations and the number of participants fitting into each category is summarised in Table 5-3 below. All participants' responses could be placed in one of the groups. Although only one participant was placed in the category of enforcing limitation, their response to physical sensations was very different from the other participants. This solitary participant was the only one who told their story from the perspective of being unwell and this influenced all other aspects of this individual's recovery.

Response to Physical Sensations			
Attributed to an external cause. N=3	Enforcing limitation of daily life N=1	Prompting an adaptation in daily life N=3	Not consciously impacting on life N=4

Table 5-3 Responses to physical sensation

The way in which participants responded to physical sensations influenced the ways in which they undertook and reflected on other actions as they attempted to make sense of their lives following their heart attack.

### 5.5.1.2 Undertaking a health-related behaviour change<sup>28</sup>

The decision to undertake any changes in their health-related behaviours was a response to the physical sensations participants had experienced. This varied across the four groups already identified, both in the changes they had or had not made and in discussing the details of these changes. In order to aid identification of the specific group being discussed Table 5-3 is reproduced with the group currently under discussion highlighted in the remainder of this section. The groups will be referred to as Narratives 1, 2, 3 and 4, working from the left of the table.

Response to Physical Sensations			
Attributed to an external cause N=3	Enforcing limitation of daily life. N=1	Prompting an adaptation in daily life. N=3	Not consciously impacting on life. N=4

Table 5-4 Responses to physical sensations: highlighting response of Narrative 1

The group who attributed their physical sensations to an external cause (Narrative 1) reported they had not undertaken any health-related behaviour change following their heart attack.

*...I go and have meals out quite a lot, and I go on local holidays quite a lot, but – none of that's changed. Actually, my life hasn't changed at all.*

*Edward*

*...I just live and carry on as I did until whatever. Live day by day see how things go.*

*Charles*

*...I am not motivated to do anything about it because it doesn't make me feel ill.*

*Andrew*

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<sup>28</sup> Health-related behaviour change refers to the processes in which individuals who have experienced a heart attack reduce their risk of future heart attacks by introducing behaviours such as not smoking, undertaking regular physical activity and consuming a cardio-protective diet.

These participants had returned to a life unchanged following their heart attacks. They had related any physical sensations to external causes. They had been able to return to their previous lifestyles with no issues and thus did not perceive any need to change any of their health-related behaviours.

The narrative of the second group (one person), (Table 5-5) who had been forced to reduce her activities as a response to physical sensations, told of undertaking health-related behaviour change. However, the change had been forced upon her as a consequence of her physical sensations.

Response to Physical Sensations			
Attributed to an external cause N=3	Enforcing limitation of daily life. N=1	Prompting an adaptation in daily life. N=3	Not consciously impacting on life. N=4

Table 5-5 Responses to physical sensations: highlighting response of Narrative 2

*...I still get this pain between my shoulder blades if I do anything like ironing, after about an hour I have to give up, and I think that is to do with my heart because if I sit down it goes away.*

*Barbara*

*...anything with my arms and the same applied. In the garden, if that starts to happen then I come and sit down.*

*Barbara*

*...It's a form of sort of angina really? And I get that now a bit just walking along up the high street which is quite a slope up. I think if I am carrying anything, and I stopped which I didn't before.*

*Barbara*

There was a progressive reduction in activity levels as, over time, the physical sensations in the form of a recognised symptom of heart disease

known as angina became a more frequent event in her daily life. In this narrative, the health-related behaviour change became a restriction in behaviour with the participant having to cease activity as she experienced symptoms. This is in contrast to the other narratives in which health-related behaviour change was related to maintaining or increasing activity levels.

Behaviour change related to undertaking basic activities of living was the sole concern of this group. Healthy eating and dietary considerations were absent from any discussion. Thus was unlike the other groups, who spoke of diet and activity levels as a combined package when discussing health-related behaviour change.

In this narrative, some behaviour change was imposed as a consequence of medical regimes.

*...if you take some in the morning and some at lunch time (diuretic medication<sup>29</sup>), if you want to go out... you know, it's awfully difficult to fit it all in, you know, so I said 'Can I take the double dose in the morning or whenever it's convenient?' because if I go out in the morning I take it when I come back, so he (GP) said 'That's fine by me, so I do that.'*

*Barbara*

*...I think what I might do is wait until I get back (to the hotel each evening) because they usually give you three or four hours when you come back before dinner at night, so I think I might do it then (take diuretic therapy) otherwise I will be up until midnight, you know, waiting for it to... it is a nuisance isn't it, it's really a nuisance but I will work it out somehow.*

*Barbara*

In adhering to medication regimes, behaviour change was imposed on this group by her condition. Manipulation of these regimes in consultation with health care professionals was undertaken. This enabled this participant to adapt her behaviour and participate in daily activities. On occasions, this

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<sup>29</sup> Diuretic therapy increases the amount of urine passed in the 3-4 hours following ingestion. It results in frequent trips to the toilet during this time and as a consequence can limit the range of activities undertaken.

could involve adapting the regime for longer periods to allow for specific events. The planned changes to the timing of some of her medications during a holiday as described above is a good example.

Behaviour change in this group was focused on short-term juggling and internal bargaining to limit the restrictions imposed by ill-health. This focus on adapting imposed behaviours such as the taking of medication was centred on achieving short-term goals. This reduced the participant's ability to consider changing inherent behaviours such as dietary or activity regimes which would usually involve planning for the longer term.

In contrast to this, the narrative of the third group, who had adapted their activities in response to physical sensations, told how they had undertaken health-related behaviour change related to diet and exercise.

Response to Physical Sensations			
Attributed to an external cause N=3	Enforcing limitation of daily life. N=1	Prompting an adaptation in daily life. N=3	Not consciously impacting on life. N=4

Table 5-6 Responses to physical sensations: highlighting response of Narrative 3

*...I do not eat the healthiest diet but it is much better, I emotionally eat but now choose fruit not chocolate, half wholemeal bread for example.*

*Helen*

*...Regular exercise does help, I can swim 40 lengths, I cycle everywhere because walking is painful and so ironically I am getting more exercise because it is difficult to walk to the bus stop.*

*Helen*

*...On the diet side we tend to check the labels. I am about 13 (stone) 4 (lbs) where I was 15:6 before I went in, so I have done quite well on that part and I sort of consciously do*

*check my weight if I am honest, probably a little bit too much because I don't want to go back up to that situation.*

*Frank*

*...He (sports instructor) has just sorted me out a 45 minute programme that I have stuck to the letter, a bit of rowing, a bit of arm exercise and cross trainer and exercise bike – it all adds up to about 45/50 minutes.*

*Frank*

*...I go to the allotment 5 days out of 7 for a good hour or more.*

*Isobel*

This group, who had to monitor physical sensations, also monitored the health-related behaviour changes they had undertaken. They spoke in specific detail about the changes they had made in relation to their activity levels and their diet. Undertaking health-related behaviour change was perceived as a factor that would help manage and reduce the overall impact their physical sensations had on their daily lives.

Health-related behaviour change was undertaken as a means of helping to maintain their current state of health. They identified objective signs that they were achieving the health-related behaviour goals which reduced the chances of having a further heart attack. These are the goals promoted in national guidelines, public health campaigns and specific programmes such as a comprehensive cardiac rehabilitation programme.

The decision to undertake health-related behaviour change suggests that this group perceived they had control over aspects of their recovery. This supported the earlier suggestion that this group had personality traits consistent with those who have an internal locus of control (Rotter, 1966).

Response to Physical Sensations			
Attributed to an external cause N=3	Enforcing limitation of daily life. N=1	Prompting an adaptation in daily life. N=3	Not consciously impacting on life. N=4

Table 5-7 Responses to physical sensations: highlighting response of Narrative 4

The narrative of the fourth group, who were no longer conscious of physical sensations impacting on their lives, recalled how their attitude to health had changed following their heart attack.

*...I'm not the most self-motivated but I now do activity more consciously.*

*Kenneth*

*...I would sort of cherry pick the bits that I wanted to rather than sort of buy into the whole lot. 'This is the good way of living, this is not so good'. I thought I was doing enough to live a long and healthy life and it obviously wasn't – I need to do a little bit more.*

*George*

*...I was always determined to be fat and happy not thin and miserable but I have lost 8kg since the heart attack as my diet has changed slightly to include some of my wife's eating habits. My awareness of food has increased and I don't keep binge foods in the house now.*

*James*

A general belief in following the principles of a healthy lifestyle prior to their heart attack had now become a personal issue. These participants described how they needed to change or had changed the way they lived their lives. They perceived a value to their health in engaging with healthy living. In telling of their issues with self-motivation and self-determinism they acknowledged that they had the ability to change their lifestyle.

This group all described ways in which they were making changes with the aim of reducing their risks of future ill-health.

*...Golf is no good as an exercise but I now also walk with a purpose of meeting the exercise goals.*

*James*

*...formulate my own sort of plan mentally as to where I need to be and how I am going to go about reaching it...I'd like to lose a bit of weight, I am not fussed about how heavy I am, I just want to change my body shape<sup>30</sup> and I have noticed that as I have got older I am storing it all round the middle which is a classic place for a guy, but being short it's going to create... if I store it there, it's going to give me lots more problems than I need to have.*

*George*

*...Health keeps the exercise and diet regime a conscious decision. I have made changes and determination not to let it happen again and keep the diabetes I was on the edge of, at bay.*

*Kenneth*

This group did not monitor their health-related behaviour change as closely as those in Narrative 3, who had adapted as a response to physical sensations. Those in Narrative 4 had undertaken activity and dietary changes. They spoke of general goals they were working towards such as meeting exercise targets or changing body shape. However, their reporting of these changes lacked the quantifiable measures of achievement recounted by the group who had adapted as a response to physical sensations. However, this fourth group talked of a life that was perceived as being improved when compared with life before their heart attack.

For both Narratives 3 and 4, the trigger to undertake health-related behaviour change came from a desire to both maintain their current health status and prevent future ill-health. The physical sensations experienced were the principal factor in the setting of personal goals and the level of monitoring undertaken. Those who experience physical sensations reminding them of

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<sup>30</sup> Body shape, in particular carrying excess weight in the abdominal area, has been associated with a higher incidence of coronary heart disease.

the limitations that have been placed on them following a heart attack may be more likely to set and measure the specific impact of their personal health-related behaviour change goals. Those for whom physical sensations do not consciously impact on their daily lives measure achievement in a more general manner.

### Summary

The rationale under which health-related behaviour change was taken by participants within the four narratives identified was associated with the manner in which they responded to physical sensations. These are presented diagrammatically in Table 5-8. These two factors assisted participants in making sense of their overall situation. Participants reflected on the impact of behaviour change on their physical sensations. They undertook further behaviour changes driven by physical sensations linked to health or ill-health in the action and reflection feedback cycle (Figure 5-7).

The physical sensations experienced by individual participants were a consequence of their heart attack. Changes in their behaviour were a response to these physical sensations. In this way participants undertook actions and reflected on these actions. However, other perceptions influenced the reflective part of the process and these perceptions were in turn reinforced by the action and reflection cycle.

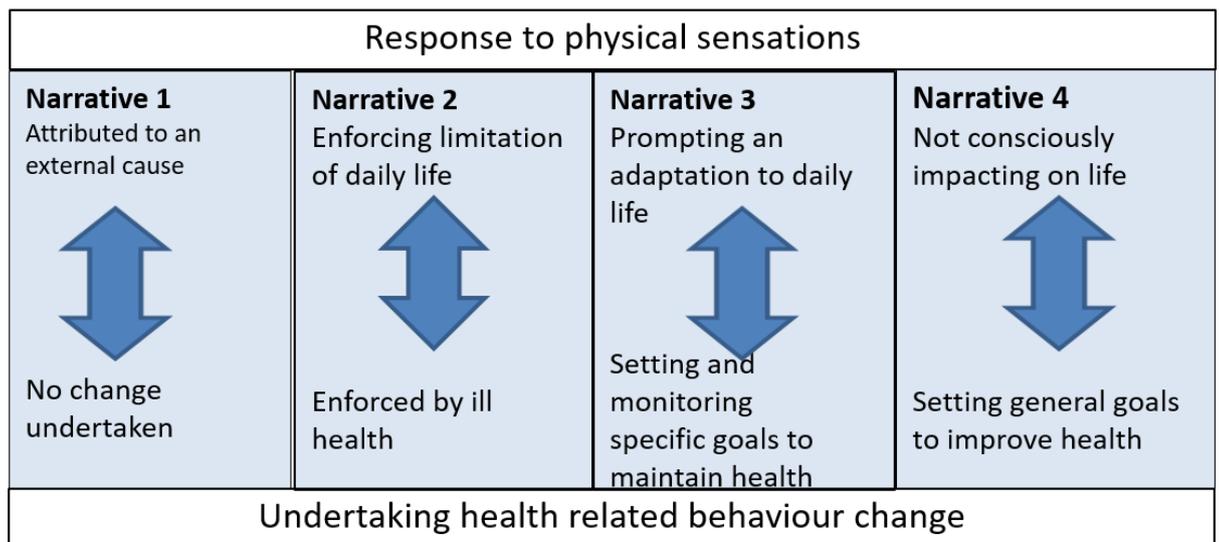


Table 5-8 Relationship between responding to physical sensations and undertaking health-related behaviour change

### 5.5.2 Perception of health

The behaviour changes were linked to the individual participant's perception of either health or ill-health. The reason for undertaking a change was a desire to improve or maintain a feeling of being in good health. Three of the four participant narratives who perceived their behaviour had changed following their heart attack could be placed on a continuum of health as depicted in Figure 5-8.

The respondents in Narrative 4, who perceived they had greater control over the behaviour changes they made, reported that they felt well. The respondent in Narrative 2, who was forced into behaviour change, reported this was from a perception of poorer health. Those in Narrative 3 undertaking behaviour change reported positive effects. They described feeling well as a result of the benefits they perceived were related to the behaviour change.

*...I consider myself to be in good health because I don't feel ill.*

*Helen*

There was a belief in this group that health equated to the absence of ill-health and an acknowledgement that their current state of well-being may not last.

Those participants in Narrative 1 perceived they were well from the perspective of their heart attack but their overall perception of their health was that as a consequence of their age it would decline.

*...How do I feel? Good, I feel good... I am 67 in December, you know, so you can't keep going forever obviously.*  
Andrew

*...Well, I've been all right really... I don't think that's to do with the heart; that's just age – I'm pretty old.*  
Edward

This group did not perceive they could influence their health. They did not identify any change in their behaviour which could account for any change in their health. They did not fit on the continuum if it is purely based on behaviour change influencing perception.

The concept of perception of health reported by the participants has been suggested in the wellness–illness continuum. This is a model reflecting the degree to which an individual can perceive themselves as being well or ill (Travis 2011). The continuum is a scale based on an individual's perception irrespective of the manner in which it was formed.

Those in Narrative 1, with their belief in declining health, would be placed towards the left side of the scale below (Figure 5-8). Those in Narrative 3, who were positive about their current state of health and saw it as an absence of feeling ill, were positioned further to the right of the continuum.

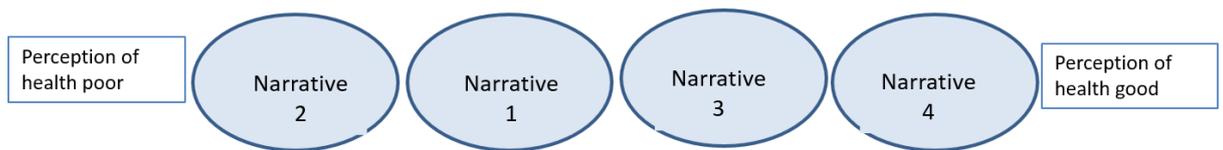


Figure 5-8 Continuum of perception of health

### 5.5.3 Growing in confidence

Participants told of the ways in which their confidence,<sup>31</sup> which had been dented during their admission to hospital, was being restored as they recovered from their heart attack.

For Narrative 1, who reported that their physical sensations were attributed to an external cause (

Table 5-9 Responses to physical sensations: highlighting response of Narrative 1), there was no reported change in confidence levels.

Response to Physical Sensations			
Attributed to an external cause N=3	Enforcing limitation of daily life. N=1	Prompting an adaptation in daily life. N=3	Not consciously impacting on life. N=4

Table 5-9 Responses to physical sensations: highlighting response of Narrative 1

*...things could happen but who knows what is going to happen. I just live and carry on until whatever. Live day by day see how things go.*

*Charles*

*...That's just common sense I'm using rather than fear.*

*Edward*

<sup>31</sup> Confidence is defined as belief in oneself and one's powers or abilities; self-confidence, self-reliance and assurance are often used in the same situation and are attributed with the same definition.

*...No I don't feel as if I need to be cautious.*

*Andrew*

When asked if their confidence had been reduced since having their heart attack this group did not use the word confidence in their response. Instead they described how they approached life. Living day by day and using common sense were general principles by which they led their lives. These were seen as the reason why they had not experienced a loss of confidence.

This belief that their confidence levels had not been affected can be explained by their having returned to most of their previous activities with no difficulties following discharge from hospital. For this group there was no reason for them to consider loss of confidence a consequence of their heart attack.

For the participant in the second group, where physical sensations had enforced limitation of activity (Table 5-10 Responses to physical sensations: highlighting response of Narrative 2), confidence had not returned.

Response to Physical Sensations			
Attributed to an external cause N=3	Enforcing limitation of daily life. N=1	Prompting an adaptation in daily life. N=3	Not consciously impacting on life. N=4

Table 5-10 Responses to physical sensations: highlighting response of Narrative 2

*...But I suppose the biggest thing about heart attacks is it does destroy your confidence a little bit doesn't it?*

*Barbara, Interview 1*

*...I don't know why, I suppose my confidence has gone but now I just don't want to get in the car and drive.*

*Barbara, Interview 2*

With most of the participants there was an acknowledgement that their

confidence to undertake activities had been reduced following their heart attack. However, in this group, confidence had not been regained. The comments above were from the same participant but reported six months apart in different interviews. They told the great impact that loss of confidence can have to prevent the return to an activity such as driving a car. The enforced reduction of activities, as a consequence of physical sensations, and health-related behaviour change being driven by ill-health, combined to reduce the opportunities for the positive feedback mechanism that assisted the participants in other groups to rebuild their confidence.

For the third group, in which health-related behaviour change centred on setting very specific goals (Table 5-11), small achievements led to an improvement in the participant's self-confidence and supported further achievements.

Response to Physical Sensations			
Attributed to an external cause N=3	Enforcing limitation of daily life. N=1	Prompting an adaptation in daily life. N=3	Not consciously impacting on life. N=4

Table 5-11 Responses to physical sensations: highlighting response of Narrative 3

*...In general I took everything slowly and gradually gave it all a tick. All the achievements were noted and I have not referred to the red book as much recently.*

*Isobel*

*...I have my moments but they are getting few and far between now and I probably don't take any notice of it because I am quite confident with what has been going on.*

*Frank*

Participants discussed the different perspectives from which their confidence grew. This group's setting of specific goals gave them a benchmark against which they were able to measure change over time. One told of the positive reinforcement to their confidence through achieving pre-set goals. For another it was a reduction in the more negative 'moments' of concern, at the possibility of symptoms recurring, which improved their confidence.

This suggests that the capacity to monitor and measure change is more important than whether that change is positive or negative in origin. In assessing their recovery and measuring themselves against specific but personally set criteria, the participants perceived their situation was improving. This positive feedback boosted the confidence levels that had been reduced as a consequence of their heart attack.

The fourth group, who had undertaken general health-related behaviour change (Table 5-12), described how their confidence to undertake activity returned following the heart attack.

Response to Physical Sensations			
Attributed to an external cause N=3	Enforcing limitation of daily life. N=1	Prompting an adaptation in daily life. N=3	Not consciously impacting on life. N=4

Table 5-12 Responses to physical sensations: highlighting response of Narrative 4

*...so there was a bit of rebuilding your self-confidence a bit, but that does come.*

*George*

*...there was an anxious few days after going home but as I got into doing more, then my anxieties reduced and dispersed.*

*Kenneth*

*...It was a good service (cardiac rehabilitation) with reassurance being provided during exercise sessions which helped to raise confidence again.*

*James*

This group, like the group who measured against very specific goals, spoke of a loss of confidence associated with having a heart attack. Similarly, the return of confidence was associated with a resumption of previous activities. This group, with no conscious physical sensations of their heart attack, reported that their confidence returned within a few days or weeks of discharge.

This return of confidence was much quicker than the other groups and potentially linked to a positive feedback loop in which there were no intrusive symptoms or other health-related conditions to restrict their return to previous activities. This was a situation in which being able to undertake any activity became a positive feedback for the individual that they were recovering. This led to a greater confidence to undertake further activities.

For those participants in whom loss of confidence was reported after their heart attack, positive feedback loops appear to be important in the regaining of confidence. In the situations where confidence returned, Narratives 3 and 4, the speed at which it did return was potentially linked to fewer physical sensations impacting on an individual's recovery. In situations where confidence did not return, Narrative 2, ongoing ill-health, which was increasingly restrictive on life, prevented a return of confidence and appeared to contribute to a further reduction.

An increase in confidence levels appears to support an increase in the feeling of control individuals had over their condition. Those who reported a reduction in confidence perceived they had less control over their current state of health. The positive feedback loop and higher levels of confidence increased the individuals' belief in their ability and competence to tackle other tasks. This increased their self-efficacy (Sallis, et al., 1988). In those

reporting a loss of confidence their self-efficacy in respect of undertaking tasks was also reduced.

The different levels of confidence experienced by the four identified groups can be placed on a continuum (Figure 5-9). Confidence levels increased as you move from the left to the right of the continuum. As with the perception of health, positioning Narrative 1 on the continuum is undertaken in the knowledge that they have assessed their levels of confidence based on different criteria from the other groups. The positioning of this group below Narrative 3 is based on their perceived lack of control over events related to their heart attack.

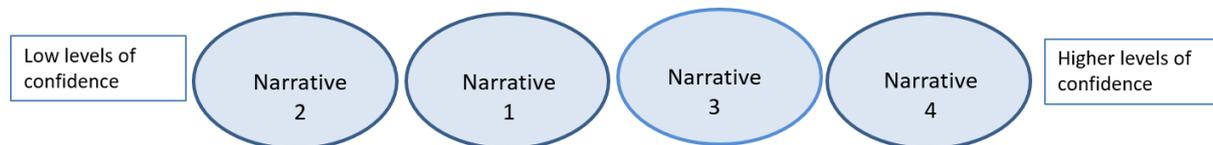


Figure 5-9 Continuum of levels of confidence

### 5.5.4 Living a more limited life

Two groups of participants, Narrative 2 and 3 were living lives in which one of the consequences of their heart attack was a life that was more limited than the life they had lived prior to their heart attack.

For the Narrative 2 participant, where physical sensations had enforced limitation of activity (Table 5-13), the consequences were an inability to participate in activities enjoyed prior to her heart attack.

Response to Physical Sensations			
Attributed to an external cause N=3	Enforcing limitation of daily life. N=1	Prompting an adaptation in daily life. N=3	Not consciously impacting on life. N=4

Table 5-13 Responses to physical sensations: highlighting Narrative 2

The major consequence for this group was the presence of angina, the major symptom of the process which leads to heart attacks. This was a symptom which had developed over time since the heart attack.

*...I don't suffer from angina or anything.*

*Barbara, Interview 1*

However, by the time of her second interview six months later this participant spoke of symptoms progressively limiting her activities.

*...I think that is to do with my heart because if I sit down it goes away. It is a form of sort of angina really.*

*Barbara, Interview 2*

This symptom forced the participant to cease participation in her current activities. This led to the curtailment of participation in activities to below the threshold at which symptoms would commence.

*...I still potter about in the garden and that but I limit myself, I know when I have done enough, you know. So I haven't given it up, you know, I love pottering about.*

*Barbara Interview 2*

As a way of self-managing her condition, activities are limited to prevent the symptoms occurring. This has enabled a degree of independence and control over her condition to be achieved. This continuation and progression of symptoms tells of a situation in which the acute event of the heart attack has become a more chronic condition. The ongoing symptoms and clinical trajectory for this Narrative 2 group is one of a progressive decline interspersed with episodes of acute illness.

For Narrative 3, in which health-related behaviour change centred on setting very specific goals (Table 5-14 **Error! Reference source not found.**), the consequences were of a life in which they had to pace themselves to complete activities.

Response to Physical Sensations			
Attributed to an external cause N=3	Enforcing limitation of daily life. N=1	Prompting an adaptation in daily life. N=3	Not consciously impacting on life. N=4

Table 5-14 Responses to physical sensations: highlighting response of Narrative 3

*...When I am doing the health walks I know that if I adjust my pace when I get breathless everything settles down and I can continue and when I go to the allotment instead of four hours it is now no more than 1 hour.*

*Isobel*

*...It (heart attack) has forced me to slow down but I still have a life. There is nothing I can't do, I may be doing it less or slower but I am still doing it all.*

*Helen*

*...since I have been doing the work on my house I haven't been to the gym because I thought well I am not going to overdo it, I will just sort of... But I have been going to the gym and I felt quite good really.*

*Frank*

This group of participants were limited in some of their activities by symptoms such as breathlessness. Since their heart attack they had identified that they could not achieve previous levels of effort when undertaking routine activities such as gardening or walking. However, by adjusting factors like the length of time they were physically active or the effort applied, they had found a way of continuing to participate in activities previously enjoyed. They told a positive story of continued participation in these activities.

All of these positive stories of continued participation were balanced by an acknowledgement of the limitations they now lived with.

*...I now get someone else to dig the allotment and I stick to the lighter work. I can't walk uphill and talk as I used to.*

*Isobel*

*...A major hobby was hill walking and I am doing little hills and building up but I cannot see myself getting to the top again. I still cannot walk as far or fast and stairs are very difficult.*

*Helen*

*...I can't work as hard as what I used to have done.*

*Frank*

All of the participants in Narrative 3 readily acknowledged that their heart attack had reduced the amount of physical activity they could undertake. Consequently, they had reset their expectations of what they believed they could achieve. One participant, who was further limited by a range of other long-term conditions, described it as a constant bargaining with herself of gains and compromises to live as full a life as possible. This group had been forced to reset their goals and were now pacing the way they lived their lives. In doing this they were able to tell of a life in which the compromises made were outshone by the continued participation in previous activities.

Only two groups of participants, 2 and 3, reported they were leading more limited lives following their heart attack. These limitations reflected the impact of physical sensations on their lives following their heart attack. These limitations added to the consequences of having experienced a heart attack for these individuals.

The attitudes of these two groups towards the consequences of the heart attack on their lives varied. Both groups of participants acknowledged their lives were more limited but for Narrative 3 there was an ability to tell of these consequences in a positive manner of what was achievable and to discuss how they were maintaining their health. However, for Narrative 2 the story

being recounted was one of a progressive reduction in what was achievable and a story of life being limited by ill-health.

The Narrative 4 participants, (Table 5-15) in whom physical sensations were not consciously impacting on their lives, did not as a result have any limitations to the lives they were leading after their heart attack.

Response to Physical Sensations			
Attributed to an external cause N=3	Enforcing limitation of daily life. N=1	Prompting an adaptation in daily life. N=3	Not consciously impacting on life. N=4

Table 5-15 Responses to physical sensations: highlighting response of Narrative 4.

*...I see myself out on the street running again; I see myself just feeling how I did this time last year.*

*George*

*...My next ski holiday is in the planning and I am gardening, cutting lawns and hedge cutting with no restriction.*

*James*

This fourth group had no thoughts about limiting their lives in any way. They either had returned to physically demanding activities or foresaw themselves doing so in the future.

The participants in Narrative 1, who attributed physical sensations to ageing, did not report any limitations to their lives as a consequence of their heart attacks. This attribution led this group to believe little could be done to influence how long they would live. Limitations were outside their control and would be accepted. As an explanation, as to why they had not felt limited in their daily lives or had to adapt the way they lived, all three of the participants

in this narrative group expressed doubts about their actually having had a heart attack.

*...I never considered myself to be a heart attack victim, you know, I didn't have the classic symptoms, I never have. I know I have never had pain since. I didn't have then, and I haven't had, so that doesn't bother me.*

*Andrew*

*...As far as I am concerned I feel fine, in a way I would say I haven't had a heart attack, obviously I have but the way I am feeling, No.*

*Charles*

*...– logically I didn't, but – I'm an optimist, and I convinced myself I don't think I really had a heart attack,*

*Edward*

This group expressed their doubts about their diagnosis as a reason for not needing to make any health-related behaviour change. This also provided a rationale as to why they attributed their physical sensations to a cause other than their heart attack. If they doubted their diagnosis they would not attribute any post-event symptoms to having had a heart attack. In being able to resume a life unburdened by physical sensations and in questioning their diagnosis, this group did not perceive a need for any health-related behaviour change.

For the participants in Narrative 1, the speedy return to all of their previous activities led them to consider that the heart attack had not actually occurred or been of minor importance. The questioning of their diagnosis was related to a difficulty in believing they could recover as quickly as they had if they had had a heart attack. In all three cases the response to their diagnosis was linked to their perceived good state of health after the event rather than a denial of having been ill.

The degree to which the participant groups considered their life to be limited could also be placed on a continuum (Figure 5-10) with Narrative 2

expressing the greatest level of limitation and Narrative 4 the least degree of limitation to their activities after their heart attack. In this instance, Narrative 1 have been placed further to the right than Narrative 3 as the latter are living with some limitations, unlike Narrative 1 who report no limitations on previous activity. They are to the left of Narrative 4 as this group identified an improved life with fewer limitations than prior to their heart attack.

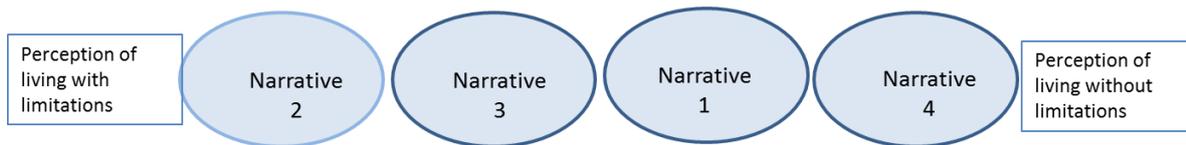


Figure 5-10 Continuum of limited life

### 5.5.5 Undertaking and reflecting on action to create a different narrative

This relationship between responding to physical sensations and undertaking health-related behaviour change is one of undertaking action, reflection on the effect of that action and planning subsequent actions. This was undertaken as individuals evaluated the level of control they have over the physical sensations they experienced following their heart attack (Figure 5-7). This process of action and reflection influences and is influenced by the participants' perception of the degree to which they are in a state of health or ill-health, how limited their life has become, and their perception of how much confidence they have regained. These three factors can all be regarded as a continuum with the four groups of participants sitting at different points on each continuum (Figure 5-11). However, these are not linear, exclusive perceptions but are all intertwined in the action and reflection feedback cycle.

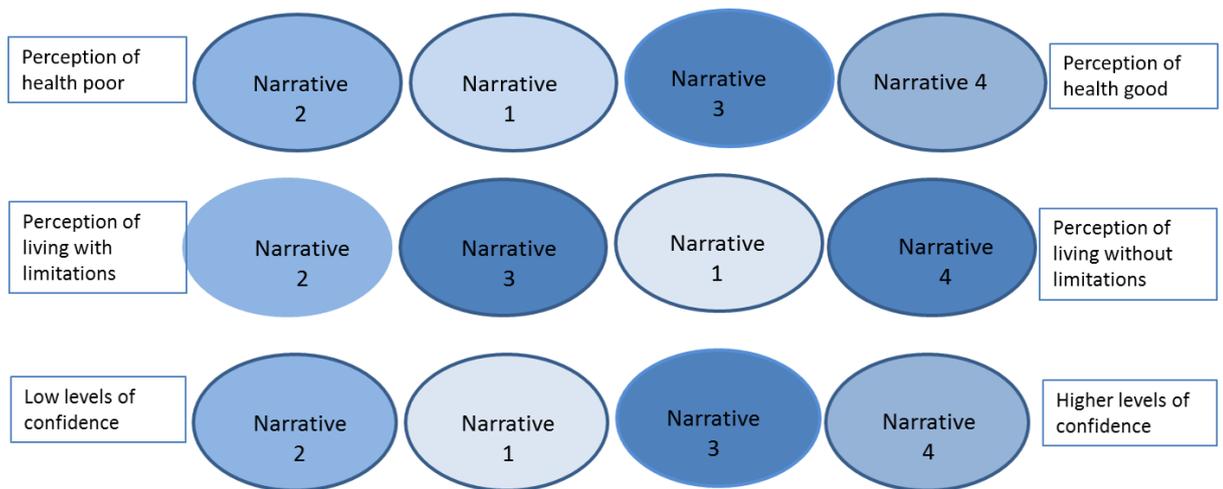


Figure 5-11 Positioning of narrative groups along continua of perceptions of health, confidence and living with limitations

The individuals in three of these groups, Narratives 2, 3 and 4, made changes to their health-related behaviour as a consequence of physical sensations following their heart attack. The impact of these changes on physical sensations allowed individuals to develop beliefs around the level of control they had over their health or ill-health, following their heart attack. The belief that they had control over their health, and life in general (Narrative 4), after their heart attack was increased when an individual regained their confidence in undertaking and increasing activities.

However, beliefs about being in control of their condition were reduced in those who experienced ongoing symptoms they could not control (Narrative 2) and this prevented a return of confidence. Individuals who experienced limitations to their lifestyle after their heart attack acknowledged that the consequences of the event were greater than for those whose life was not limited. These additional consequences were more limiting in the group whose confidence had not returned.

In considering the overall impact of this, Narratives 2 and 4 had consistent positioning at the lower and upper ends of the continua respectively as shown in Figure 5-12. In this figure, the three continua radiate out from a single starting point denoting the more negative end of the continua. Each

narrative group is positioned once within the grid to reflect their position on the continua in relation to each other.

The participant in Narrative 2 is positioned near the originating point. This reflects her story that her behaviour change was enforced by symptoms, she perceived her level of health to be poor, her self-confidence to be low and the limitations under which she lived were considerable. Conversely, the participants in Narrative 4 reported that they had chosen to undertake health-related behaviour change. The physical sensations they experienced were all positive outcomes of those changes and are positioned nearer the top right of the grid. As a result of this they were healthy, with no limitations on their lifestyle and possessing high levels of self-confidence.

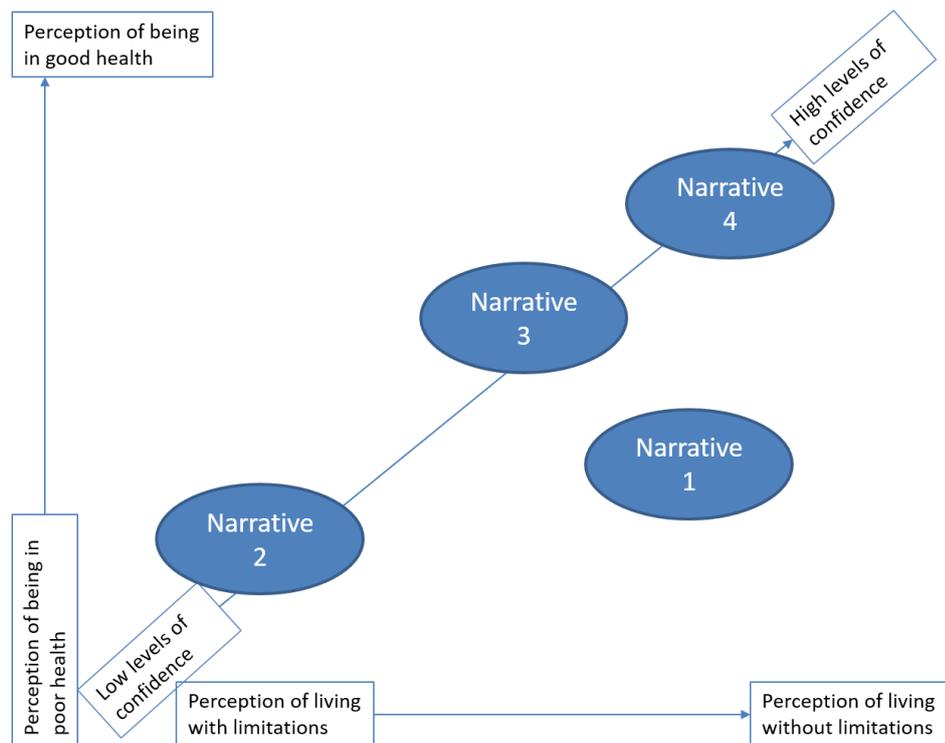


Figure 5-12 The impact on perceptions of undertaking and reflecting on action

The positioning of Narratives 1 and 3 was less clear but there were differences between the narratives of the groups. Those in Narrative 3 reported a higher perception of health than those in Narrative 1 potentially due to their believing they could control health through health-related

behaviour change. Those in Narrative 1 related their physical sensations to ageing. In this scenario declining health is considered inevitable and a situation over which there is no control. Levels of confidence were also greater for Narrative 3 and this related to the positive feedback this group received when undertaking health-related behaviour change. Narrative 1 had not perceived any change in their confidence levels. However, Narrative 1 reported fewer limitations in their lives when compared with Narrative 3 and so are positioned further to the right but lower than Narrative 3.

### **5.5.6 Creating a new knowledge base**

The participants all undertook and reflected on their actions (Section 5.5.1). These actions were influenced to varying degrees by their interaction with others. These others included family, friends, health care professionals and also non-human sources such as television, internet and written media.

#### 5.5.6.1 Developing a relationship with medical practitioners

The health care professionals with whom participants interacted were primarily doctors: either general practitioners or hospital consultants.

For those participants in Narrative 1, contact with health care professionals was perfunctory.

*...GP? he's not my best friend, actually, But I see anybody:  
But my doctor is – he's supposed to be excellent, but he's  
very abrupt.*

*Edward*

*...I can't remember the details of the conversation, he said  
'Goodbye, thank you very much, we won't be seeing you  
again'. What he meant was you are fine.*

*Andrew*

This group had limited contact with medical practitioners. They recalled little detail of the content of consultations they had attended. Contact with a medical practitioner was usually in response to a request for the participant to attend a routine appointment for a review of medication as opposed to the participant initiating the contact.

The participants in Narrative 1 all acknowledged they were taking medication.

*...I am taking such a concoction of pills, 11 a day and that is long term so I am thinking if I am taking those and watching my diet, I think it is going to go a long way towards preventing another one obviously or I wouldn't be on them otherwise and that reassures me quite a bit.*

*Andrew*

*...It doesn't bother me at all. I don't like swallowing tablets much, but they're very, very small tablets.*

*Edward*

*...if they say I got to take the tablets I'll take the tablets. The other ones I have been taking for nearly twenty years and they have done me no harm. As far as I am concerned they know what they are doing or they should know what they are doing.*

*Charles*

Compliance with medication regimes was viewed as a part of preventing further heart attacks. However, in describing the regime as a 'concoction' and continuing to take medications despite concerns with the regime, the participants told how they accepted rather than embraced this. There was no perception that these regimes might be adjustable or negotiable if they were discussed with medical practitioners.

There was a passive acceptance that they, and regular reviews by general practitioners, were now a necessary part of life. This passive acceptance

was a further indication of the external locus of control this group displayed in following the instructions of an individual whom they perceived had expertise and therefore authority. They were externalising the issue and ceding control to the health care professional.

The participant in Narrative 2, who reported ongoing symptoms, told how this necessitated more frequent contact with health care professionals.

*...Up the perindopril and there was some other change she (doctor) did...*

*Barbara*

*...He increased my beta-blocker because he said he thought that might help a bit with the function of my heart, he thought it was going a bit fast.*

*Barbara*

*...that's one thing that I have noticed also since I didn't feel so well, I am much more conscious of it (heart) fibrillating now, where I didn't always notice, and apparently I am doing it all the time so the cardiologist said.*

*Barbara*

This participant accessed health care professionals, in particular her general practitioner, more frequently than other participants. She told of a need to seek advice on a range of concerns including management of symptoms, regular blood tests, and medications to be titrated with subsequent attendances to re-assess their effectiveness. Her heart attack, initially perceived to be an isolated acute event, had progressed into a more chronic illness. This was associated with ongoing symptoms in which her normal pattern of living had become one in which interaction with health care professionals was increasingly frequent and potentially important.

Within the daily pattern of managing symptoms there were sudden changes in health status.

*...I am not as well as I was, but I don't know why I had this real spasm of real breathlessness, and he (GP) did some*

*blood tests BNP, and mine came back 1,000. And then after a week of furosemide he repeated the test and it was down to 100 which was normal, so he said it all pointed to it being completely that it was my heart that was causing it.*

*Barbara*

This sudden onset of symptoms required an emergency visit to her general practitioner both to relieve the symptoms and identify a cause. This participant only disclosed those symptoms which intruded acutely on her daily activities and which she perceived required a consultation with a health care professional to resolve.

However, this participant had spoken of ongoing symptoms such as angina placing increasing restrictions on her activity and disrupting her life (Section 5.5.1.1) which she did not discuss with their health care professional. The participant in Narrative 2 reported acute symptoms at the expense of more frequent symptoms as she dealt with the consequences her heart attack had on her daily life. This excluded the potential for gaining better control over the symptoms, such as angina, that she considered to be less acute.

The focus for the Narrative 2 participant was on differentiating between the different physical sensations experienced. Were they symptoms of illness, therefore requiring a consultation or were they the sensations which progressed more insidiously and were now considered a part of daily life to be managed independently.

This group made attempts to see a specific health care professional.

*...sometimes it's a job because Dr W gets booked up quite well, but I do stick with him because I don't know, we're on the same sort of wavelength,*

*Barbara*

Identifying a general practitioner in whom she had confidence was viewed as important. She would delay a consultation if there was limited availability of

her preferred health care professional. Her relationship with her general practitioner was one where she could discuss the current condition and together agree changes to the management of her symptoms and the degree of flexibility that could be tolerated in the medication regime. There was a perception of shared decision making. This sharing aimed to achieve a balance between the need to follow a best practice regime based on the evidence from the scientific domain and the individual's overall quality of life.

As with Narrative 2, the participants in Narrative 3 sought contact with the same general practitioner where possible.

*...I have sussed out which doctor has the most expertise in cardiac conditions and I and see them if I need anything.*  
Isobel

However, unlike Narrative 2 their contact was usually planned and they viewed contact with medical practitioners as a source of information.

*...I need time to prepare for consultations. The Echo result point is a point in case and I have another appointment to see the consultant and discuss the specific issues from the report.*

Helen

*...she (Consultant) sort of explained, you know, 'you are going on the right path, you're as fit as you can get.' I went on the treadmill and she said, you know, 'We're not going to be able to make your heart beat any quicker because of the drugs you are on'.*

Frank

This group reported regular but routine contact with medical practitioners and within those consultations gained further insight into their condition. Unlike the Narrative 2 participant, who saw medical practitioners at times of ill-health or in response to a change in her condition, this group attended for planned reviews which had occurred at times when they had all felt well. This feeling of being well allowed the consultation to focus on wider aspects of

their condition such as test outcomes rather than the narrower issues of trying to manage and alleviate symptoms which were the focus of consultations for Narrative 2. These contacts with doctors provided an opportunity for confirmation that as an individual they were managing their condition and supported their beliefs that they were able to retain control of their health.

Those in Narrative 4, as Narrative 1, reported little or no contact with medical practitioners. For Narrative 4 the contact was usually patient initiated for a specific issue for which they desired support and advice.

*...The doctor never contacted me, it all has to come from the patient now and I am okay.*

*James*

The principal reasons for this group contacting their medical practitioner were issues around medications.

*...I have got the ACE cough and it needs to be changed to another tablet. It (the cough) is not life changing but it is intrusive and there is alternative, so it is a quality of life issue.*

*Kenneth*

*...I am getting some indigestion but I am taking yellow capsules which are supposed to protect stomach and I don't know whether that is doing its job properly, whether I am taking a big enough one. But I think I am taking too high a blood pressure tablet when I stand up I am sometimes light headed. I think the statin is causing trouble because I get sweaty half of the night. It is not quite as bad now as when I first came out. I have got to go back to the clinic at some point so I was waiting to go back there and find out what they thought.*

*David*

As with the participants in Narrative 3, this group sought support from medical practitioners from the perspective of feeling relatively well. They had

specific concerns, all around the potential side effects of medication, which they would raise at the next routine appointment. However, there was no expressed need to see a health care professional with a perceived expertise in their cardiac conditions.

Alongside the problem to be discussed with their doctor, this group had identified a potential cause and solution for their concerns. This group, similar to Narrative 3, undertook an active role in managing their condition to reduce its impact and to improve the quality of their lives. This was in contrast to Narrative 2, who sought the support of health care professionals in response to a reduction in the quality of her life.

The relationships developed by all four groups with their medical practitioners impacted on the factors influencing their condition and perpetuated their status on the acting and reflecting on action grid (Figure 5-12). The Narrative 2 participant experienced a further erosion of her confidence as she was forced to seek the support of medical staff to support day-to-day living. In contrast, the confidence levels of those in Groups 3 and 4 were supported and potentially enhanced as their consultations focused on how to maintain their current health for the longer term. This in turn reinforced the perception of health and the impact of limitations for each of the groups. Interaction with medical practitioners reinforced the individual participants' developing beliefs around living with the consequences of a heart attack.

#### 5.5.6.1.1 Conflict with medical knowledge

There were instances where individuals expressed concern over their interactions with medical staff.

*...a doctor came and put another cannula in my arm and got me to sign a consent form for the stenting to take place..., you have to sign it, as I did when I had the angiogram, you sign a piece of paper but just as you sign it they say 'We have to let you know that you're having an angiogram or the stenting done and it can also cause a heart attack or*

*strokes', but I think you're sort of in that frame of mind that you want it all to happen, that you sign it, and it's not until after you have had it all done you think 'Actually I could have had another heart attack while I was laying there' although albeit they do reassure you to say it's quite rare.*

*Frank*

*...they asked me to go on a trial for (name of drug), I found that off-putting because they pounced on me the minute I got there, it was half past three, the theatre slot was four o'clock, I was trying to get out of my clothes and there were people appearing and they just said 'oh you would really fit into this trial' and you are reading it and thinking 'oh I should'. In the end I phoned my husband and we agreed to do it.*

*Isobel*

These participants described situations in which they felt pressurised to make decisions regarding their treatment. The providing of consent for a procedure and participating in a medical trial are situations in which the giving of consent is based on appropriate information being provided. There should be sufficient time to absorb the information prior to reaching an informed decision to proceed. Both these situations occurred during their time in hospital and the participants, both from Narrative 3, perceived the processes to be rushed and they found themselves in a situation in which it was difficult to refuse consent.

In describing how the consent form is presented to be signed, with information about the risks and benefits of the procedure being a side issue, the participants commented that the consent form appeared to be signed as a means of continuing with the treatment plan as decided by medical staff. In this situation, it was perceived to be difficult not to accept all the potential consequences and allow the procedure to be undertaken. Similarly, one participant felt pressured to agree to participate in a clinical trial, without having time to consider the potential consequences, to enable her procedure to go ahead.

Informed consent is intended to be a non-coercive process but there was a perception that it was difficult to refuse a procedure which medical staff were

putting forwards as being of benefit. Both of those participants became proactive in managing their situation following discharge. They sought out medical staff with whom they could communicate and who would allow them to actively participate in the management of their condition.

However, in the situation described, which occurred during their in-patient stay, they were not able to undertake this. This raises questions regarding the ability to obtain fully informed consent from patients in an acute or urgent situation. Responsibility must lie with health care professionals to ensure the situation in which the information is delivered meets the criteria for ensuring consent is fully informed. The moral and ethical issues raised by these situations will be discussed more fully in the next chapter.

Another participant challenged the treatment offered and declined invasive investigations:

*...They put on the medical thing 'refused invasive...' but I didn't actually refuse, I just said 'Oh I am not mad about medical procedures'; and he said 'Well that's all right.' And I spent another day or two until he said, 'You can go'... they talked about keeping me in until Monday if I'd have had the procedures but he said 'You might as well go home Saturday' so yeah, I came out Saturday.*

*Edward*

The declining of invasive investigations occurred because this participant was not willing to undergo coronary artery bypass surgery, one of the potential outcomes of the investigation. He preferred to live without knowing the extent of any coronary artery disease rather than live with the knowledge of having a disease for which he would not undergo the recommended treatment should it be discovered to be a potential outcome. This participant was in Narrative 1 and in declining to discover the extent of any disease he might have, he was enabled to continue to believe that the cause of his symptoms was related to an external cause such as ageing. If an invasive procedure identified coronary heart disease as the cause of his current predicament, his own beliefs would be challenged. This was a situation he

perhaps did not wish to find himself in. This rationale was in keeping with the external locus of control traits seen in this narrative group.

This was an approach whose rationale was not easily understood by medical staff. In the withholding of consent, the participant perceived that he was seen as deviant and, not then wishing further treatment, was advised he could go home. The use of the word 'refused' as opposed to a term such as 'declined' on his discharge letter was viewed by the participant as an example of the medical profession's reaction to having their authority challenged.

Although this participant's beliefs were potentially the main cause for them to decline further treatment, the opportunity for a full discussion between the participant and medical practitioner might have increased the latter's understanding of the participant perspective. This could have left the participant feeling more included in the decision-making process.

These difficult conversations all took place in the hospital setting and were very different from the interactions with medical staff which occurred after discharge. The biographical disruption identified as occurring during hospitalisation for an acute illness would limit participants' confidence and ability to actively participate in these situations (Section 5.4.1).

The participants described situations in which they felt powerless to question the care being offered by medical staff. Those who did challenge the treatment proposed by medical staff were perceived to be deviant in their behaviour. This places increased responsibility on medical staff in particular, but all health care professionals, to ensure conversations around issues such as consenting for procedures do take place in an environment where an informed discussion is possible. The environment should also be conducive to patients challenging the authority of medical staff without fear that their treatment will be adversely affected.

#### 5.5.6.1.2 Generating personal narrative knowledge

Those who experience a heart attack have the potential to acquire new knowledge about a wide range of factors relevant to their heart attack and medical staff were a source of that information:

*...I thought I'll have it done in the wrist again because I thought well all the veins will be stretched out and ready to take everything.*  
Frank

*...then I have had the pacemaker so that should guard me and I thought I was very well protected (from another heart attack).*  
Barbara

Having acquired information from medical staff, participants had to assimilate this into an understandable and supportive format. Participants' interpretation of the information became their personal narrative knowledge of their heart attack. However, this personal narrative often differed from the perspective of the medical narrative. Participants were unlikely to ask medical staff to clarify comments which might have helped them gain an increased understanding of their condition; instead they began to make sense of these concerns for themselves. The different perspectives are presented in Table 5-16.

These participants from Narrative 1 viewed their heart attacks as an isolated event.

*...this heart attack's been quite a small... blip, really. I'm not convinced it's a major thing. I've got on with my life.*  
Edward

*...Yeah, it (the heart attack) was kind of an isolated one-off, but the diabetes, I am living with it every day.*

Andrew

The experience of having a heart attack was perceived as a minor intrusion into their lives and one which would not impact greatly on their futures. One

participant provided greater insight into why this group may have considered their heart attack an isolated event.

*...as far as I can tell my main arteries were not blocked, they looked OK. So they are not blocked so I cannot see I am going to have a major heart attack.*

*Andrew*

This participant also spoke about his approach to managing his diabetes. This gave further insight into why a heart attack could be considered as an isolated event.

*...but because I don't feel ill and I don't feel that this diabetes is affecting me, I am not motivated to do anything about it because it doesn't make me feel ill. If I had some manifestation of the diabetes, you know, getting short of breath or arteries blocked, you know, feeling unwell or whatever, I might think well you ought to do something about this but I don't feel any of that.*

*Andrew*

This participant told about living with his diabetes every day. He then went on to tell how the lack of symptoms or any overt measurable signs that his diabetes was progressing reduced his motivation to actively manage his condition. His approach to managing health conditions was one in which some form of physical manifestation which can be attributed to the condition would need to be apparent before he would undertake any active management.

The lack of ongoing symptoms or physical sensations perceived to be attributable to a heart attack was a tacit confirmation that the heart attack had probably not happened or had been an isolated event. This belief that a lack of overt physical sensations or symptoms of disease were a sign of health support the theory that the participants in Narrative 1 displayed an external locus of control in relation to matters of health generally, not just their recent heart attack.

Participants in the other groups also interpreted the information in a way that made sense to them. Similarly, this did not always align with the interpretation that others, in particular health care professionals, would make.

*...Originally it was 8 point something (cholesterol level) and it was down to around 6. And I said 'oh that's good' and he (GP) said 'No it's not' and I said 'well it is for me' (Grim laugh).*  
David

*...which I thought I'll have it done in the wrist again because I thought well all the veins will be stretched out and ready to take everything.*

Frank

*...then I have had the pacemaker so that should guard me and I thought I was very well protected (from another heart attack).*  
Barbara

Having been given information by health care professionals, participants developed narratives which made personal sense. This interpretation at times seemed to contradict or at least be interpreted in a way that is not supported by the medical evidence (Table 5-16). The participants' interpretations of medical staff comments may not have been physiologically correct but they allowed the participants to resolve an internal concern. These enabled participants to rationalise events associated with their heart attack.

Participants were unable to clarify if these rationales were made at the time of the event or if they had reached them in the subsequent months. For those where the conversation covered similar areas in both first and second interviews, their recall and explanations given were very consistent. This would suggest that once an explanation which satisfied participants' questions was reached, it was retained. This interpretation then became part of the story of that individual's recovery from their heart attack.

There appear to be clear divisions in the types of information delivered by the different health care professionals. Participants recalled receiving information

on the causes and treatment of their heart attack from doctors. However, information on risk factor identification, health-related behaviour change and recovery came from cardiac rehabilitation specialist nurses and information on dietary matters from the cardiac rehabilitation specialist dietitian. Information was provided by cardiac rehabilitation staff both in hospital and at a cardiac rehabilitation programme following discharge.

Personal narrative interpretation	Medical narrative interpretation
<p><i>...as far as I can tell my main arteries were not blocked, they looked OK. So they are not blocked so I cannot see I am going to have a major heart attack.</i></p>	<p>Coronary heart disease is an ongoing process of plaque formation and subsequent narrowing of the coronary arteries that there is currently no known way of halting. A current lack of visible disease does not offer protection from disease developing in these vessels in the future.</p>
<p><i>...but because I don't feel ill and I don't feel that this diabetes is affecting me, I am not motivated to do anything about it because it doesn't make me feel ill. If I had some manifestation of the diabetes, you know, getting short of breath or arteries blocked, you know, feeling unwell or whatever, I might think well you ought to do something about this but I don't feel any of that.</i></p>	<p>The damage resultant from diabetes does not manifest itself until late in the disease trajectory. Shortness of breath is unlikely to be a manifestation of diabetes but due to nerve damage. It is a common manifestation of coronary heart disease in those with diabetes.</p>
<p><i>...Originally it was 8 point something (cholesterol level) and it was down to around 6. And I said 'oh that's good' and he (GP) said 'No it's not'.</i></p>	<p>The GP was working to an absolute target for cholesterol levels; however, current guidance supports a percentage reduction as a target for those who have high initial cholesterol levels.</p>
<p><i>...as far as I can tell my main arteries were not blocked they looked OK. The doctor said they looked pretty normal for a 65-year-old with diabetes, that is what he said to me. So they are not blocked so I cannot see I am gonna have a major heart attack because you would only have that if your arteries were really furred up I guess.</i></p>	<p>A medical perspective would understand that in those with diabetes major arteries are often clear but smaller vessels are significantly diseased increasing the risk of a further and multiple 'smaller' heart attacks. This has a greater cumulative risk of a life governed by chronic ill-health from multiple co-existing conditions.</p>
<p><i>...and he said that could be because you are diabetic a lot of the small capillaries and nerve endings could already be dead because I have had diabetes for 6 years now. I thought that's a good point so they may already be dead and that is why I didn't feel as much pain as maybe you would expect you would feel.</i></p>	<p>Diabetes does damage the peripheral nerve endings and reduces the likelihood of one experiencing severe chest pain. However, in coronary heart disease the severity of symptoms and in particular chest pain does not in any way correlate with the degree of coronary narrowing. The severity of pain is due to the subjective nature of how pain is experienced and managed.</p>
<p><i>...I thought I'll have it done in the wrist again because I thought, well all the veins will be stretched out and ready to take everything</i></p>	<p>The procedure is undertaken through an artery as opposed to a vein. Arterial walls have elastile properties but a previous procedure does not</p>

	necessarily make future procedures more straightforward and can lead to complications if there is scarring of tissue present.
<i>...then I have had the pacemaker so that should guard me and I thought I was very well protected (from another heart attack).</i>	The function of a pacemaker is to control the heart rate and rhythm. This device does not affect the process of plaque formation in the coronary arteries which cumulate in a heart attack.

Table 5-16 Comparison of medical and personal narrative understanding and interpretation.

### 5.5.6.2 Participating in a comprehensive cardiac rehabilitation programme<sup>32</sup>

The participants in Narratives 1 and 2 did not participate in cardiac rehabilitation. All of the participants in Narratives 3 and 4 had completed or were near to completion of a comprehensive cardiac rehabilitation programme by the end of the data collection period.

Once again for those in Narrative 1, there was no perceived need to change current approaches to living healthily.

*(Talking about attending cardiac rehabilitation) ...Well I'll see, I was always pretty health conscious about that sort of thing and I think I generally eat quite well.*

*Andrew*

This group varied in their approach to cardiac rehabilitation. One participant considered but never started to attend the comprehensive cardiac rehabilitation programme. The others in the Narrative 1 group had not deemed it necessary to attend a programme. This group did comply with medication regimes prescribed by medical staff but did not comply with a recommendation made by nursing and allied health professionals to attend a comprehensive cardiac rehabilitation programme, both of which are recommended by NICE guidance.

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<sup>32</sup> A comprehensive cardiac rehabilitation programme is composed of patient evaluation, risk factor reduction (e.g. lipid control, weight management), physical activity, and longitudinal care designed to reduce the effects of cardiovascular disease, and is an effective means of mitigating disease and disability.

The voluntary nature of attendance and the lack of endorsement of a comprehensive cardiac rehabilitation programme by medical staff have been cited as reasons for poor uptake of cardiac rehabilitation following a heart attack. This, compounded by the external locus of control present in this group, suggests there are multiple factors in the decision to attend cardiac rehabilitation or not (Cooper, et al., 1999; Evenson and Fleury, 2000).

However, the Narrative 2 participant was unable to attend a comprehensive cardiac rehabilitation programme.

*...And she (daughter) did try to persuade me to go to the aftercare classes (cardiac rehabilitation) but I didn't because I wasn't driving.*

*Barbara*

The loss of confidence, which prevented a return to driving, associated with her heart attack was the reason given for not attending cardiac rehabilitation. The level of ill-health revealed by this group is also recognised as a reason for individuals not attending a cardiac rehabilitation programme. An individual has to be considered to be in a stable condition prior to commencing cardiac rehabilitation (ACPICR 2015).

The potential benefits of attending a comprehensive cardiac rehabilitation programme include the supporting of individuals to achieve good symptom management. In this situation, the cardiac rehabilitation programme may have been able to support symptom control but again multiple factors contribute to the non-attendance at a comprehensive cardiac rehabilitation programme.

All those attending the comprehensive cardiac rehabilitation programme had found the programme to be supportive during their recovery

*...But I have been going to these rehabilitation classes, I have been attending those which I have found really useful, incredibly so, so yeah, I am sort of making some progress there and I am much more understanding of what I have got, why I have got it, what I can do, kind of what is realistic to do, what... and how it's... I haven't got all the pictures of the*

*puzzle yet but I am kind of fairly confident that the outlook is going to be favourable.*

*George*

*...Initially I did not really want to go to cardiac rehab but now I don't not want to go so I will go to the sports centre on the way to work to build it into my day and attend classes a couple of times a week.*

*Kenneth*

Participants in Narratives 3 and 4, all attended the comprehensive cardiac rehabilitation programme. Those in these groups believed they had control over some elements of their condition. The comprehensive cardiac rehabilitation programme provided an environment where they were encouraged to take control of those elements such as increasing the amount of activity they undertook and changes to diet. There was an incremental process of change during the comprehensive cardiac rehabilitation programme. In this time the individual participants continued to make sense of the events and consequences of their heart attack which led to the changes they undertook.

*...Attending the cardiac rehabilitation, I am not quite finished. It is excellent exercise which is not too strenuous but then it is ramped up to make it so with the staff there during exercise to help with confidence.*

*James*

*...It was useful to talk in a group with different questions being asked, you found out quite a lot. Useful to talk about things that I found confusing such as how to judge safe exercise levels in the context of my other conditions.*

*Helen*

*...Started cardiac rehab 2 weeks after the heart attack before I went back to work. Started with the education then the exercises it was useful. I was cautious undertaking the activity but the structured exercise helped strengthen my knee and my growing confidence. I was working physically harder over the time pushing the boundaries to return to full-*

*time work.*

*Kenneth*

The support provided by both health care professionals and other patients attending the comprehensive cardiac rehabilitation programme contributed to the benefits participants believed were provided by their involvement with the programme. Specifically valued was the support provided to aid individuals to increase the intensity of physical activity they could safely undertake.

The belief that intensive physical activity will induce a heart attack is commonly held, but is not supported by evidence (Thompson et al. 2007). This improved confidence was then applied to physical exertion in other contexts such as returning to work. This further increased the amount of control these groups believed they had over their condition.

This set up a positive cycle of increasing confidence and self-belief for Narrative 3 and 4 participants which was not present in Narrative 2. Narratives 3 and 4 were also more likely to be receptive to the message of health professionals promoting engagement in health-promoting behaviours if they themselves had experienced these benefits. This perpetuated the positive cycle of engagement with health-related behaviour change.

#### 5.5.6.3 Accessing patient-focused literature as a source of information

Participants had all been issued with a cardiac rehabilitation information booklet, produced by the local cardiac rehabilitation service.

*...the big booklet there's a load of it. Well yeah, I did read it all (of course I would), I read it there but I haven't really referred to it but my daughter never stops.*

*Edward*

*...when I came out they gave me a booklet informing me of everything I needed to do and what I must not do and how you know how to gradate myself for exercise. I have followed that very carefully because obviously I am doing my best to get back to what I was before. I am very anxious to do and I*

*have found this extremely useful even as far as how many times to go upstairs and things like that and what not to do.*

*Barbara*

*...In general took everything slowly and gradually gave it all a tick. All achievements noted and referred to red book.*

*Isobel*

*...I am more of a person that would like read the information that I have been given by a person that actually is an expert in that field and I would rather read that and take that in and then talk to them.*

*Frank*

The information provided in the cardiac rehabilitation service booklet was useful to all participants and their families. It served as a practical guide to resuming previous activities. All participants reported having used it either directly or indirectly through relatives. This was the only written information participants reported using in the first few weeks following discharge.

The information provided in the booklet was accorded a high level of trustworthiness and authority as it had been written by health care professionals who became known to the participants during their in-patient episode or the cardiac rehabilitation programme. Some participants also accessed other patient-focused literature, such as that provided by charities or patient groups, such as the British Heart Foundation, later in their recovery.

The only group who reported regularly accessing health-related information was Narrative 3.

*...I read the (names newspaper) and follow up some bits and the BHF newsletter provides a good interesting read.*

*Isobel*

*...I do read the Heart magazine (BHF Magazine) but that's about all. If I saw something sitting in say a doctor's surgery*

*and it had hypertrophic cardiomyopathy, I might pick it up and read it.*

*Frank<sup>33</sup>*

*...The internet does not give me control over my condition, but does give me an element of knowing what I am talking about in a medical consultation and I can ask more relevant questions.*

*Helen*

The source of the health-related information varied but this was the only group that sought information on a regular basis. They had all attended a cardiac rehabilitation programme and all those who had received the BHF newsletter at the cardiac rehabilitation programme had subsequently taken out a personal subscription. Participants would browse this type of literature and focus in on sections they considered personally relevant.

In actively seeking out information which improved their understanding, this group sought to retain control of their condition through increased knowledge. Participants then used this knowledge to prepare the questions they wanted to ask during consultations with medical practitioners. This enabled them to retain a degree of control over the management and direction of the conversation during medical consultations. In accessing patient-focused information, participants viewed the signposting to a specific source such as the British Heart Foundation by health care professionals to be an endorsement of the trustworthiness of the information (Wathen and Burkell, 2002).

#### 5.5.6.4 The media as a source of information

Traditional media such as television, newspapers and magazines were a source of information when accessing health-related information. None of the

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<sup>33</sup> Two months after his heart attack Frank was diagnosed with hypertrophic cardiomyopathy, a condition in which the heart muscle thickens. This led him to seek out information.

participants could identify a specific source for their knowledge, reporting it as being part of common knowledge.

*...And general knowledge; stuff I have seen in magazines or whatever, it's nothing I have looked for, just stuff I have seen.*

*Andrew*

It was 'out there' according to Charles; Barbara described it as 'common sense'.

This common-sense knowledge<sup>34</sup> was known prior to their heart attack. Participants absorbed this information in a passive manner as they browsed through reading materials rather than actively seeking it. Across the participants there were differing views on the usefulness of the same potential sources of health information.

*...I read the health pages in the (names newspaper) and follow up some of the bits I fancy.*

*Isobel*

*...Not a great reader of (names same newspaper) health columns. James*

The value placed on the information lay in the credibility that the individual participants attributed to the newspaper rather than the authors of specific health items within the newspaper. This diversity of opinions and value was also seen when participants responded to questions regarding medical or health-related programmes on the television.

*...I find them (medical documentaries) very educational, very entertaining and the human body is absolutely fascinating anyway, as a machine I think it's just kind of, you know, the best.*

*George*

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<sup>34</sup> Common-sense knowledge is the collection of facts and information that an ordinary person is expected to know

*...if I catch medical parts on the daytime television then I might watch but if it becomes frightening I will switch over.*

*Kenneth*

*...I knew what an ECG was and because of television programmes i.e. Casualty and things like that which we tend to watch.*

*Frank*

This was the range of responses to a general question about television. The responses reflected the television viewing preferences of the individuals rather than the perceived usefulness and relevance of the information. Participants acknowledged they gained information from television dramas. The knowledge gained in this situation influenced participants' actions when considering the cause for their symptoms and has been discussed in Section 5.4.2.5.

The range of traditional media such as newspaper and television accessed by participants was heterogeneous, and was a result of long-held habits and preferences. There may have been broad cultural and social reasons involved in their selection but the newspapers read or types of television programmes viewed had not changed as a consequence of their heart attack.

Only one participant expressly articulated concerns with media-based information:

*... I am wary of their presentation (health-related issues) in television news, and newspapers I want to check them first.*

*Helen*

This participant was a very competent user of the internet who had previously undertaken academic research online. She also had other co-existing conditions for which she had thoroughly researched and sifted all of the information she felt was relevant to those medical conditions.

These examples illustrate how participants' gathering of information from the media was often a passive activity. Health information was absorbed in daily activities such as reading the newspaper. Watching television was a social activity rather than an active search in the traditional media for specific information.

Participants did not consider television and newspapers an important source of health-related information following their heart attack. Information from these sources was not accorded the same level of trustworthiness as those sources provided by health care professionals.

#### 5.5.6.5 The internet as a source of information

Once they had returned home two participants reported accessing the internet for a specific health-related reason.

*...I had a lot of trouble with the DVL, COD/DVLA or whatever it is, I went down the list and they have got so many heart... the cardiac, heart, hypertension and all that down, and I picked the one with the least banning (of driving), which was heart attack.*

*Edward*

*...Yes I did have a look (on the internet) at stents to find out what they did and that. It wasn't particularly useful. It didn't tell me the nuts and bolts which is what I was looking for. But it gave me enough information.*

*David*

They described clear search aims and both participants reported only opening one site and accepting the information provided, however limited it may have been. All participants had access to the internet and used it for shopping, booking holidays and playing card games such as Solitaire prior to their heart attack.

Three participants had used an internet search engine prior to their own heart attack to increase their understanding of health issues being experienced by family members.

*...used the internet for a bit about (husband's) knee op but only after it was all over.*

*Isobel*

*...Well I went online and looked it up the prognosis (brother's) wasn't good and five years was about the lifespan apparently.*

*Andrew*

*...My wife was taking some (statins) at the time and she was having problems with them so I looked up on the web and found out what all the side effects were and decided against it.*

*David*

However, no one had accessed an internet search engine to explore anything related to their own health following their heart attack.

*...Sometimes but that is a bit dangerous (using internet for info). You could end up thinking 'Oh I have got that, I've got that' and I don't like to go there. So I haven't been on the internet since I came home looking at heart disease. I know enough about it I think.*

*Andrew*

*...I tend not to because but I just feel that sometimes too much information that you gather yourself can be more damaging than... I am more of a person that would like read the information that I have been given by a person that actually is an expert in that field. Frank*

*...No, I haven't really, no, because I haven't felt the need to. I feel like I'm fairly OK with what the programme (cardiac rehabilitation programme). I didn't want to frighten myself, I will wait and see.*

*George*

There was minimal use made of the internet as a source of information in the early stages of recovery. There was a general awareness of the range of information on the internet and awareness that credibility was an issue. Participants at this stage wanted reliable information and they all felt this came from health care professionals.

The age range of the participants in this study may have influenced their use of the internet. This is not an information source they have 'grown up' with and as such is not their first source of information. This is a situation which may change for those who seek information related to a heart attack in the future.

Only one participant reported making regular use of the internet for health-related issues.

*...Use internet for my multiple conditions to research specific elements and look at potential studies to be involved in.*  
*Helen*

Those who did access the internet reported using it for specific information. They were looking to improve their knowledge and sense of control over a specific aspect of their condition rather than surfing the web for health-related information. The variable accuracy of websites was the reason most commonly given for not using the internet more widely when seeking information on health-related matters.

One participant was very specific in the terms she used when searching online for information and was the most frequent user of general search engines. This participant had made use of the internet for the research element of a distance learning degree. She reported this prior use gave her the confidence to assess the reliability of the information she was reading.

#### 5.5.6.6 Interacting with family

During the period of hospitalisation family members undertook the role of visitor to the situation:

*...It was nice to have children visiting from all over and everyone fussing around.*

*Isobel*

*...Wife and children were concerned when I was in hospital and for 3 days we weren't sure what was going on.*

*James*

During their time in hospital the participants had a disjointed relationship with their family as access to them was restricted to a few hours in the day. Participants reported that conversation remained very general during these periods. Participants hid their innermost fears and thoughts from health care professionals and relatives (Section 5.4.3.2); this may have been the driving force in keeping conversation at a general level.

Following discharge, the role of family members, both those living in the house with participants and close relatives living nearby, in providing information and support became more prominent:

*...Because I play bowls and I was told not to and I was going to play a game last night with my grandson because he plays bowls as well but he persuaded me not to. All telling me not to do it; please don't do it but so they persuaded me in the end. Grandson said I'd rather have you alive grandad than dead.*

*Charles*

*...Well yeah, I did read it all, (written literature on recovering from a heart attack) I read it there but I haven't really referred to it but my daughter never stops, she never stops, she says 'Have you done this, have you done that?' so I don't need to read it much more.*

*Edward*

*...B...(Husband) was overly conscious of looking after me and would say 'don't, sit, stay - stay like ...' like Barbara Woodhouse. I found that overpowering but knew it meant well and so I bit my tongue*

*Isobel*

The input from family members was viewed as supportive but it was also perceived as restrictive. This support was derived from relatives' interpretation of medical advice regarding recovery. This was frequently related to restricting participation in physical activity. Family members did not provide new information but rather served as a reminder or reinforcement of knowledge provided by health care professionals.

Participants found this type of support challenging. They felt well enough to undertake the activity but relatives were concerned that they would become overtired or potentially have another heart attack. This led to an internal conflict for participants as they tried to balance the concerns of loved ones against their own desire to resume activities previously undertaken.

The response of family members appeared to be universal. There were no identifiable differences in the response of family members across the four groups of participants. There was a difference in the ways in which participants reacted to this support. Those in Narratives 1, 3 and 4, who had returned to previous activities, all perceived this support to be well-meaning. The Narrative 2 participant, who was struggling with recovery, viewed the support which was offered differently.

#### 5.5.6.6.1 Feeling less needed

One participant perceived that she was not as useful to her family as she had been prior to her heart attack.

*...I used to be able to nip in the car and go and do... and I used to do lots of bits of shopping. But now my daughter usually rings me up from work and says 'Is there anything we need?' and she'll pop in because there's a supermarket*

*where she works so she pops in, and does any bits that we need or she does it on the internet and gets that delivered.*

*Barbara*

*...And she doesn't need me now like she did before with Natasha because she gets the bus to school.*

*Barbara*

This was the single participant in Narrative 2 who was now living with a chronic heart condition. She told of the ways in which she was no longer needed by explaining how circumstances had changed. She no longer undertook the food shopping for the family explaining it was more convenient to do it on the internet and her grand-daughter had moved school which provided transport. The consequences of the heart attack for the Narrative 2 participant were a loss of their previous role and perception of being of less value to the family.

At the time of her heart attack, and first interview, this participant had expressed concerns about the disruption the event might cause.

*...I was upset, although all I could think through my mind was what it was going to stop me doing. To be honest that is all I could think about was the disruption it was going to make to my life and to the help people needed.*

*Barbara*

Her fears had come to fruition in that she was no longer undertaking previously useful and valued activities. She gave a rationale for these changes that was not necessarily linked to her heart attack. This participant did not consider that these changes to her home-maker and carer roles may have been triggered by her inability to resume driving after her heart attack. She rationalised that the changes to her role within the family had been made for convenience rather than being forced on the family as a result of her changed circumstances.

In explaining the changes in this way her story was enabling her to share some of the responsibility for change on the external situation rather than her own ill-health and loss of confidence after the heart attack. This sharing of responsibility for no longer being able to meet previous social obligations enables a greater measure of self to be retained (Charmaz ,1983).

One other participant, from Narrative 3, raised a concern during his first interview that he might become a burden:

*...you do actually think 'oh am I going to be a burden?' Are people going to be sort of fed up with the fact that you're sitting about for a couple of months and all this sort of thing because it's something I have never done.*

*Frank, Interview 1*

This was a group of participants who had returned to previous activities with some limitations; however, by the time of the second interview this was no longer a concern:

*...yeah, I don't actually feel like a burden, no I don't. I think that was just, you know, when I first come home I just thought Christ, is this how it's going to be? you know*  
*Frank, Interview 2*

For this participant an ability to return to activities, even within limitations, had enabled him to feel he was contributing and useful to the family unit. The fear of becoming a burden or feeling less needed had not been realised, unlike the Narrative 2 participant for whom those initial concerns had become real.

#### 5.5.6.7 Interacting with friends

Those attending cardiac rehabilitation did so to aid their recovery from a cardiac event. Discussing elements of recovery in a group situation provided an opportunity for conversation and questions not present in everyday conversation with friends.

*...Nobody mentions anything, we don't talk about it.*

*Andrew*

*...I have friends all telling me take care and not do too much.*

*David*

*...it hasn't changed their (family and friends) lives at all and they have not tried to change mine.*

*James*

*...Maybe if someone was talking to me about the heart attack that they had, I'd probably say 'Oh yeah, that's terrible, I am ever so sorry about that,' but really wouldn't be that interested in the end results of it all as long as they're OK.*

*Frank*

Conversation with friends was very generic and limited to nonspecific comments about 'taking care'. Friends were not perceived as sources of support or information in managing their condition. The lack of shared experience was a contributing factor in the limited discussion about their heart attack. Interactions with friends potentially provided an opportunity to forget about their heart attack and its consequences.

#### 5.5.6.7.1 Experiencing social isolation

The Narrative 2 participant who had spoken of feeling less needed by her family also described how she felt more socially isolated since her heart attack:

*...but I have got friends that I used to go and visit and she said to me 'Well just let me know and I will come and pick you up' but that is one thing I hate, you know, having to ask people.*

*Barbara*

This participant had become socially isolated as a consequence of the independence she lost through not driving. This was compounded by a belief regarding what was an appropriate use of resources and a difficulty in acknowledging a dependence on others to meet her social needs.

*...and I wouldn't dream of like going and getting my nails done and that, I wouldn't dream of asking the volunteer car people to do that.*

*Barbara*

There is a legal requirement to stop driving for a period after a heart attack but at the end of this period she had been unable to resume driving. The inability to drive prevented her attendance at the cardiac rehabilitation programme and restricted her resumption of social activities. She sought advice from her family regarding whether she would be able to drive again.

*...My son, who I thought would say something like 'Oh yeah, about time', said 'I don't blame you one little bit with some of the idiots that are on the roads these days' so everybody thought that was quite a good idea.*

*Barbara*

*...after not driving for four weeks, my daughter said 'Well it's sitting on the drive, you know, you might as well get rid of it' so that's what I did.*

*Barbara*

The comments of family members were perceived by the participant to indicate she should not return to driving. Given the low level of confidence this participant had in being able to resume previous activities, the decision was made not to resume driving. These potentially discrediting comments were perceived by the participant to contribute to a shared decision between

her and her family. This enabled the participant to apportion some of the resultant social isolation to a shared rather than individual decision not to resume activities.

Support from family and cardiac rehabilitation health care professionals enables individuals to regain their confidence and return to their previous activities (Dunbar, et al., 2008). However, if that support becomes demeaning or discrediting then rebuilding confidence and a positive self-image can become problematic (Charmaz, 2006b). None of the other participants identified any concerns with social isolation or of feeling less needed after their heart attack and the perception of family encouragement to give up activities may have contributed to this.

#### 5.5.6.8 Creating a new knowledge base through interaction

In interacting with others, participants described how they interacted with both human and other sources. In considering media interaction participants reported they did not change the newspapers they read or television programmes they watched as a result of their heart attack. They continued with their previous heterogeneous patterns which were socially and culturally based.

Those participants who demonstrated an internal locus of control and believed they had a degree of control over their condition: Narratives 3 and 4 did access literature related to their heart condition. This tended to be material suggested by health care professionals in either printed form or online. This information was then used to inform consultations with health care professionals, in particular medical practitioners.

Following a heart attack all participants had increased their interaction with health care professionals. They sought the advice of medical practitioners for guidance on medication regimes and the cardiac rehabilitation professionals for advice on lifestyle issues such as undertaking physical activities and adapting their diet.

### 5.5.7 Summary

Following disruption to their narrative identity, individuals have to make sense of what has happened to them and rebuild their narrative identity incorporating the impact their heart attack has made on their lives. They do this through a cycle of action, reflection on that action which is then informed by interaction with other people and sources of information. This process is illustrated in Figure 5-13.



Figure 5-13 Overview of a Theory of Restoring Narrative Identity after a Heart Attack

The physical sensations experienced by an individual are the principal factor individuals monitor when trying to make sense of their recovery from a heart attack. These physical sensations drive health-related behaviour change.

The physical sensations experienced can range from symptoms such as difficulty breathing, which enforce behaviour change, to signs which result from choosing to implement a behaviour change such as increased fitness. Maintenance or further adaptation of those behaviour changes is influenced by the responding change in the physical sensations in an ongoing cycle of action and reflection; within this cycle three responses, Narratives 2, 3 and 4, were identified.

The cycle of action and reflection provides feedback to individuals on their recovery from their heart attack. This feedback is expressed in terms of levels of confidence, perception of health and how limited life is following their heart attack. When these terms were expressed as continua, a

relationship between the reflective cycle responses and position on the continua is seen in Figure 5-14.

The greater the choice individuals perceive they have in selecting behaviour change the closer to the positive end of the continua they were positioned and the greater their belief they had made a good recovery from their heart attack. The cycle of acting and reflecting on change is further informed by interaction with other sources. The position on the continua determined whether this interaction was a pro-active or reactive action. The closer to the positive end of the continua the more pro-active their interaction with these sources.

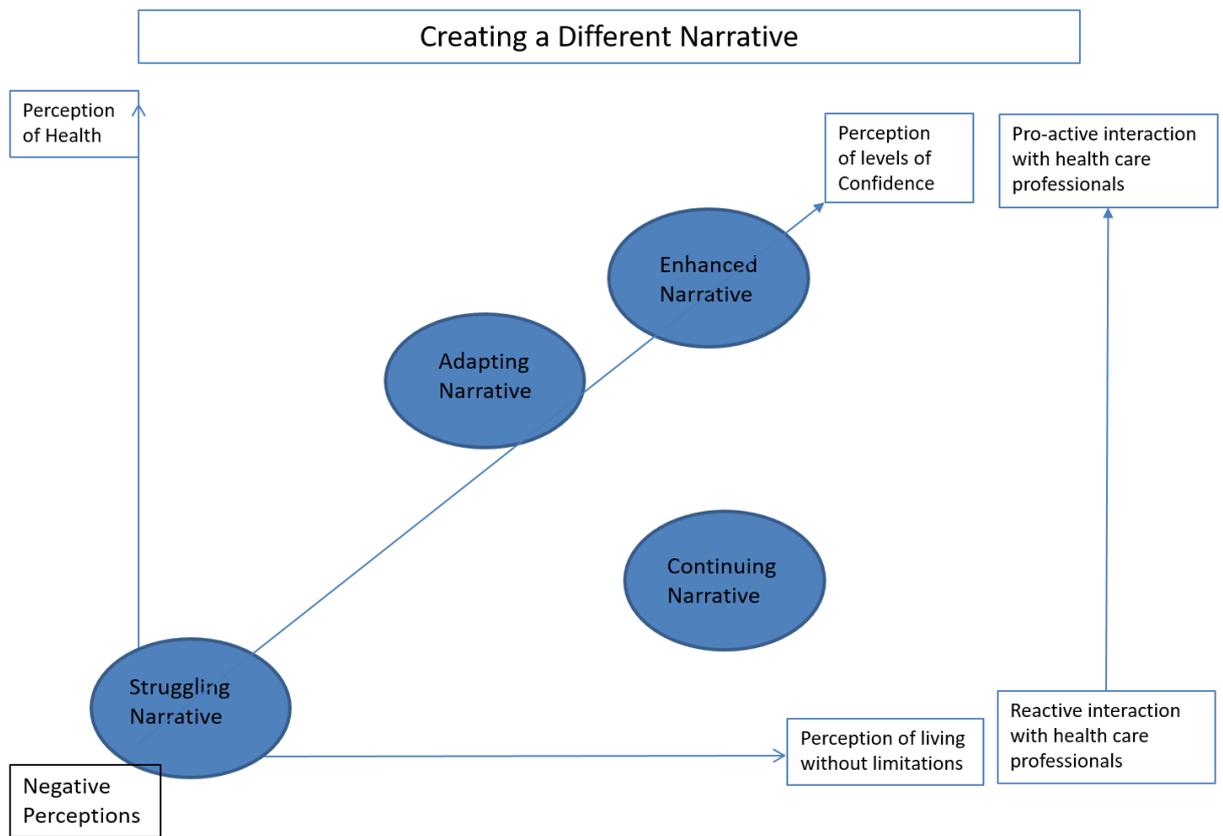


Figure 5-14 Creating a different narrative

A fourth type of response, Narrative 1, was seen in those who did not believe they had experienced a heart attack. This group attributed their physical sensations to a cause such as ageing and as such did not believe any

changes in their health-related behaviour were necessary or useful in changing these manifestations. This response was associated with individuals who had an external locus of control whereas those in the other three groups exhibited behaviour traits supportive of an internal locus of control.

## 5.6 Restored narrative identity

The four narratives which emerged from the data told of the ways in which participants had adapted their lives following their heart attack and restored their narrative identity (Figure 5-15).

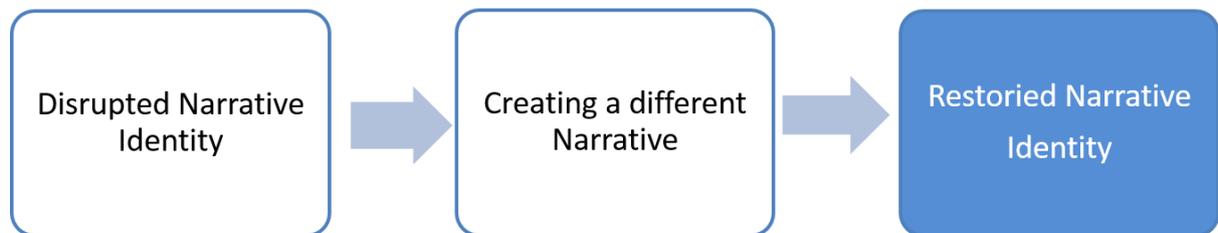


Figure 5-15 Conceptual trajectory of biographical restorying after a heart attack.

The narratives described the ways in which the physical sensations experienced by the individuals influenced their health-related behaviours and impacted on the lives they were now leading. The four narratives will now be presented.

### 5.6.1 A continuing self

The **narrative for the first group was one of a life which had continued uninterrupted** since their discharge from hospital. They did not identify themselves as individuals who had experienced a heart attack as their experience of recovery did not match their perception and beliefs about what recovery from a heart attack should look and feel like. The ease with which they perceived they had returned to previous activities supported this rationale. As a group, they reported they had returned to a good state of

health with no consequences resulting from their diagnosis. Unlike all other participant groups, they did not report any loss of confidence in their ability to return to a full and active life following their heart attack.

Any physical sensations experienced by this group were attributed to an external cause such as ageing rather than a specific consequence of their heart attack. These are traits associated with those who have an external locus of control. The outcome of their attribution of potential symptoms to a cause outside their individual control and doubt over the diagnosis was that none of the group undertook health-related behaviour change. They did not attend a cardiac rehabilitation programme which would have supported any behaviour change they may have considered undertaking. This group did adhere to medication regimes but this was perceived as an external factor as it was ordered by an external agent, their medical practitioner. Following a medication regime placed little or no requirement on the individual to acknowledge or change any aspect of their behaviour.

### **5.6.2 A struggling self**

The overall story of **Narrative group 2 was one of progression of their heart condition from an acute event into a chronic condition.** This was a situation in which life was increasingly centred upon managing the consequences of their heart attack. This group lived a day-to-day existence unable to make long-term plans as they were not confident their level of health would enable them to fulfil them. They reported ongoing symptoms of ill-health which impacted on their lives forcing them to reduce their involvement in everyday daily activities.

Health-related behaviour change for this group was in response to symptoms. Change was aimed at reducing their feelings of ill-health rather than increasing their feelings of well-being or good health. This cycle of symptoms and enforced behaviour change led to an increasingly limited life, loss of confidence and social isolation.

This group told of a life over which they had little control. Change was perceived to be the result of the decisions of family and health care

professionals rather than themselves. A modicum of control is regained through the non-disclosure of information to family and health care professionals, but this frequently leads to further consequences for the individual.

### **5.6.3 An adapting self**

This group, Narrative group 3 told of a **life in which adaptations had been made following their heart attack**. This group adapted and paced their activities to prevent the physical sensations, which they attributed to their heart attack, intruding into and limiting their lives. Being able to maintain control enabled this group to consider themselves to be in good health.

They acknowledged the chronic nature of their condition and were aware of the temporality of this perception. However, all envisioned maintaining their current level of health for the foreseeable future. Undertaking health-related behaviour change for this group was focused on maintaining the level of health they had achieved.

Pacing of their activities and living within the limitations of their condition was a key part of retaining that perception of health. There was a continual monitoring of their condition and small signs of maintained or improving health supported a growth in the confidence of this group. There was a belief, associated with having an internal locus of control, that control of their situation rested within their power.

This group were active managers of their condition. They attended cardiac rehabilitation. They sought out information to increase their knowledge which they used in their interaction with health care professionals. They valued medical practitioners whom they perceived to have an interest in cardiac conditions. This is a group who are currently achieving effective self-management of their long-term health.

### **5.6.4 An enhanced self**

This was the story of Narrative group 4 who described their **lives and health as being enhanced following their heart attack**. Physical sensations

associated with their heart attack had been short lived. They had been able to return to previous activities within a few weeks of discharge from hospital. This had supported a return of their confidence and a belief that they could return to a good level of health after a heart attack.

Undertaking health-related behaviour change from a position of having an internal locus of control ensured this group believed they had the ability to change health behaviours linked to diet and exercise for the better. Receiving positive signs of success from these changes supported maintenance of the change. This group were not monitoring progress and change with the same detail as those who were struggling or adapting their daily life.

This group perceived their heart attack as an acute event. They expressed no concerns around their health in the near future but they did acknowledge that health-related behaviour change was taken to reduce the risk of future events.

## **5.7 Summary of the substantive theory of biographical restorying following a heart attack**

The theory of biographical restorying after a heart attack proposes that people rebuild their lives in different ways after a heart attack. This study has identified four narrative types which portray how individuals live either a continuing, struggling adapting or enhanced life after their heart attack and is summarised in Figure 5.16.

	<b>Narrative Typology</b>	<b>Associated physical sensations</b>	<b>Behaviour change undertaken</b>	<b>Interaction with health care professionals</b>
<b>Antecedents</b> Previous experience of heart attack. Prior knowledge about heart attacks.	<b>Continuing narrative</b>	Nil attributed to heart attack	Minimal adaptation	Reactive contact for routine monitoring
	<b>Struggling narrative</b>	Restricting daily activities	Enforced change in response to ill-health	Frequent contact with preferred health care professionals.
	<b>Adapting narrative</b>	Absence is contingent on controlling levels of activity.	Maintenance of behaviour limiting intrusion of negative physical sensations	Proactive contact with preferred health professionals to support self management
	<b>Enhanced narrative</b>	No intrusion on increasing levels of activity.	Continuation of positive health related behaviour change	Proactive contact to support self-management
<b>Biographical Restorying following a heart attack.</b>				

Figure 5-16 The theory of biographical restorying following a heart attack

The theory proposes that the biographical restorying of those who experience a heart attack is founded on the physical sensations they experience (Section 5.5.1.1.). These physical sensations lead individuals to change their health-related behaviours (Section 5.5.1.2), and influence the interaction they have with health care professionals (Section 5.5.6.1).

An individual's previous experience of having a heart attack and their prior lay understanding of what a heart attack should feel like influenced the narrative they told (Section 5.6). The continuing narrative group did not believe they had been ill enough to have experienced a heart attack and so attributed the physical sensations they experience to the ageing process.

Physical sensations were assessed against the individual's ability to undertake physical activities (Section 5.5.1). These ranged from undertaking basic activities of daily living to vigorous physical activity such as brisk

walking. Individuals responded to these sensations by restricting, adapting or extending the activity they attempted.

The process of undertaking and assessing the response to activity was an ongoing internal interaction which resulted in behaviour change (Section 5.5.1.2). The behaviour change undertaken was linked to the level of control the different narrative groups perceived they had over their physical sensations. A greater perceived level of control of these sensations was associated with health-related rather than ill-health related behaviour change (Section 5.5.5).

In the enhanced narrative group there was an ability to increase levels of physical activity without physical sensations limiting the activity. This encouraged the continuation of health-related behaviour change and this group told a story of enhanced health and well-being when compared with their pre-heart attack status. The adapting narrative group could hold limiting physical sensations at bay by controlling the amount and intensity of any activities they undertook. However, in situations where the physical sensations experienced were perceived as inducing symptoms such as chest discomfort then there was an enforced change as activity was restricted to preclude symptoms.

The narrative typologies also interacted with health care professionals in different ways. In situations where physical sensations can limit behaviour – the struggling and adapting narrative groups – then contact with specific health care professionals was sought. The level of control individuals perceived they had over their physical sensations dictated whether contact with health care professionals was pro-active or reactive.

The four narrative typologies provide an explanation of the ways in which individuals recover from a heart attack. A discussion of these findings in the context of the current literature will now be undertaken in Chapter 6.



## 6 Discussion

This chapter will discuss the findings in the context of the research question, methodological approach and relevant current literature.

The research question was:

In what ways do illness beliefs adapt following a myocardial infarction?

Do these adaptations influence decisions regarding whether or not to make a health-related behaviour change?

The theory generated in this study proposes that following a heart attack individuals undergo a reorganisation of their daily lives that is strongly influenced by the physical sensations they experience. A conceptual trajectory of biographical restorying (Figure 6-1) proposes that an episode of acute biographical disruption associated with hospitalisation at the time of their heart attack required individuals to restory their lives. Four different narratives of lives which were continuing, a struggle, limited or enhanced emerged.



Figure 6-1 Conceptual trajectory of biographical restorying after a heart attack

The discussion will be undertaken in five sections and for continuity implications for practice will be discussed within each section.

First, in Section 6.1 the ways in which illness beliefs contribute to the biographical restorying of those who have experienced a heart attack are

explained. The substantive theory identifies how the individual illness domains adapt at different times in the recovery journey in response to the physical sensations experienced. How this varies across the four different narratives is set out in in Figure 6-2. The role of illness belief and behaviour change will be compared with the contemporary literature. The implications for current evidence based health care, utilising illness belief theories, for those who have had a heart attack will be explored in the light of the proposed theory.

Secondly, Section 6.2 explores concepts of health and illness and why they varied across the identified narratives. The section considers the links between these concepts with the categories of associated physical sensations and behaviour change in the substantive theory, (Figure 6-2). It offers a critique of the health and illness related concepts proposed by other relevant, published qualitative studies.

	<b>Narrative Typology</b>	<b>Associated physical sensations</b>	<b>Behaviour change undertaken</b>	<b>Interaction with health care professionals</b>
<b>Antecedents</b> Previous experience of heart attack. Prior knowledge about heart attacks.	<b>Continuing narrative</b>	Nil attributed to heart attack	Minimal adaptation	Reactive contact for routine monitoring
	<b>Struggling narrative</b>	Restricting daily activities	Enforced change in response to ill-health	Frequent contact with preferred health care professionals.
	<b>Adapting narrative</b>	Absence is contingent on controlling levels of activity.	Maintenance of behaviour limiting intrusion of negative physical sensations	Proactive contact with preferred health professionals to support self management
	<b>Enhanced narrative</b>	No intrusion on increasing levels of activity.	Continuation of positive health related behaviour change	Proactive contact to support self-management
<b>Biographical Restorying following a heart attack.</b>				

Figure 6-2 The theory of biographical restorying following a heart attack

Thirdly, Section 6.3 will consider the ways in which knowledge is gained and interpreted by those restoring their lives after a heart attack. This will explore the different means by which knowledge from the wide range of available sources is utilised and valued by those experiencing a heart attack. It will examine the role of information provided from the medical profession during the process of biographical restoring.

Fourthly, this longitudinal constructivist grounded theory study has used narrative theory as a lens through which to view recovery from a heart attack from the perspective of those experiencing the event and Section 6.4 will appraise the contribution of narrative theory. It will examine the potential role of the narrative approach as a strategy for enabling health care professionals to acknowledge the complexities of those living with long term conditions. This section will specifically suggest ways in which future adoption of this theoretical approach could increase the numbers attending cardiac rehabilitation programmes.

Finally, section 6.5 will summarise the contribution made by this study to what is already known about illness beliefs following a heart attack. The implications for practice, education and research and the limitations of this study will follow. Throughout these sections the major findings from the study will be in bold text.

## **6.1 Role of illness beliefs in biographical restoring after a heart attack.**

All five domains of illness perception identified in the common-sense model of self-regulation (CSM) by Leventhal, Brissette and Leventhal (2003).were recognisable in this study. Illness beliefs adapted along the post event trajectory with differences in these interpretations and adaptations apparent across the four narratives.

Beliefs in the identity and cause domains were influenced early in the journey as participants sought to make sense of the physical sensations that had led

to their hospitalisation. Interpretation of their physical sensations, in the weeks and months after their heart attack, led to the adaptation of illness beliefs in the consequence and control domains. Beliefs in the consequence and control domains were more fluid, influenced by the allocation of meaning to changing physical sensations.

This section will begin with a resumé of the five domains in the CSM. It will then discuss the ways in which the different domains were represented in the study and relate that to the current literature.

Illness perceptions are defined as frameworks or working models that patients construct to make sense of their symptoms and medical conditions (Petrie and Weinman, 2012). These are updated and enriched by actions to promote health, detect risk and prevent illnesses and by behaviours to manage acute and chronic illnesses (Leventhal, et al., 2011). The CSM postulates that illness perceptions which influence subsequent health-related behaviour develop in five domains: identity; cause; timeline; consequences; and control (Table 6-1).

Domain	Descriptor
Identity	Symptoms and name given to symptoms
Cause	Factors perceived to cause symptoms
Timeline	Expected duration of symptoms and impact on life functions
Consequence	Severity of symptoms and impact on life functions
Cure / Control	Extent to which disease is curable or controllable

Table 6-1 Five content domains of common-sense model of illness (Leventhal et al. 2003, p49)

### **6.1.1 A disrupted narrative: the influence of identity.**

When individuals experience symptoms, a prime aim is to provide a name or identity for those symptoms in order that a chain of events to deal with the situation can be instigated. The challenge around identifying what was happening to them, (Section 5.4.2.), was a major contributor to the disrupted narrative identity, experienced by participants in the initial phase of the trajectory of biographical restorying.

The onset of symptoms not previously experienced led participants to seek first social support and then medical support in an attempt to identify what was happening to them (Cameron, et al., 2005; Suls, David and Harvey, 1993). Consistent with other studies the involvement of family members was associated with early seeking of medical help (Lesneski, 2010; Khraim and Carey, 2009; Turriss, 2009). The principal factor triggering help-seeking behaviour in this study was the novel nature of the symptoms participants were experiencing. This does not appear to have been identified as a factor in previous studies which have suggested that duration of symptoms was the trigger for seeking help (Mora, et al., 2002; Khraim and Carey, 2009).

Participants' previous experience of cardiac-related pain did support recognition of the symptoms as potentially being related to a cardiac condition (Leventhal, et al., 2011). However, this did not lead participants to immediately acknowledge that this was the cause of their current symptoms or to seek quicker access to the medical help associated with improved outcomes (Hartwell, et al., 2005).

On being informed that a heart attack was the cause of their symptoms, participants experienced shock and concern that the symptoms experienced had not matched their perception of what a typical heart attack should look and feel like (O'Donnell, et al., 2014). Horne, et al., (2000) had previously suggested that this mismatch could also lead to a delay in treatment but for the participants in this study, the concern identified was the discrediting of their lay knowledge discussed in Section 5.4.2.5. This discrediting

contributed to the disrupted narrative identity associated with the period of hospitalisation. The participants questioned the reliability of their commonly used sources of lay knowledge such as television medical dramas and folklore.

Research around the domain of identity in those experiencing a heart attack has been driven by health care professionals focused on the impact that misattribution of symptoms has on delaying treatment (Cornally and McCarthy, 2011; Mackay, et al., 2014). This information has been used, successfully, to develop public health campaigns aimed at early recognition of and seeking help for cardiac symptoms. The symptoms exhibited by the participants in this study are considered to be typical, if not classical, symptoms of a heart attack (Canto, et al., 2000; Finn, et al., 2007), but this information was not included in the public health campaigns or dramatisations of those experiencing a heart attack.

In this situation, it would seem that public health information designed to support early recognition of a potentially life-threatening condition may also have the opposite effect if the media message is oversimplified. In addition to potentially delaying treatment this situation contributed to the discrediting of the participants' illness belief around the cause of a heart attack and their subsequent disrupted narrative identity.

The portrayal of heart attack symptoms in the media contributed to the beliefs of participants in this study. In the absence of those specific symptoms in public portrayals the participants did not consider a heart attack as a possible cause of their symptoms. The role of the media in providing health related knowledge is discussed more fully in Section.6.3.4.

Three of the narrative groups, the Struggling, Adapting and Enhanced narratives, accepted the authority of medical knowledge as an explanation of their symptoms. In providing the symptoms with a label of heart attack the other illness perceptions of timeline, cause, consequences and control began to adapt, as these three narrative groups of participants considered their future as heart attack survivors.

However, the participants who became the continuing narrative group, expressed the belief that they would have expected to feel more ill if they were experiencing a heart attack. This became a rationale for the continuing narrative group to question the validity of the diagnosis they had been given by health care professionals (Dullaghan, et al., 2014; Horne, et al., 2000).

In questioning the medical explanation and cause of their symptoms, the previously held knowledge and beliefs around the identity of a heart attack of those in the continuing narrative were not discredited. Maintaining the integrity of their previously held knowledge and belief about the cause of their symptoms enabled the continuing narrative group to maintain confidence in their own abilities to manage their illness. This continuing narrative group did not report the disruption to their narrative identity reported by the other participants. This supports a link between discrediting of previous knowledge and disruption to narrative identity. The illness perceptions of this continuing narrative group adapted in a different way to those who accepted the identity given by the health care professionals.

There was a suggestion by Dullaghan and colleagues (2013) that the delay in diagnosis associated with a non ST elevation myocardial infarction (NSTEMI) was linked to patient doubts over the diagnosis. All of the participants in this study experienced a NSTEMI but only the continuing narrative group disputed the identity of their illness in this. All experienced a delay in receiving their diagnosis however, in this study, doubt over the diagnosis was linked to a perception that the symptoms experienced were not severe enough for a heart attack.

Previous cross-sectional studies have suggested that both identity and subsequent attributions of cause in cardiac conditions can impact on future behaviours (Weinman, et al., 2000). This prediction was realised in this study as the continuing narrative group did not consider undertaking any health-related behaviour change as a consequence of their identity beliefs.

Once they had accepted, or not, the diagnosis of heart attack, none of the participants in this study sought any other identity and this perception was

then unaltered during the study period. **The domain of identity became fixed during the period of disrupted narrative identity suggesting that influencing the development of beliefs in this domain may need to occur during the hospitalisation phase of the process. However, accepting that a heart attack was the cause of the symptoms appears to be a necessary precursor to the development and adapting of illness perceptions related to cause.**

### **6.1.2 Creating a different narrative: the domain of cause in influencing behaviour change.**

The theory of biographical restorying proposes, in Section 5.5.1.2, that as participants considered the potential causes of their heart attack their views on undertaking behaviour change had shifted from a detached common sense knowledge perspective to a much more personalised perspective (Fors, Dudas and Ekman, 2014; Rudy, 1980). Common-sense knowledge in relation to cause was not discredited but it became personalised as participants acknowledged the risk factors (Table 2-1) they carried as individuals.

In the early interviews, a few weeks after their heart attack, there was acknowledgement of the factors which might have contributed to their own heart attack. All of the narrative groups who accepted they had experienced a heart attack identified lifestyle factors such as smoking, poor diet and lack of exercise as being contributory causes of their heart attacks.

However, the two participants with very strong family histories of heart disease did not initially consider the hereditary element to be a contributory factor in their event. This is consistent with previous studies in which participants struggled to identify the individual risk factors which had contributed to their heart attack (Cameron, et al., 2005; Darr, Astin and Atkin, 2008; French, et al., 2001; Astin and Jones, 2004).

Stress was identified as a potential cause by two female participants and both considered it a contributory factor in their heart attack. The low number of participants attributing their heart attack to stress does not correlate with

other studies (French, et al., 2001; Reges, et al., 2011). This may be gender-related as women are more likely than men to cite stress as a cause of their event (Aalto, et al. 2005). However, some participants attributed their poor diet or lack of exercise to pressures in their general life which could infer a stress-related causal attribution.

Information regarding the physiological causes of the heart attack was provided by medical staff. This new information came from diagnostic tests and was therefore specific to the individual. The participants' interpretation of this technical information such as the degree of narrowing of their coronary arteries, did not always align with the original information provided (Section 5.5.6.1.2). Their reinterpretation of medical knowledge was articulated by individuals as a reduction in their risk of a further heart attack. This is discussed more fully in Section 6.3 when the influence of health care professionals in the creation of a new knowledge base is discussed.

This interpretation of cause-related information has been seen in other studies with cardiac patients (Wiles and Kinmonth, 2001) and in studies with cancer patients (Armstrong and Murphy, 2008; Mackillop, et al., 1988). The understanding of patients was based on a complex mix of prior experience, contextual factors and causal attributions. Patients make sense of causal information in ways that conflict with the information senders' intentions.

The continuing narrative group, who were unconvinced as to the identity of their symptoms, acknowledged the factors contributing to heart attacks but did not address any of these issues personally. The continuing narrative group associated ongoing physical sensations with the process of ageing, a factor which is outside an individual's control.

The substantive theory proposes that not associating the physical sensations they experienced with a heart attack explains why this group did not undertake health related behaviour change. This coupled with their doubt over identity, may have contributed to their not attending a cardiac rehabilitation programme where their perceptions around the identity and cause of their heart attack might be explored (Sanders, et al., 2007).

Previous studies have suggested that attributions of cause in cardiac conditions can impact on future behaviours (Roesch and Weiner, 2001; French, et al., 2005). If those causes are deemed to be under the control of the individual, then health-related behaviour change is more likely to occur (Weinman, et al., 2000). If there is misattribution of the cause of the heart attack, as occurred in the continuing narrative group in this study, there are implications for decision making associated with health-related behaviour change.

Two of the narrative groups, the adapting and enhanced, perceived that lifestyle issues were causative factors contributing to their heart attack. These participants believed they had the ability to control their diet and levels of physical activity. These participants changed their behaviour soon after their heart attack. All of the participants in these narrative groups attended a cardiac rehabilitation programme (Janssen, et al., 2013).

The participant in the struggling narrative group identified the potential causes for her heart attack but had not addressed any of these factors. This was not due to an unwillingness to address these issues. Rather the issue lay in her energy being taken up dealing with the ongoing symptoms that were a consequence of her heart attack. This reduced her capacity to undertake and monitor lifestyle change designed to prevent a future heart attack.

Addressing causative factors through changing behaviour to reduce the risk of future heart attacks involved being able to make long-term plans, something the struggling narrative participant was currently not undertaking. In considering why individuals do not undertake action to address modifiable causes, the substantive theory suggests that for some individuals this is related to ongoing ill-health reducing the capacity to undertake change rather than a failure to perceive a need to undertake change.

As stated above, Weinman and colleagues (2000) suggested there was a link between the domains of cause and control and attendance at a cardiac

rehabilitation programme. The theory of biographical restorying supports a link with cause and control and suggests an explanation in Section 5.5.1.2.

A cyclical process is occurring in which the tangible benefits of the health-related behaviour change reinforce the belief that causative factors can be controlled. This enhances feelings of well-being which further promote the maintenance of the behaviour and the beliefs around control. Cardiac rehabilitation programmes currently reinforce and support this cycle.

In considering the causes of their heart attack, participants reported they had not identified with personal risk factors prior to their event. Some participants had made attempts to address lifestyle risk factors prior to their heart attack. However, these had been for general health measures and were not undertaken specifically to prevent a heart attack. These pre-heart attack attempts had been short-lived but the personal experience of the heart attack gave further impetus to adhere to the changes they had put in place. Attending a cardiac rehabilitation programme supports health-related behaviour change but participants reported they had started to undertake change prior to commencing the cardiac rehabilitation programme.

The participants in this study identified potential causes of a heart attack in a broadly similar pattern to previous studies, (Roesch and Weiner, 2001; French, et al., 2005). Illness perceptions around identity and cause adapted as knowledge and information were received from others early in the course of their illness; once formed, these perceptions appear to become relatively fixed. Attributing symptoms to a heart attack is, naturally, a key part of looking for a cause of the heart attack. **This would suggest that intervention strategies designed to influence beliefs in the identity and cause domains should be targeted around the time of diagnosis.**

### **6.1.3 Planning a future; creating a different narrative over time**

Two elements of timeline were identified in this study: the belief that life in general was likely to be foreshortened as a consequence of the heart attack, and the impact the heart attack had made on being able to plan for the future.

The first of these timeline perceptions were linked to situational factors during the period of biographical restorying and were not prevalent in any specific narrative groups. All participants expressed a belief, correctly, that having a heart attack would be likely to foreshorten their lives (Pennells, et al., 2014). This belief was present as the 'elephant in the room' without impacting or restricting their daily lives. Negative thoughts around this belief intruded on participants' thoughts at current family events. These thoughts centred on future family events such as weddings of grandchildren they would potentially miss out on. These are reported in the literature across a range of potentially life-shortening conditions such as cancer (Andersson, Borglin and Willman, 2013; Groleau, et al., 2010).

Situational stress induced by the trauma of witnessing the death of another patient, discussed in Section 5.4.4.2 raised the fear of death during the period of disrupted narrative identity. This contributed to the foreshortened life element within the disrupted narrative identity experienced in hospital, but the fear of imminent death resolved with distance and time from the acute event (Lazarus and Launier, 1978).

As the time from the original event passed, differences in the perceptions on the impact of timeline between the narrative groups emerged. The substantive theory proposes that the limitations imposed by the physical sensations experienced throughout recovery influenced the timeframe in which participants lived their lives.

The continuing and enhanced narrative groups were living a life free of physical sensations attributable to their heart attack. Those groups planned for future events such as holidays with little consideration for the impact their heart attack might make. This approach makes sense for those in the continuing group who questioned the identity of having had a heart attack. The enhanced group did acknowledge their diagnosis whilst planning future events. However, their current state of living a healthier enhanced life following their heart attack enabled them to plan for the future with confidence.

The timeline and future planning for the adapting narrative group was contingent on their physical health being maintained. They acknowledged the chronic nature of their heart condition and the temporality of their current status. Events within the days and weeks ahead would be scheduled around other activities to ensure they could be completed with minimal disruption from physical sensations. Despite planning ahead this group lived in the present, assessing how they felt and adjusting activity accordingly to enable completion of their planned activity in the knowledge they were currently in control of their lives.

The struggling narrative group thought of time in days and planned from day to day in response to the intrusiveness of symptoms (Charmaz, 1991). The daily variation and unpredictability of their health prevented the formation of any longer-term plans. Neither the adapting nor struggling narrative groups perceived that their ability to plan further into the future would improve and expected that over time this would in fact worsen.

Illness perceptions associated with timeline were driven by the unpredictability and potential intrusiveness of physical sensations and clear differences in timeline perceptions were identified between the four narrative groups. The greater the reality of or potential for symptoms, or other consequences, of the heart attack to occur, the more restricted the timeframe of individuals became.

**Beliefs around timeline were much more fluid than identity and cause perceptions (Llewellyn, McGurk and Weinmann 2007). They adapted in response to a change in the nature of physical sensations and their impact on the daily lives of individuals.**

#### **6.1.4 Creating a different narrative: A blurring of the boundaries between consequences and control.**

Within the common-sense model (Leventhal, Brissette and Leventhal, 2003) the five domains are considered separately. This was observed in the domains of identity, timeline and cause in this study. There were clear

boundaries between the domains but relationships between them in that the identity of heart attack directed thoughts on causality in a certain direction.

However, the theory proposes that the domains of consequence and control were interrelated. Participants' belief as to whether an element lay within the consequence or control domain depended on their perspective and differed across the four narrative groups, a phenomenon previously suggested in a qualitative study with cardiac patients (Lau-Walker, 2004).

Consequence within the common-sense model is considered to be an

*'expected outcome including both somatic and non-somatic side effects'* (Leventhal, Brissette and Leventhal, 2003, p53).

The Cambridge English dictionary definition expands this to include the proviso that the outcome is often bad or not convenient. The participants in this study worked with the Cambridge English dictionary definition and considered a consequence to be associated with a poorer outcome.

When reviewed from a medical perspective the implicit negativity of the consequence domain is not always considered. A medically expected outcome (consequence) of having a heart attack is that individuals will adhere to their medication strategy and adapt their lifestyle behaviours. These outcomes were not always considered to be consequences by the participants.

Those within the continuing narrative group did consider medication adherence to be a consequence of their heart attack. The enhanced narrative groups considered medication adherence and lifestyle change to lie within the control domain. The adapting group considered the adapting of lifestyle factors to straddle both as they were in control of any change but a consequence of their heart attack was that their physical capacity was more limited.

The struggling group located medication adherence and lifestyle change within the consequence domain. The changes the participant was forced to make in these areas were considered to be an outcome of her heart attack.

The development of illness perceptions around consequence and control will be considered together in this discussion chapter. The impact of the differences in interpretation and meaning of these perceptions will be discussed later in Section 6.3.

All participants identified becoming a burden to others as a potential consequence of their heart attack in the disrupted narrative period immediately after their diagnosis. This was a part of the disruption to self which was a component of the disrupted narrative identity participants experienced. These fears around becoming a burden resolved in those participants who resumed activities with minimal or controllable physical sensations.

The narrative group within the substantive theory who considered themselves to be an ongoing burden to others were the struggling narrative group. This group, with ongoing symptoms which they could not control perceived the symptoms to be consequences of their heart attack. Bury's, (1982; 1991) work on the biographical disruption associated with chronic illness identified similar concerns regarding fears around becoming a burden. However, his work did not report the resolution found in the enhanced, adapting and continuing narrative groups in this study.

Other studies have reported that those who experience a heart attack do not necessarily consider themselves to have a chronic condition (Astin et al 2009, Wiles and Kinmouth 2001). The association of on-going, limiting physical sensations with becoming a burden differentiated the struggling narrative group from the other narratives in the substantive theory. Perhaps the ability to live without intrusive limiting symptoms is one reason for those who have experienced a heart attack to not consider themselves as having a chronic condition.

A further consequence of their inability to control symptoms was their reliance on health care professionals to manage their condition. This struggling narrative group did not believe they had control over their health as even the health care professionals could not offer a treatment regime

which effectively controlled their condition. They experienced continued physical sensations characteristic of a chronic cardiac condition. However, as individuals they had not yet acknowledged this feature of their current health status. The unpredictability of their clinical condition resulted in a continuing disruption to their sense of self-confidence and control (Bury, 1991; Charmaz, 2006b).

The participant in the struggling narrative group told of both somatic and non-somatic consequences. This group was situated to the more negative ends of the continua of health and illness, levels of confidence and living without limitations. The participant spoke of an associated reduction in her levels of confidence and perception of self (Markus and Wurf, 1987; Brink, 2009). The struggling narrative group perceived that these non-somatic consequences were a consequence of ongoing symptoms (Bury, 1982; Hagger and Orbell, 2003).

A lack of belief that they were in control of their behaviour was also seen in the continuing group. They attributed ongoing physical sensations to be a consequence of ageing, and the period of hospitalisation associated with their diagnosis of heart attack was viewed as an acute event. Both of these rationales are linked with low adherence to health recommendations (Affleck, et al., 1987; Wiles and Kinmonth, 2001).

These traits have also been associated with having an external locus of control (Lefcourt, 2014; Parkes, 1984). In considering the taking of medication to be a consequence of their hospital admission, the continuing narrative group perceive it as an action imposed by an external other, the doctor, whose expert authority they will follow (Attebring, Herlitz and Ekman, 2005).

For both these groups, lack of control originated with their perception that the physical sensations they experienced were consequences of their heart attack. In the case of the continuing narrative group, through attribution, and in the struggling narrative group, imposition.

The perception that there were few consequences to their heart attack was seen in the enhanced group. They perceived they were in a good state of health and their internal feedback from undertaking behaviour change was that the change was under their control and of benefit. The factors which encouraged and maintained their behaviour change were the tangible benefits of weight loss and increased fitness they had achieved. All these somatic and non-somatic outcomes gave rise to a belief they were in control of their health (Allan, et al., 2007; Janssen, et al., 2013).

The adapting narrative group identified they were living with the consequences of their heart attack but were able to limit the impact of physical sensations by controlling aspects of their behaviour. The adapting narrative group also reported an increased capacity for activity before symptoms intruded as time passed. These benefits increased their perception of health and their levels of self-confidence which enhanced the belief that they had the ability to control and limit the influence of causative factors (Brink, 2009).

This control led to higher levels of confidence and a perception of being in good health, unlike the struggling narrative group who considered her physical symptoms as consequences (Hagger and Orbell, 2003). The ability to control symptoms was the confounding factor in considering symptoms to lie within the consequence or control domain.

**Within the substantive theory the development of illness perceptions in the consequence and control domains was influenced by the level of control individuals believed they had over their physical sensations.** A high level of control, which would be associated with having an internal locus of control, and the linking of physical sensations with health benefits was associated with the belief that there were few if any consequences from their heart attack. Symptoms of ill-health were considered to be consequences and associated with more negative perceptions of control and self and displaying traits associated with an external locus of control.

### **6.1.5 Opportunities to influence the adaptation of illness beliefs during biographical restorying.**

Studies reviewing illness beliefs are usually cross-sectional. These studies attempt to assess belief and behaviour simultaneously with a conclusion as to the way in which the belief will predict behaviour. The substantive theory proposed in this longitudinal qualitative study has demonstrated that **affirmation of illness beliefs comes from behaviours, in particular those related to physical activity which reinforce the belief.**

The study proposes that beliefs in the identity and causal domains are developed and become relatively fixed during the initial disrupted narrative phase of biographical restorying (Figure 6.1). If interventions which address those domains can be developed and delivered in the hospital setting, then future misattribution of symptoms which are associated with delayed help-seeking may be reduced.

Beliefs within the cause domain are linked to identity and associated with subsequent health-related behaviour change. Ensuring individuals are cognisant of the potential causes of their heart attack in the early stages of their recovery may increase their likelihood of undertaking health-related behaviour change.

The theory proposes suggest that the domains of control, consequence and time are interdependent and that they adapt during the period in which a different narrative is being created by individuals (Figure 6.1). Illness perceptions in these domains are bound up in the complex lives that people live following a heart attack.

Unless these contextual issues are considered, the impact of interventions designed to improve outcomes is likely to be reduced. This was previously proposed in a meta-analysis (Hagger and Orbell, 2003). However, incorporating the contextual factor into interventions designed to adapt illness perceptions will increase both their complexity and the level of support required for implementation. **Interventions to address the domains of control and consequence may be better undertaken post-discharge**

**where health care professionals can facilitate change within the context and complexity of the patients' lives.**

A questionnaire (the Illness Perception Questionnaire – IPQ) designed to assess illness beliefs across the five domains and establish links between them has been developed (Moss-Morris, et al., 2002). There is both an 80-question and 9-question version of the IPQ; the latter is designed for assessment in time-constrained clinical situations. Studies using the questionnaire have predicted links between the domains and outcomes on coping with illness (Moss-Morris, 1997), functional capacity (Petrie and Weinman, 1997) and adherence to medication therapy (Weinman, et al., 2000; Horne, Clatworthy and Hankins, 2010).

In the light of this study, the further development of the questionnaire to identify beliefs within individual domains could be useful. The individual questionnaires and appropriate interventions could then be delivered at different times across the trajectory of biographical restorying. This has been suggested by Leventhal himself (Leventhal, et al., 2011) but reported developments of interventions based on the model appear to be limited to those with diabetes and asthma

## **6.2 Biographical restorying of health and illness related concepts,**

In exploring participants' biographical journey after their heart attack, three distinct concepts were identified. These were: level of self-confidence, perception of health and the extent to which the individuals were living with limitations. The perceptions of those concepts differed across the four narrative groups but were linked to the levels of consequence or control discussed in Section 6.1.4. The relationship between the concepts and the narratives is depicted in Figure 6-3.

Those in the enhanced narrative group who perceived they had a greater degree of control over their condition had the highest levels of self-confidence and perception of health. The greater the perception that they

were living with consequences of their heart attack the greater the limitations on their lives and perception that they were ill rather than healthy. Self-confidence was lowest in the struggling narrative group.

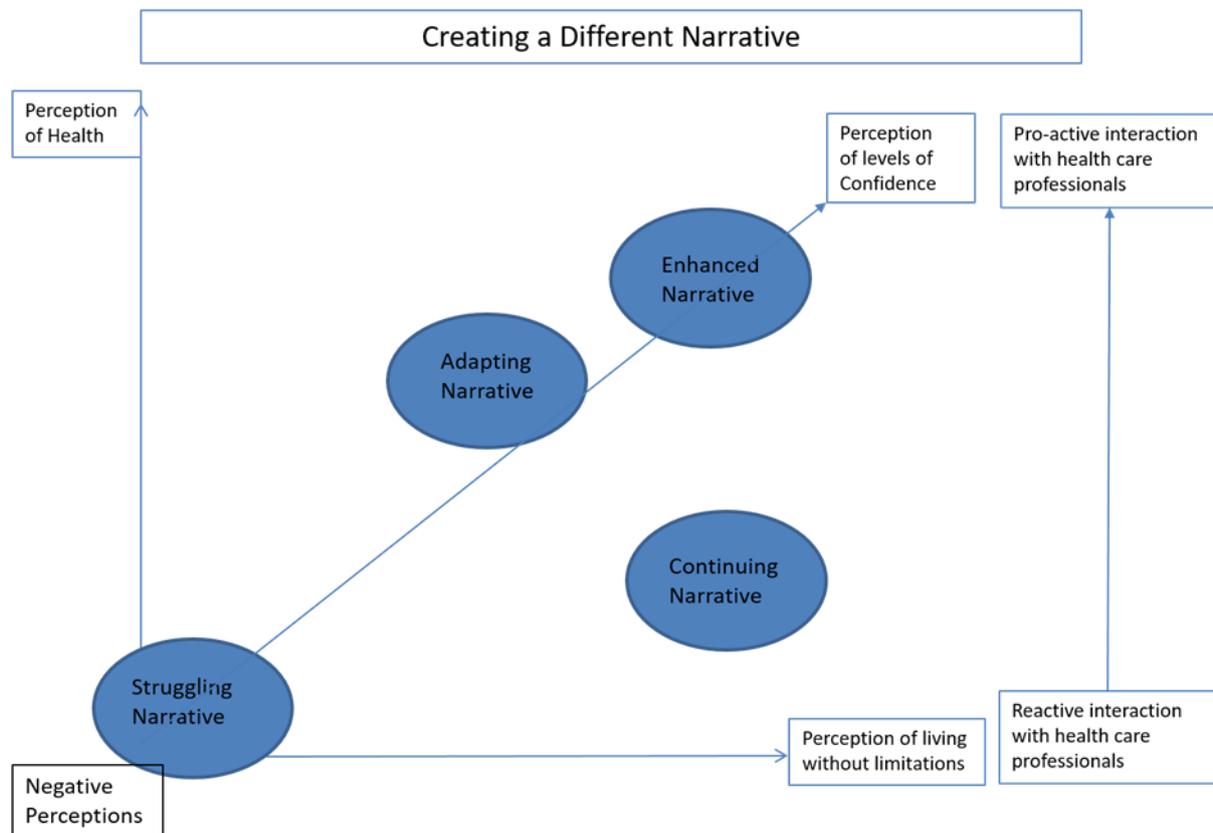


Figure 6-3 Health and illness related concepts across the different narratives.

### 6.2.1 Adapting levels of self-confidence

Self-confidence is part of the self-concept, a term, in social and health psychology, used to encompass how a person thinks about themselves.

Various aspects of 'self' have been explored in relation to those who have experienced a heart attack. Brink, (2009; 2006) explored self-agency and adaptation following a heart attack; Lau-Walker, (2004) and Burns and Evon, (2007) have each explored self-efficacy; and Fleury, (2007) has explored self-knowledge. In common with this study all of the above identified that 'self' is a complex and multi-faceted concept whose role in health-related behaviour change is difficult to quantify.

The participants in this study spoke of self-confidence and the way in which it grew or diminished following their heart attack. Self-confidence was greatest in the adapting and enhanced narrative groups where control was associated with being able to maintain health-related behaviour change focused on reducing the risk of a further heart attack. Lau-Walker's, (2004) study supported this in reporting that high dietary and physical activity self-efficacy were associated with a perception of being able to control their condition and undertaking long-term preventive measures.

An American study, also studying self-efficacy but with only male participants, reported that higher self-efficacy was specifically associated with an improved physical performance (Burns and Evon, 2007). In this study, those in the enhanced narrative group linked high levels of self-confidence with a return to previous or higher levels of physical activity. This was also a male-only group suggesting that physical performance may be an important contributor to restoring the self-confidence of men who have experienced a heart attack.

The movement towards more or less self-confidence, discussed in Section 5.5.3, appeared to have a feedback mechanism in that increased self-confidence increased the amount of activity undertaken which further increased self-confidence. The feedback loop has fit with the undertaking and reflecting on action cycle described in Section 5.5.1. This mechanism for increasing self-confidence and activity, in which success appears to lead to further success, could explain that feeling of empowerment. A meta-analysis reviewing the common-sense model of self-regulation supported these findings in its suggestion that the realisation that an illness was within their control empowered people to report positively on well-being outcomes in general (Hagger and Orbell, 2003).

Conversely, an increasingly limited ability to undertake activity reduced self-confidence. Lau-Walker, (2004; 2007) used validated questionnaires to assess general, dietary and exercise self-efficacy and illness beliefs in her post-heart attack study population. This identified that a lower general self-efficacy was associated with a greater belief that respondents were living

with the consequences of the heart attack. This is supported by this study where the struggling narrative group participant identified that low self-confidence was associated with ongoing symptoms she considered to be a consequence of her heart attack.

The struggling narrative participant spoke of requiring all her resources to manage the consequences of her condition. She told of the limitations these consequences placed on her ability to undertake everyday tasks and could not address activities aimed at long-term prevention of future illness. Lau-Walker, (2004) identified that there was no significant relationship between diet and exercise self-efficacy for those who perceived they were living with greater consequences of their illness. This inability to address these issues in the struggling narrative group may explain that lack of significance.

The theory of biographical restorying supports previous studies in associating high levels of self-confidence or self-efficacy with an individual perceiving they have a degree of control over their illness. The centrality of responding to physical sensations within the substantive theory also confirms that the capacity to undertake physical activity plays an important part in increasing self-related perceptions. Lau-Walker's, (2004) study identified relationships and behavioural intentions between illness perceptions and self-efficacy near the time the heart attack occurred but did not consider actual outcomes. This current longitudinal study reported on actions undertaken in the months following a heart attack and the findings and substantive theory demonstrated that intentions can be carried through to action.

It would appear from this and previous studies that the ability to carry out physical acts supports increased perceptions of self-confidence. The suggested link between causality, control and self-esteem has been previously reported in a review of quantitative studies (Roesch and Weiner, 2001). However, the authors were unable to identify statistically significant predictive relationships between their variables. They noted that the complexity of defining and measuring terms such as self-esteem and locus of

control reduced the predictive power of the review reinforcing the limited role of quantitative methodologies in such studies.

As human beings we appear to need the physical experience to inform our cognitive experience in both a positive and negative direction. Supporting individuals to minimise the perceived and real consequences of their condition could be important when developing interventions to support increased self-efficacy. **This study and evidence from the range of studies discussed above, (Hagger and Orbell, 2003, Lau-Walker, 2004, 2007, Roesch and Weiner 2001), suggests that if an increase in the amount of physical activity which can be undertaken can be achieved, then a greater perception of control and therefore self-confidence may result.**

### **6.2.2 Perception of health and illness**

In discussing their state of health or illness, participants spoke of health as being a lack of symptoms or other physical sensations suggestive of illness. As with self-confidence, perception of health was highest in the adapting and enhanced narrative groups who believed they were in control of their health following their heart attack. The meta-analysis undertaken by Hagger and colleagues (2003) also identified a positive link between controllability of an illness and psychological well-being.

In another study, Myers (Myers, Drory and Gerber, 2011) measured sense of coherence (SOC) post-myocardial infarction and identified that a positive SOC predicted the undertaking of physical activity post-event. Sense of coherence is a construct within the salutogenic model of health, which was designed to explain movement in an individual's location along the health–illness continuum (Antonovsky, 1993; Bengtsson-Tops and Hansson, 2001). SOC represents a person's confidence that they have the resources to cope with problems and challenges. Those with a higher perception of health and well-being were those whose belief in their ability to undertake specific activities was realised.

The perception of health and illness are essentially internally created constructs. The participants' perceptions of their level of health or illness were created through internal interpretation in line with the symbolic interactionist perception of the self as an object of their own action (Charon 2010). The ability to measure and quantify a tangible experience of physical health enables individuals to relate to more cognitive aspects of health. When physical ability is limited by illness and particularly if that illness is deemed to be of a chronic nature the cognitive perceptions of health are affected to a greater degree. **The ability to undertake physical activities impacts positively on perception of physical well-being and the belief individuals have that they can control their illness.**

### **6.2.3 Living with limitations:**

The third category that was identified in this study was living with limitations. Two groups, the adapting and struggling narrative groups, felt that their life was limited to a greater or lesser degree following their heart attack. These limitations were experienced in different ways by the two groups. The adapting narrative group perceived that despite these limitations they were in control of their current health. The struggling narrative group participant did not perceive she had control over her health and this was attributed, at least in part, as a consequence of these limitations.

The continuing and enhanced narrative groups did not consider they were living with limitations. The continuing group reported they had returned to their previous activities and lifestyles. The enhanced group perceived they had returned to their lives and to an extent improved them. The lifestyle changes they had undertaken give them health benefits rather than limitations.

For those in the adapting and struggling narrative, the limitations of a chronic illness meant that for the participants their heart attack and its consequences could not be ignored. Living with health limitations entailed living with restrictions, either controlled or not, and this made their situation visible to

others. During the time participants were building a different narrative this visibility threatened their social identity as the limitations led to uncertainty about their ability to fulfil previous roles and functions. There was a recognition that the intrusion of chronic illness into daily life made returning to their pre-heart attack lives unattainable. This challenged their previously held image of who and what they were.

The threat to self within chronic illness has been explored in detail by Charmaz (Charmaz, 1983; 1991; 1995; 1999; 2002;). This threat to self is associated with ongoing physical symptoms, an increasingly restricted existence and reduced control over their lives and futures. This loss accumulates over time, leading to a reduced self-esteem and self-identity and a diminished self-concept (Charmaz, 1983). These characteristics were a part of the different narrative told by the adapting and struggling groups in this study.

The ability to control these limitations enabled the adapting narrative group to maintain their previous social roles albeit with a reduced physical capacity. This group adopted protective mechanisms in relation to physical activity. They adjusted the amount and time of activity they undertook to ensure they could still participate in selected activities and events. Retaining that control and monitoring their bodily response to activity became a constant work in progress as they constructed an altered story of self which accommodated their limitations (Charmaz, 1995; 2006b). The importance of measuring and achieving activity, or other pursuits such as employment, as an important indicator of both the health and self-concepts of those with chronic illness has previously been suggested (Charmaz, 2006b).

The struggling narrative group participant experienced limitations in all aspects of her daily life. The limitations were imposed by recurrent symptoms which reduced her physical capacity to undertake even basic activities of daily living. These symptoms could be unpredictable in their occurrence which meant that planning and undertaking daily life was challenging. This group continues to strive to retain previous roles and functions but has

experienced increased social isolation and a perception she is a burden to others.

The limitations enforced on the participant in the struggling narrative group required accommodation of a negatively altered self. The inability to return to her 'normal' life led to the diminished self-concept identified by Charmaz. The loss of self in the struggling narrative group in this study was associated with the loss of control over her body and her daily life. A questionnaire-based study of over 200 patients who had experienced a heart attack four months previously also identified this association between ongoing physical symptoms and a perceived lack of control (Alsén, et al., 2010).

The perpetual struggle experienced by the struggling narrative group is characteristic of those with a chronic illness. The narrative of this group is one of 'struggling against their illness' as depicted by Charmaz in her early studies of those who live with chronic illness (Charmaz, 1995). This struggling narrative group still strives to regain her previous health status, unable to acknowledge that her previous life may be unattainable.

The adapting narrative group were able to exert some control over these limitations. They could prevent their intrusion through careful planning and strategizing and are learning how to live with the limitations that are a consequence of their heart attack. This group are aware that they have a chronic health condition whose impact on their lives is only likely to increase. However, in grappling with it and adapting they currently remain in control of their bodies and illness. Although not at the level of chronicity of Charmaz's participants, the adapting narrative group in this study could be described as 'struggling with their illness' (Charmaz, 1995).

In a Swedish grounded theory study, Brink, (2009) also explored the adaptation undertaken by patients who had experienced a heart attack. She identified four types of adaptation following myocardial infarction and also sought a comparison with Charmaz's, (1995) concepts of struggling with and struggling against illness. In view of those apparent commonalities other

similarities between the Swedish study and this current British study were sought.

Both Brink's study and the theory proposed in this study could identify participants who were struggling AGAINST illness. However, the characteristics attributed to this group by Brink bore a greater similarity to the adapting narrative group which this study considered to be struggling WITH their illness. Brink characterised her group as having a high level of self-agency and who undertook protective behaviour to retain control of their illness. The adjustments undertaken by the adapting narrative group in the substantive theory of biographical restorying could be considered to be self-protective in the manner in which they paced and regulated their activity to prevent symptoms occurring.

Despite the different labels given to these groups by the researchers their characteristics would suggest **there is a category of those with chronic illness who are living limited lives. However, through active management of their health they are able to keep the chronic nature of their condition at bay. The core characteristic of this group is the belief that they have control over their illness.**

Brink, (2009) identified coping with illness consequences and self-agency as the mechanisms underlying adaptation following a myocardial infarction. These mechanisms resulted in the four groups having either strong or weak self-agency and they either avoided or accepted coping with illness strategies. Individuals then undertook either self-modifying or self-protecting behaviour as they adapted to life after a heart attack (Brink, 2009).

It is interesting to note that both the theory of biographical restorying and that of Brink (2009) identified that a concept of self was an important mechanism in adapting to life after a heart attack. Brink's other mechanism of either avoiding or coping with the consequences suggested a link with illness beliefs. However, the term 'consequence' was selected by Brink for its 'fit' with the data as opposed to its use as a domain within the common-sense model of self-regulation. Although the published study is limited in the

description of the categories, Brink's four groups do not appear to share strong characteristics with the four narrative groups proposed in the substantive theory.

The four groups identified by Brink described lives which appeared more limited and focused on illness. The narrative groups in this study spoke less of illness and more of regaining health. Within this study those who spoke of consequences perceived them to have a negative connotation and, in that respect, the negativity inherent in the term consequence may have been identified by participants in both studies.

The focus on illness consequences and the inherent negativity contained within the term, or cultural differences between Swedish and British attitudes to chronic illness, may have contributed to the differences between the two studies. Alternatively, the standpoint of the researcher may account for the different interpretation between the studies.

This study identified that participants experienced a disruption to their narrative identity associated with their heart attack. They also experienced a loss of self-confidence in their abilities to undertake activities during the period in which they created their different life narrative. However, for all but one of the narrative groups self-confidence recovered as previous activities and pursuits such as work were resumed. The struggling narrative group not only experienced a loss in confidence, but her entire concept of self was reduced as a consequence of her heart attack. The factor which differentiated this narrative group from the others was the lack of control she had over the symptoms she was experiencing. This struggling narrative group was living with a chronic illness impacting on every aspect of her life on a daily basis.

Coronary heart disease is considered to be a chronic condition. Illness perception studies have suggested that acknowledging the chronic nature is a key factor in the decision to undertake health-related behaviour change aimed at controlling progression of the disease (Astin, et al., 2009; Wiles and Kinmonth, 2001). Many people live with coronary heart disease and do not

experience the intrusive symptoms associated with the chronic stages of the condition. Those in the enhanced, adapting and struggling narrative groups understood the chronic nature of coronary heart disease. Only one participant in this study was having to adjust to living with the loss of self which has become associated with intrusive chronic illness (Charmaz, 1983).

### **6.3 Creating a new knowledge base.**

Within the substantive theory of biographical restorying participants accrued information from a range of sources after their heart attack. This information was added to their current knowledge and was gleaned from both somatic and non-somatic experiences and interpreted in a way that made sense for them as individuals. This interpreted information contributed to the formation of the different narratives portrayed in this study. The social processes and interactions involved in this process of information gathering crossed all narratives and will now be considered.

#### **6.3.1 Medical knowledge as valued knowledge**

The participants in this study regarded **health care professionals as the primary source of trusted information related to their heart attack.** Interaction with health care professionals differed across the four narratives within the theory of biographical restorying as shown in Figure 6-2.

During the period of disrupted narrative identity, the patient's own previous knowledge and to a certain extent its source had been discredited. This discrediting arose when their own knowledge and experience had been unable to provide a cause for their symptoms, and on occasion even misleading them. In seeking medical help, participants sought expert advice to identify a cause for their symptoms. In a study exploring the differences in patient decision making between acute illness and acute injury situations, Rosenfeld, (2006) supports this view that medical knowledge is afforded the status of expert knowledge when personal knowledge cannot identify a cause for symptoms. In both that study and this current study, the provision of a diagnosis or identity for patients' symptoms affirmed the perception that medical knowledge was expert knowledge.

Participants reported receiving information such as the extent of their heart attack and test results from medical staff. Within the medical narrative doctors limited their role in information provision to that which lies within the decontextualized, systems-based, biomedical model. Responsibility for providing information on the lifestyle aspects of cardiac disease was relinquished to other health care professionals.

**Communication between medical staff and patients in this study was brief and little opportunity was offered to ensure that both patient and doctor had a similar understanding of the conversation that had just taken place.** Despite this perception that communication was brief, the information provided by the medical staff was afforded a high level of credibility by the participants. This is consistent with previous studies in those with diabetes who valued brief interventions from medical personnel (Longo, et al., 2010), and those using internet health advice (Cotten and Gupta, 2004). Both studies reported that sites with contributions from health care professionals were more likely to contain accurate information (Longo, et al., 2010; Cotten and Gupta, 2004).

However, the absence of a further conversation with medical staff to check on their understanding of the information provided led to participants interpreting this information in a way that made sense to them (Table 5-16). The outcome of this was two competing versions of causes, extent and future management of their cardiac event, a factor recognised in the literature (Karner, Goransson and Bergdahl, 2003; Petrie and Weinman, 2012). A review of European cardiac rehabilitation programmes supported the finding in this study that addressing these contested understandings in the cardiac rehabilitation programme led to conflict and confusion for participants (Bjarnason-Wehrens, et al., 2010; Attebring, Herlitz and Ekman, 2005).

This division and the need for concordance between health and lay understandings is well documented but unresolved in the literature (Attebring, Herlitz and Ekman, 2005; Dunckley, et al., 2007; Fors, Dudas and Ekman, 2014; Timmins, 2005). One of the reasons for this is the assertion

that patients do not always retain the medicalised understanding of their condition (Prior, 2003). This has potentially contributed to the current status whereby lay knowledge and its role within health care is contested (Broom, et al., 2013; Prior, 2003).

However, if the origin of this lies in a lack of checking understanding at the point of information delivery, the situation is unlikely to improve without changes to the method of delivery. Information delivered to participants by the medical profession was often considered to be general and was reinterpreted by individuals to suit their own circumstances. Astin and colleagues (2014) identified similar findings in their synthesis of studies exploring lifestyle change after a coronary event.

The attempts to address this through the introduction of initiatives into medical training such as patient-centred medicine (Stewart, 1995) and patient-focused conversation (Mazur, 2002) would appear to be having limited effect to date. Specific interventions such as offering communication skills training for qualified staff do not appear to be part of an overarching strategy to improve outcomes in this area (Ampt, et al., 2009). If the desired outcome is a shared understanding, then, as asserted by Beck, Daughtridge and Sloane, (2002), **information needs to be provided in a language and context that is within the comprehension of the recipient.**

### **6.3.2 Barriers to knowledge acquisition**

The disrupted narrative identity experienced by the participants in this study was a consequence of the emotional turmoil associated with a heart attack. This has been associated with a reduced capacity to absorb the information that health care professionals are attempting to deliver (Astin, et al., 2009; Astin, Horrocks and Closs, 2014). This turmoil increases the potential for a mismatch between the medical and lay understanding. A reduced ability to absorb information has also been linked with a reduced uptake of health-related behaviour change (Sampson, O'Cathain and Goodacre, 2009; Astin, et al., 2009).

However, Dullaghan, et al., (2014) suggest that those who believed their heart attack was life threatening were more likely to express a desire to participate in a cardiac rehabilitation programme to support health-related behaviour change during their hospital stay. The theory of biographical restorying supported this as participants in the continuing narrative initially expressed an interest in attending but on discharge, the seriousness of their event was reduced in their mind and they no longer felt the need to attend.

**Those who did attend cardiac rehabilitation identified that a tangible perception of controllability of symptoms was a prime factor in their decision to attend rather than an emotional decision linked to the seriousness of the original event.**

Previous studies ( Dullaghan, et al., 2014; Astin, et al., 2009) have identified that the shorter length of hospital stays, on average forty-eight hours, for individuals experiencing a heart attack has consequences for information delivery and assimilation. All of the participants in this study recollected being provided with a range of information regarding recovery from a heart attack to support them following discharge. Local protocols for transfer to tertiary centres caused all participants to be in hospital for a minimum of five days supporting their theory that a longer stay offers more time to assimilate information.

During hospitalisation there was a reluctance to discuss emotional concerns with health care professionals as staff were perceived to be too busy dealing with physically ill patients to support emotional and social issues. This led to increased emotional turmoil contributing to their disrupted narrative identity (Bury, 1982). The prioritising of physical issues over emotional or 'lifeworld' concerns (Mischler 1984, cited in Barry, et al., 2001) has also been identified in those attending emergency appointments in primary care. In both studies, patients picked up cues that the biomedical perspective or 'voice of medicine' was the priority with little place for contextual concerns (Barry , et al., 2001). The context of the two clinical areas differs but, in both situations patients accepted that the decontextualized 'voice of medicine' should take

precedence over their contextual 'voice of the lifeworld' issues in an acute setting (Barry, et al., 2001; Rosenfeld, 2006).

Within the substantive theory, the struggling and adapting narrative groups reported seeking out medical staff, usually general practitioners, who they perceived understood their cardiac conditions. These two narrative groups both reported that their condition did impact on their daily activities and their general practitioner acknowledged this. Perhaps some of the medical understanding valued by these participants lay in acknowledging the 'voice of the lifeworld' during consultations.

### **6.3.3 Narrative knowledge**

The information patients gather and reinterpret about their health and illness concerns has been variously labelled within the research literature and society as narrative knowledge (Gabriel, 2004, Popay and Williams, 1996), or lay beliefs (Armstrong and Murphy, 2008; Shaw, 2002). The term narrative knowledge will be used in this study. The impact of specific illness beliefs on biographical restorying after a heart attack were discussed in Section 6.1 and illness beliefs are a component of narrative knowledge.

The important element of narrative knowledge is that it is more encompassing than the traditional systems-based medical knowledge as it incorporates the circumstances of the individual (Popay and Williams, 1996). The narrative knowledge of the participants was founded in part in the medical narrative but their interpretation and implementation was contextualised by their individual situations. This substantive theory of biographical restorying after a heart attack proposes that the interpretation of the impact of symptoms or physical sensations is key in the development of narrative knowledge.

The active balancing of physical activity demands and available capacity undertaken by the adapting narrative group in the study population demonstrates how their illness needed to be managed on a daily basis. Self-management based on narrative knowledge was further evidenced by those who adjusted medication to better manage their symptoms around their

social obligations. This relational aspect between narrative knowledge and self-management was identified many years ago by Davison and colleagues in their exploration of the relationship between lifestyle change and illness prevention (Davison, Frankel and Smith, 1992). The role of narrative knowledge is greater in those with a chronic illness where patients have to actively balance health and social demands.

The narrative knowledge accumulated by participants in this study was one of managing physical sensations that are a consequence of the event. They focussed on minimising the limitations placed on their life and attempting to regain confidence following a heart attack. The biomedical narrative for those who are recovering from a heart attack is one of offering intervention to reduce symptoms and disease progression with simultaneous addressing of lifestyle issues. This focusses on issues such as maintaining a healthy weight, consuming a cardio-protective diet and reducing levels of physical inactivity.

Participants developed beliefs in the domains identified within the common-sense model of self-regulation but their experiential knowledge base was much greater than this. Their narrative knowledge developed from the day-to-day actions undertaken as part of their biographical restorying.

Participants stored and reflected on information with an internal feedback which was called on in future similar situations. This enabled the participants to develop self-management strategies which are viewed as important in managing chronic illness or long-term conditions.

Narrative knowledge that is premised on this experiential knowledge is much more individualised than medical knowledge. Studies exploring how patients with cancer develop their narrative knowledge showed it to be a sophisticated and complex process (Armstrong and Murphy, 2008; Broom, et al., 2013). Narrative knowledge is not currently valued to the same degree as knowledge based on systems learning.

The current supremacy of medical knowledge over narrative knowledge is supported by the credibility and value afforded medical knowledge by the

general population. This has been attributed to medicine retaining the dominant voice in policy development and continuing to limit the infiltration of narrative knowledge into medical consultations (Barry, et al., 2001). Government policy initiatives such as 'The Expert Patient' (Donaldson, 2003) and 'Public Patient Involvement' (Florin, 2004) programmes, which were conceived with the aim of increasing lay involvement within UK health care, have seen mixed success.

#### 6.3.3.1 Narrative knowledge to support self-management of health and illness

Participants within this study identified that medical personnel retained this emphasis on acute illness by concentrating on the technical aspects of care required in hospital. Long-term elements of lifestyle change were considered the role of nursing and allied health care professionals. Disease-based medicine was designed to deal with acute and curable conditions. Arguably within the world of chronic illness the expertise lies with those who are experiencing the illness (Broom, et al. 2013; Prior, 2003; Walker, et al., 2015). Prior, (2003) has suggested that the term 'lay expert' was an oxymoron but if interpreted as someone outside of the medical speciality who has experience of a condition then it can be applied to many people. This emphasis on self-management of chronic illness has enabled the medical profession to retain their focus on acute conditions.

Within the clinical world the rise in chronic illness has been associated with a shift from the biomedical model to one which includes psychosocial concerns and an interest in the patients' perspective of their illness (Engel, 1977; Stewart, 1995). The role of the health professional in supporting those with chronic conditions is one of identifying how they can increase motivation and support change in their patients (Donaldson, 2003). This requires a different skillset from the traditional medical roles of diagnosis, treatment and cure. Many of the services designed to support those living with a chronic illness, such as cardiac rehabilitation programmes, are led by professions allied to

medicine (Dennis, et al., 2008; Rogers, et al., 2011) whose training has evolved to reflect the need to include psychosocial concerns.

One of the outcomes of the development of narrative knowledge has been the passing of the responsibility traditionally held by doctors back to patients. Participants made decisions on issues such as titrating medication based on their narrative knowledge of their condition and reconciling this with their daily life. This had been perceived as a positive outcome of empowering patients through self-management of chronic illness (Salmon and Hall, 2003). Initiatives such as 'The Expert Patient' programme (Donaldson, 2003) were designed to increase this ability to self-manage chronic conditions but reports of their success are limited (Greenhalgh, 2009; Warsi, et al., 2004).

In addition to creating patients who are expert in the self-management of chronic illness, programmes enabling self-management are also viewed as a potential means of containing health costs. This study suggested that those living with a chronic illness, which is currently stable or at least predictable, do self-manage their condition with minimal usage of health care resources. Cardiac rehabilitation programmes as attended by the adapting and enhanced narrative groups support patients and have been shown to reduce morbidity and health care costs (Heran, et al., 2011; Yu, et al., 2004).

In situations where there is greater intrusion of the illness into daily life there is a corresponding increased usage of health care resources. However, this group who have most to gain from support with self-management programmes struggled to attend because of the limitations of their illness.

#### 6.3.3.2 Narrative knowledge as valued knowledge

The narrative for medical management is placed in the public domain in the evidence-based guidelines from the National Institute for Health and Clinical Excellence, a part of the Department of Health (NICE, 2013). The experiential knowledge of those living with the condition is not so widely or publicly disseminated. Research on the role of narrative knowledge has identified the ways in which patients self-manage the intrusion of chronic

illness into their lives (Balmer, Griffiths and Dunn, 2013) but the current evidence base remains much smaller than that of the medical narrative.

The biopsychosocial approach to care is reflected in postmodern behavioural and social science research where qualitative and mixed methods studies exploring health care from this perspective are becoming more accepted. This is less evident in medical research which still values randomised controlled trials as the basis for evidence-based medicine (Petrie and Weinman, 2012; Schoenthaler, et al., 2013). The continued privileging of experimental knowledge over experiential knowledge, the basis of narrative knowledge, has been viewed as medicine's means of maintaining its dominant position in the knowledge hierarchy (Salmon and Hall, 2003).

Research considering the role of illness beliefs in undertaking behaviour change would appear to support this assertion. Much of the illness belief research reported in this study has been undertaken from the perspective of the medical paradigm in a search for links between beliefs and action. There have been repeated calls over the years for research into the patient perspective of illness beliefs but key authors and supporters of the model continue to report on work with a quantitative focus. Thus, the complexity of thoughts and actions associated with the formation of illness beliefs and narrative knowledge in this context remains less understood.

The discussion currently afforded narrative knowledge arises from changes in sociological, clinical and political ideologies. In the postmodern world the supremacy of science, of which medicine is the dominant part, as the authoritative paradigm has been challenged. There are calls for other paradigms to be afforded a similar voice and respect to that which the positivist paradigm has enjoyed for many years. Within the sociological world, Foucault, (1980) has been one of the main challengers of the power afforded the discourse of medicine. He claimed it organises and controls us from the cradle to the grave both physically and socially through preventive, social and community medicine.

It can be argued that the influences of those such as Foucault have facilitated the emergence of other discourses such as that of the patient who is now seen as an active agent in managing their illness and health care (Rose, 2002). The emergence of other discourses also increased research into areas such as patient empowerment and individuals' means of controlling and coping with chronic illness (Salmon and Hall, 2003).

Perhaps both patients and health care professionals would benefit from a joint learning experience in which the virtues of expertise in both domains, lay and medicine are recognised. More recent studies and reviews have suggested that a joint approach would strengthen, refine and support formalised expertise as health care becomes increasingly pluralistic (Petrie and Weinman, 2012; Broom, et al., 2013). This would require the medical profession to increase their engagement in research from other paradigms, a scenario currently afforded a low priority within the profession.

#### **6.3.4 Media sources of narrative knowledge**

In gathering information, the participants in this study, consistent with other studies, relied mostly on that provided by health care professionals (Longo, et al., 2010; Cotten and Gupta, 2004). Those who subsequently accessed reading information on their condition from other sources sought recommendations from their health care professionals. This was undertaken either by directly requesting signposting or vicariously through the reading of condition specific material available in the waiting rooms of health care facilities. Patient focused literature produced by the British Heart Foundation was the most frequently named source of written information.

The roles of television and the internet in providing information to inform illness beliefs elicited a more specific response from participants and this will now be discussed.

#### 6.3.4.1 Informing narrative knowledge through public health programmes.

In considering the causes of their heart attack, participants' prior knowledge of risk factors for heart disease was derived from information in the media as a consequence of public health campaigns. Advertising strategies to highlight the value of changing diet, stopping smoking or increasing physical activity had raised awareness and had potentially influenced decisions to adapt a behaviour to benefit their general health in the short term. However these campaigns had not directly influenced a risk reduction related behaviour change for any participants in the time before their heart attack (Balmer, Griffiths and Dunn, 2013).

In considering potential causes of their heart attack participants reflected back on such campaigns to identify why their risks of a having a heart attack, such as being 'reasonably fit', should have been reduced in comparison to others. This deflection of perceived risk onto others has been found in other studies examining the perceptions of those who have experienced a heart attack (Balmer, Griffiths and Dunn, 2013; Davison, Frankel and Smith, 1992). Thus, public campaigns seemed to raise general awareness of risk factors but, without a specific individual message, do not appear to effect long-term risk reducing behaviour change.

The dominance of the medical discourse is seen in the public health and health promotion campaigns which are frequently targeted at cardiovascular risk factors of stopping smoking, physical inactivity and poor nutrition. These continue to be centrally developed and remain in the grip of medical science (Williams, 2003). They are delivered as a single topic in a rational fashion which does not address the context in which people undertake and change those behaviours or how the different risk factors are interrelated. The devolving of power to local areas does not appear to have effected change within localities. Innovative local programmes such as 'Fag ends', which use local lay advisors rather than health professionals to facilitate smoking cessation with excellent outcomes, remain in the minority (Springett, Owens and Callaghan, 2007).

Participants did raise concerns that opportunities to personalise their risk of having a heart attack had been missed by health care professionals. Health checks are offered in the United Kingdom and are expected to identify and discuss an individual's risk of developing cardiovascular disease. The concern raised by participants was that specific risk factors for heart disease, such as family history and diabetes, carried by some participants, had not been highlighted by a health care professional during these checks. The absence of any recollection of such a discussion by the study participants attending such appointments and the result from Ampt's study (2009) suggests these interventions are not as rigorous or effective as they could be.

In an Australian study, Ampt and colleagues (2009) studied medical practitioners undertaking health checks to detect lifestyle risks for coronary heart disease. They identified that doctors did not discuss nutrition or physical inactivity as a risk factor if the patient looked intrinsically healthy. Additionally, any discussion on behaviour modification was based on a relatively subjective assessment of the level of the patient's intrinsic motivation as opposed to assessing how they, as health care professionals, might increase the patient's motivation for change (Ampt, et al., 2009).

The role of medical staff in risk factor modification was raised by the practitioners in the study. They considered that specialist health professionals such as nutritionists may be better equipped to address these issues and if better outcomes could be achieved this should certainly be considered (Ampt, et al., 2009). In the United Kingdom where consultations are generally undertaken by practice nurses, outcomes are no better (Robson, et al., 2016). This calls into question the overall effectiveness of this national screening policy in reducing future health costs for cardiovascular disease.

Patients attending health review type consultations arrive with an expectation of a discussion regarding their individual risk of future events. The presence of non-modifiable risk factors such as a strong family history increases the challenge of these conversations. Their presence can lead to an attitude that

lifestyle issues are of no use in the presence of a genetic predisposition to the disease (Emslie, Hunt and Watt, 2001). However, a failure to relate their medical risk to their personal situation reduces both the likelihood of acceptance of risk and potential for a change in behaviour to reduce personal risk. The belief that develops from such a consultation is one of misattribution of future risk which has to be addressed should a cardiac event such as a heart attack occur.

Cardiac rehabilitation programmes aimed at supporting health-related behaviour change following a heart attack are offered across the United Kingdom. They are promoted as an evidence-based treatment which reduces morbidity and mortality following a heart attack (Lawler et al. 2011, Taylor et al. 2004). However, despite an intensive campaign by the British Heart Foundation to improve awareness of the benefits, the uptake of cardiac rehabilitation remains relatively low at 45% (NACR 2016).

The planning and development of the programmes occurs from the perspective of the voice of medicine. Patient involvement in the planning and delivery of these programmes is promoted (BACPR, 2017) but the reality is one of nominal lay involvement. The encouragement to increase activity levels by following an exercise *prescription* suggests that the biomedical model may continue to be a dominant force in the planning of these programmes. **Uptake of cardiac rehabilitation may increase if the voice of those with experiential knowledge had a greater input in their development.**

It would appear that centrally co-ordinated programmes deployed at both general and individual levels to reduce risk behaviour is having minimal success. The greatest success appears to occur when those who have carried the risk factor are involved in developing behavioural change programmes. The continued dominance of medical knowledge in the development of such campaigns may benefit from further review.

#### 6.3.4.2 The potential of dramatic portrayal of cardiac events to mislead

Participants did not alter their heterogeneous usage of media such as newspapers, television or internet following their heart attack. Their viewing was based on social and cultural patterns with passive receipt of both general and specific health-related information being gained through these sources (Murray, Manktelow and Clifford, 2000; Longo, et al., 2010).

The portrayal of individuals experiencing a heart attack in television programmes, where the victim experiences severe central chest pain, misled participants when considering potential causes for their original symptoms. For all but two participants, television portrayal was their only experience of what a heart attack would look and feel like. The symptoms experienced by the participants were very different from those they had been led to expect by television. This risk of the portrayal of a classic heart attack potentially delaying the seeking of treatment has been recognised in the literature (O'Donnell, et al., 2014).

If the media consistently dramatise heart attacks in such a way that the real event is then misrecognised by a significant number of individuals then there are issues for both health care and the media. In the management of heart attacks, identifying and initiating treatment within a few hours of symptoms is key to good outcomes (Hartwell, et al., 2005). The popular television dramas or 'soaps' are watched by large sections of the population. Their potential impact on individuals is acknowledged by the provision of helpline numbers at the end of episodes where the storylines cover sensitive or distressing topics. If that responsibility was to extend into portraying the range of ways in which heart attacks can present, they may encourage more patients to present for treatment sooner, increasing the numbers able to benefit from the early effective treatments now available (Mooney, et al., 2014; Balmer, Griffiths and Dunn, 2013).

#### 6.3.4.3 Internet as a source of narrative knowledge

Only four participants reported using the internet for health-related matters and the general consensus of participants echoed other studies. The participants in this study expressed a general distrust of internet information (Bernhardt, et al., 2002; Fox, Ward and O'Rourke, 2005), with the preferred source of health-related information being a health care practitioner (Cotten and Gupta, 2004). Of note, the participant who most utilised the internet for health-related issues fitted the profile of the frequent health-related internet user identified by Bylund, et al., (2007) as being female, under 65, educated but in poorer health, often with stigmatized illnesses.

Those participants accessing the internet undertook specific searches related to an aspect of their condition often to gain information to support a medical appointment (Fox, Ward and O'Rourke, 2005; Higgins, Barry and Domegan, 2011; McMullan, 2006). During the subsequent consultation they discussed the issue but did not share the source of their information for fear of incurring the disapproval of the health care practitioner (Bylund, et al., 2007; Hesse, et al., 2005). This reluctance to credit the source of medically related information may change in the future. Younger respondents to media-related research are reported to consider media sources of information more reliable than traditional routes of information delivery (Balmer, Griffiths and Dunn, 2013).

The range of services now available on the internet which provide health-related information is vast and includes general web surfing and specific searches. The use of online forums associated with health-related issues has also increased in recent years with up to 80% of internet users accessing one or more of these services (Bylund, et al., 2007; Cotten and Gupta, 2004; Higgins, Barry and Domegan, 2011; Keeling, Khan and Newholm, 2013;). The low usage of the internet in this study group is not supported by recent estimates of those accessing health-related information (Fox, Ward and O'Rourke, 2005; Keeling, Khan and Newholm, 2013), and can potentially be explained by their age and limited access to computers. As the generation who currently access the internet and social media as a first stop for

information develop coronary heart disease, this level of usage can be expected to change (Ayres et al. 2007; Ybarra, et al., 2008).

Another potential reason for the reduced use of the internet is inadequate signposting by cardiology health care professionals. The research identifies those with diabetes and cancer as accessing online information (Longo, et al., 2010; Keeling, Khan and Newholm, 2013). However, no instances of the use cardiac patients may make of the internet were identified during the database searches for this study. There are a range of websites relevant to cardiac patients and there are internet-based cardiac rehabilitation programmes available in the United Kingdom. The lack of a patient voice in internet-based cardiology is potentially a result of the higher incidence of men who experience heart attacks. The internet-based discourse of the patient and narrative knowledge is currently strongest in female-dominated illnesses such as breast cancer (Broom, et al., 2013). If signposting was a part of routine care for this group of patients then the usage might be more likely to increase (Wantland, et al., 2004).

Medical and narrative knowledge has become much more accessible to the general population through internet access. In this arena, internet forums have become a popular means of discussing health-related information (Cotten and Gupta, 2004). The ease and often instantaneous reciprocation on these forums has the potential to be viewed as conferring validation of information by other forum members. This peer-based ratification of narrative knowledge has led to forum users reportedly placing more credibility on narrative knowledge than expert knowledge (Balmer, Griffiths and Dunn, 2013). This, in conjunction with the previously raised issue of medical staff not reviewing patient understanding of the information provided during consultations, could further distance lay and medical knowledge if interpretations vary significantly. Future users of health care may be more vocal of their usage of narrative knowledge validated by the experience of other users challenging the current supremacy of experimental medical-based knowledge.

Summary

The participants in this study valued knowledge provided by health care professionals over that from other sources. They interpreted this information and developed lay beliefs about the management and trajectory of their recovery from a heart attack. This involved developing self-management strategies perceived as important in the management of chronic illness. This altered their traditional relationship with health care professionals as they assumed responsibility for aspects of their care previously in the medical domain. **Relationships with health care professionals appeared better where there was an acknowledgement of the impact of their condition on their lifeworld.** This group had not embraced modern technology to assist in their management to the extent suggested by the evidence. This is possibly related to their age and is one aspect I would expect to alter were this reviewed in a population of the same age in the future.

This study acknowledged that cardiac rehabilitation does support those who can effect health-related behaviour change and increase their ability to self-manage their condition. However, although it is promoted as an individualised approach, cardiac rehabilitation is not as accessible to those who are struggling to self-manage their condition. This limitation may account for some of the poor uptake of the programmes and other initiatives aimed at improving self-management of chronic illness. There are opportunities to improve this by acknowledging the value of narrative knowledge and using it to inform the development of such programmes. The current value afforded knowledge from the medical narrative in the development of these programmes and initiatives limits their applicability to those in whom chronic illness is a continual and unpredictable intrusion into daily life.

The growth in the literature on narrative knowledge as a component of a discourse of the patient and its ambivalent position and value in comparison with the discourse of medicine have been brought into focus in this study. This first became apparent in the way participants responded during interviews as it became apparent they were relaying the story of their

recovery, or otherwise, from their heart attack. This potential significance of this will now be explored.

#### **6.4 Role of illness narrative theory**

Within this study the narrative nature of the data being provided became apparent during the second interviews. The emergence of the four narratives was a key factor in the development of the substantive theory. In commencing the interview participants and researcher reoriented themselves to the end of the first interview as a starting point for the collection of new data. Participants proceeded to recount their recovery from that point forwards to the time of interview. The participants in this study probably do not consider themselves to be storytellers and their stories spoke of ordinary lives surviving an increasingly common event but within these stories there were the elements that 'fit' with the narrative theories of Frank, (2013) and Charmaz, (2002).

The theories and typologies described by these authors informed the development of the grounded theory. The participants' story is not the grand quest type narrative (Frank, 2013) but they still speak of disruption and rebuilding of a life after a heart attack. The stories acquired both a voice and a name as their fit with narrative theories evolved. (Reeve, et al., 2010) and from this the grounded theory emerged.

This theory begins with the participants experiencing an acute episode of illness which resulted in a period of disrupted narrative identity. The acute illness is part of a chronic disease and for most participants this is the first manifestation of this process.

The biographical disruption in this study disrupted the patient's sense of self, place and time. Disruption to place was the first to resolve, occurring within a few days of admission as patients acclimatised to the routine of the hospital setting. Disruption to time and self as previously discussed continued to a greater or lesser degree for most participants as they restored their lives.

This disruption is similar to that of biographical disruption repaired through a narrative reconstruction of one's life described by Williams, (1984). The original theory of biographical disruption was developed from a study into chronic illness (Bury, 1982). The chronic illness was portrayed as a major disruptive experience which threw the individual's normal and taken-for-granted aspects of life into disarray (Bury, 1982; 2001; 1991).

Since that time Charmaz,(1983) and Hubbard, Kidd and Kearney, (2010) have acknowledged that the notion of biographical disruption can also be applied in the setting of acute illness. This study supports a study on colorectal cancer in which biographical disruption was apparent in individuals experiencing an acute episode of a disease process considered as chronic by the narrative of medicine (Hubbard, Kidd and Kearney, 2010).

The substantive theory proposes that the narrative outcome was heavily influenced by what participants could physically achieve (functional) rather than a meaning making process (cognitive) of who they were. In a study exploring the illness experience of those with cancer Reeve, et al., (2010) also noted that identity was anchored in functional as opposed to cognitive events. As humans we identify ourselves from a 'doing' rather than 'being' perspective.

Not all patients need to restore their identity. This study and Hubbard, et al's., study on those with colorectal cancer ((Hubbard, Kidd and Kearney, 2010) reached similar conclusions. If an individual's self-identity remains intact, as in the continuing narrative group in this study, then lives can continue on their previous biographical path seemingly unaffected by their illness.

#### **6.4.1 The 'fit' with grand narratives**

The three typologies suggested by Frank, (1997; 2013) of a restitution, chaos and quest narrative can be seen in the four narratives generated in this study. The enhanced and continuing narratives can be likened to Frank's restitution narrative, the struggling narrative likened to his chaos narrative, and the adapting narrative to his quest narrative. Studies by Bleakley, (2005) and Brink, (2009) have also identified three or four different illness narratives

within qualitative research studies exploring a range of illnesses. Although not all of these studies have related their work to that of Frank, similarities with Frank's typologies can be identified in each of these studies.

The four adaptation positions described by Brink, (2009) researching the post-heart attack population in Sweden had some similar traits to the narrative groups in this study. Brink's study acknowledges that disruption occurs with a heart attack and that a 'newly constructed self' is part of recovery (Brink, 2009).

This suggests a link to Frank's typologies is not an unusual finding in illness research, adding support to the usefulness of Frank's typologies. The narrative groups identified in this study will now be compared to the typologies identified by Frank.

#### **6.4.2 The continuing narrative as a story of restitution**

The restitution narrative has at its base the plot of health interrupted by illness followed by a return to health. Restitution is brought about by a medically based agent such as surgery or specific treatment. It is the narrative most individuals and our contemporary culture aspire to (Frank, 2013). Those in the continuing and enhanced narratives of this study achieved this status but from different approaches to their period of illness.

The continuing narrative group experienced a short period of illness associated with a rapid return to their previous health status with little or no disruption to their sense of coherence or self. The continuing narrative group perceived their health to be contingent on the ageing process, to which they attributed all ongoing physical sensations. Their adherence to their medication was a means of reducing the impact of heart disease on the ageing process and keeping ill-health at bay. Thus, this group were able to contain the contingency of illness and its association with mortality and were able to remain within the restitution narrative (Frank, 2013).

The continuing narrative group were passive in this process. The medical establishment took the active role of prescribing the 'cure' and, in attributing

health issues to ageing, there was no requirement to address causality. The continuing narrative may be considered part of the remission society who claims membership of the restitution narrative as a result of medical involvement (Frank, 2013).

### **6.4.3 The enhanced narrative as a story of restitution**

The enhanced group also experienced a return to health but with a greater sense of biographical disruption and resultant loss of cohesion than the continuing group.

The transition back to health of the enhanced group involved changing behaviour in addition to taking medication as a means of reclaiming and maintaining good health. Remaining a part of the restitution narrative was contingent on reducing their chances of experiencing another heart attack through maintenance of these measures. This group perceived positive benefits which they maintained through monitoring of self-motivated behaviour change, making them more active participants in retaining their restitutive position than the continuing group.

The manner in which the enhanced group perceived the efforts of their behaviour change as a fight back against the progression of the incurable atherosclerotic heart disease could be considered to be an enactment of elements of the quest narrative. This is consistent with Frank's findings (Frank, 2013) that individuals can carry traits for all typologies and the prominence of any one will vary depending on the individual circumstances.

For the continuing and enhanced narratives, the initial disruption associated with experiencing a heart attack has resolved. A future in which health is possible and illness is held at bay gains them membership of the restitution narrative. For the other two narrative groups, namely that of adapting and struggling, restitution is not an option as uncertainty with regard to their health is now a part of daily life.

#### **6.4.4 The adapting narrative as a story of quest**

Quest stories tell of accepting illness and attempting to use it (Frank, 2013). The adapting narrative group described in this theory provides an example of this story.

One participant from this narrative whose second interview, in retrospect, resembled a quest manifesto provided the spark which ignited the exploration of illness narratives and their relevance to this study. The interviewee described the ways in which she bargained and juggled her way through three chronic illnesses to maintain an active and fulfilling life. She described health as 'not being ill' and it took all her energies, organised with an almost military planning, to maintain this status. The search for a theory to explain this data led me to explore Charmaz's narrative work with chronic illness and from there to the work of Frank.

Those who are adapting to illness have to acknowledge its presence as they plan and pace their participation in daily life. There is an awareness that their health is only likely to deteriorate and this is spoken about as the 'elephant in the room'. This adapting narrative group tell how they incorporated illness into their life and in emphasising what they have gained, speak of health in terms of not 'feeling ill' rather than lamenting the loss of previous health.

Within the quest narrative there is a belief that something will be gained from the endeavour required and for this group the goal was to remain in relatively good health (Frank, 2013). The participants in the adapting narrative group were more reflective of their health status than other narrative groups, potentially because of this continual requirement to monitor and adapt.

The adapting narrative group do have a degree of control over their health which offers them a remission status but there is an awareness that this is not guaranteed to last. A restitution narrative is not possible for this group as they will never achieve a position in which they will feel returned to full health. Their health is contingent on staving off episodes of ill-health and one of their aims is to avoid slipping into a chaos story.

### 6.4.5 The struggling narrative as a story of chaos

The illness narrative told by the struggling group is that of the chaos narrative. In a chaos story life has no coherent sequence or structure (Frank, 2013). However, Charmaz, (1983) identified a broader form of suffering than the purely physical when she spoke of the loss of self experienced by many with chronic illness. The participant in the struggling narrative group relayed a story in which all four sources of suffering identified by Charmaz, (1983) and listed in Table 6-2 **Error! Reference source not found.** could be seen.

The social isolation this participant was experiencing was a consequence of ceasing driving. Her inability to maintain previous supporting roles within the family left her feeling discredited. She now perceived herself to be an increased burden to her family members through both her ongoing ill-health and family members having to undertake roles previously held by the participant. These factors contributed to make her life disordered and unpredictable. In describing the limitations on her everyday activity a story of a downward spiral of self-discrediting, which echoes the stories of Charmaz's participants, was recounted (Charmaz, 1991; 2010).

Sources of suffering in those with chronic illness
<ul style="list-style-type: none"><li>• Leading restricted lives</li><li>• Experiencing social isolation</li><li>• Being discredited</li><li>• Burdening others</li></ul>

Table 6-2 Sources of suffering in the chronically ill (Charmaz,1983)

In speaking of her daily struggles this participant spoke most of what she had lost. She told how she could no longer undertake her previous range of activities and described how the few activities she now undertook filled her time as she struggled to find the stamina to complete them. Life is lived in the

here and now with a hope that life will improve. There is, however, little evidence of this happening as without the time or temporal space to evaluate her life the story becomes more chaotic (Frank, 2013). Those who are struggling have lost the capacity to predict and control their condition, with contingency becoming the normal state with a resultant increase in social isolation and discreditation.

#### **6.4.6 A role for narrative theory in cardiac rehabilitation**

In recounting their biographical restorying after a heart attack, four different narratives became apparent as the theory developed. **It is entirely plausible that if participants do not consider the narrative of cardiac rehabilitation to be relevant to their current story they are less likely to engage with the service. This may account for some of the low level of uptake currently experienced by cardiac rehabilitation programmes in the United Kingdom.**

The restitution narrative is promoted, consciously or not, by cardiac rehabilitation programmes in the United Kingdom. Through their support for medicine's ideals, such as concordance with medication regimes, eating healthily and being physically active, these programmes support the idea that ill-health and therefore mortality can be kept at bay. Currently only 45% of eligible patients participate in cardiac rehabilitation programmes (British Heart Foundation 2015) but if these programmes are organised by health care professionals from the perspective of the restitution narrative, then those who do not fit into this narrative will feel excluded.

Within cardiac rehabilitation services, calls are made for the provision of individualised programmes. Either the four narratives identified in this theory or the broader typologies suggested by Frank (1997,2013) could be utilised as a theoretical underpinning for individualising and broadening the appeal of cardiac rehabilitation programmes. If this could then be articulated in the promotion of services then cardiac rehabilitation might seem more relevant to

those who are struggling with life after their heart attack and unable to reconcile their story with one of restitution.

Greater public involvement in the development of national and local services is a component of the latest national standards for cardiac rehabilitation in the UK. (BACPR, 2017, p6). Identifying and involving potential service users from the four narratives identified in theory of biographical restorying could help develop a more inclusive model of cardiac rehabilitation. This and the inclusion of more qualitative work in their evidence base may help shift the underpinning standpoint of their programmes. A subsequent redesign from a less positivist or restitutive perspective, might reach out to more patients and raise the percentage of those participating in cardiac rehabilitation after a heart attack.

A Swedish study involving patients with heart failure developed a patient-centred care plan (PCC) based on the narrative of the individual patient (Dudas, et al., 2013). The PCC increased the patients' knowledge of and concordance in self-managing their condition. This suggests that incorporating the patient narrative into cardiac rehabilitation interventions could be an effective means of improving health-related behaviour change and warrants further investigation.

Frank, (2013) contends that individuals can have elements of all narrative typologies within their story. This offers two potential areas for further exploration of the role of narrative theory in increasing the uptake of cardiac rehabilitation. If cardiac rehabilitation retains its focus on restitution can interventions be developed to identify and build on the restitution elements of an individuals' narrative where other narratives currently dominate? If this resulted in patients perceiving the relevance of the cardiac rehabilitation programme to their narrative, then they may be more likely to attend.

Alternatively, the narrative underpinning cardiac rehabilitation could be developed to include elements of the other narratives. This could make it more recognisable to those living another narrative and increase the likelihood of engagement with the service. Undertaking change such as this

would require those considering the evidence base for cardiac rehabilitation to value qualitative research at a level similar to that currently afforded quantitative studies.

Cardiac rehabilitation currently emphasises the importance of addressing individuals' misconceptions or illness beliefs about their heart disease (BACPR, 2017, p12). However, the evidence base supporting the current BACPR standards on behaviour change is overwhelmingly quantitative. This is despite increasing support for the role of qualitative research in understanding the complexity of supporting and undertaking health-related behaviour change in those with chronic illness (Reuben and Tinetti 2012; Gray, et al., 2016).

This study has shown that illness beliefs are contextual to the narrative in which the individual is living and will be further explored in Section 6.1. Exploring illness beliefs from an evidence base which incorporates the findings of narrative research has the potential to influence future standards and interventions designed to support health-related behaviour change. This may increase the relevance of these strategies to some of those who currently do not engage with health care professionals in the field of cardiac rehabilitation.

## **6.5 What this study contributes to the body of knowledge**

- Illness perceptions in the domains of identity and cause are developed as knowledge and information is received from others during the hospitalisation phase of their illness. This is important as beliefs in the causality domain are linked to undertaking health-related behaviour change associated with preventing further heart attacks.
- Lay definitions as to whether an outcome is within the control or consequence domain differed from that used by the developers of the common-sense model of self-regulation. Lay definition incorporated the individuals' experiential knowledge, an element which is absent from the definitions in the literature.

- A high level of belief that the illness was controllable and the linking of physical sensations with health benefits was linked to higher perceptions of self-confidence and health. This was associated with the undertaking of health-related behaviour change aimed at reducing the risk of future heart attacks.
- Symptoms, or physical sensations of ill-health, were considered to be consequences and associated with more negative perceptions of control and self-confidence. These were indicative that the individual was now living with a chronic illness.
- The information provided by medical staff is regarded as credible and trustworthy by patients; however, lay interpretation of this information is not discussed with patients resulting in a lack of shared understanding. This is despite changes in the training of health care professionals aimed at gaining the patient's perspective of their condition.
- The accessing of the internet for health-related information remains low in those who have experienced a heart attack.
- The narrative typologies offered by Arthur Frank, (2013) fit with the narratives identified in this study. Based on literature searches, this is the first time this has been explored and may offer future directions for the development of interventions and research.

## **6.6 Limitation of this study**

Relatively few qualitative studies have been undertaken in this area but there is an abundance of quantitative data and some mixed methods studies. The lack of experiential research has limited my ability to critique my theory against other studies with similar findings.

Comparisons with illness belief studies undertaken in the other paradigms has produced a mixture of support for and questioning of their findings.

The longitudinal design of the trial and the nature of the grounded theory method meant that membership of the narrative groups was not predictable at the start of the study, such that participants could not be

recruited to specific groups at that point. This resulted in one narrative group containing only one member, which potentially reduced the robustness of the theory. If this single membership narrative group had not displayed strong similarities to those with chronic illness described by Charmaz, the final theory could potentially have looked very different.

Longer-term follow-up of participants would be useful as evidence suggests there is reduced adherence to health-related behaviour change undertaken in the context of a heart attack as the time from the original event increases. The patients' perspective on why this occurs, or if it did in this studied population, would have been useful knowledge.

As a novice researcher my lack of previous experience will have impacted on the quality of the data and analysis. I made every attempt to mitigate this by reading widely before selecting core texts to support me in undertaking this study. I attended seminars and special interest group sessions to facilitate learning through discussion and networking.

The limitations of qualitative works in general apply to this study. There are limited numbers in the study, making extrapolation to a wider population challenging. Theory generation is a construct of all that I and the participants brought to this study and is unlikely to be replicable. This makes comparison with other studies difficult, even if an attempt is made to replicate the study in a different population.

## **6.7 Implications for practice, education and research**

### **6.7.1 Practice**

- Illness beliefs in the domains of identity and cause appear to be relatively fixed by the point of discharge from hospital. Illness beliefs in those domains also influence health-related behaviour change aimed at reducing the risk of future events. Interventions designed to influence those domains which can be delivered during the period of hospitalisation may increase adoption and adherence of these behaviours.

- Interventions to address the domains of control and consequence may be more effective if undertaken post discharge from hospital. The impact of physical sensations which appear to influence beliefs in the cause and consequence domains are unlikely to be apparent in the hospital environment. Interventions which support an individual to attain control over their condition would seem most likely to be achieved in an environment which encompasses the context and complexity of the patients' lived experience.
- Ensuring concordance between medical and lay understandings of information exchanged between patients and health care professionals could be improved. Patients continue to value and respect the scientific knowledge base of the medical profession. Interpretation of information provided by doctors is influenced by the patients' past experience, prior knowledge and current situation. This contextualising of knowledge is a potential cause of the differences between lay and medical knowledge. Providing information in a way that is relevant to the context of individual patients may reduce some of this friction.
- Cardiac rehabilitation programmes are currently underpinned by a restitution narrative. These programmes support patients undertaking health-related behaviour change. If health-related behaviour change is not currently within the patients' control they may feel that cardiac rehabilitation programmes have little to offer them. If those planning cardiac rehabilitation programmes were to include interventions which align with other narratives, then the appeal to a wider audience and the numbers engaging with the service could increase. This will require a shift in the epistemological underpinnings of these programmes but the proportion of eligible patients completing cardiac rehabilitation programmes has remained relatively static over many years. An alternative stance may be what is required to increase overall uptake.

### **6.7.2 Education**

- Those planning public campaigns with an important health message should carefully consider the content omitted. There is a need to deliver a

short sharp message which has recall and impact if the campaign is to be successful. However, there is a risk that oversimplification of the message inadvertently misinforms the public through the omission of certain facts.

- Those with chronic illness access health resources frequently but their complex needs are not always understood or addressed. The incorporation of more qualitative research, which can articulate this complexity more effectively than quantitative studies, into the education programmes of all health care professionals may help ensure that care is focused on the issues associated with a chronic illness. A reassessment of the value afforded to qualitative research when compared to quantitative studies in considering the evidence available in caring for those with a chronic illness might help increase the focus on this increasing number of patients.

### **6.7.3 Research**

- There is a considerable body of knowledge predicting links between specific illness domains of the common-sense model of self-regulation. There are now some smaller studies, including this one, which support these predictions. It is now time to consider developing interventions based on the common-sense model of self-regulation which support patients in self-managing their condition.
- As the burden of chronic disease on health resources increases we need to build an evidence base to ensure the needs of those with a chronic illness are met. Qualitative methodologies are best placed to increase our understanding of the complexity of living with a chronic illness. A review of the knowledge gaps and the qualitative methods best placed to answer some of the questions could be developed. The major research funding bodies which are currently heavily biased toward supporting studies in the quantitative paradigm could then have a funding stream to support research in these areas.

## 6.8 Conclusion

This longitudinal constructivist grounded theory study has used narrative theory as a lens through which to view recovery from a heart attack from the perspective of those experiencing the event. An episode of acute biographical disruption associated with hospitalisation at the time of their heart attack required individuals to restore their lives. Four different narratives of lives which were continuing, a struggle, limited or enhanced by the event emerged.

Interpretation of the physical sensations participants experienced directed the stories of change within the theory of biographical restorying after a heart attack. The group who did not realign their concept of a heart attack attributed on-going symptoms to the process of ageing and told a story of life continuing unchanged. Others recounted how they controlled the occurrence of physical sensations through limiting activities and pacing themselves. With forward planning, his group were able to lead a life which was limited but minimised the intrusion of the impact of the heart attack into their lives. The third group experienced on-going sensations associated with illness. These sensations were out with the control of the individual and told of a struggling life increasingly dominated by ill-health. A final group reported their lives had been enhanced following their heart attack. They described positive physical sensations which encouraged further activity. This group were unlimited in the activities they could undertake.

Illness beliefs adapted along the post event trajectory with differences in these interpretations and adaptations apparent across the four narratives. Beliefs in the identity and cause domains were influenced early in the journey as participants sought to make sense of the physical sensations that had led to their hospitalisation. Interpretation of their physical sensations, in the weeks and months after their heart attack, led to the adaptation of illness beliefs in the consequence and control domains. Beliefs in the consequence and control domains were more fluid, influenced by the allocation of meaning to changing physical sensations. These adapting beliefs also informed

concepts such as feeling of self-confidence, positioning on a health-illness continuum and the limitations the heart attack had placed on their lives.

Thus, the theory of biographical restorying after a heart attack clarifies the time line over which illness beliefs adapt. Beliefs in the identity and cause domains, which were influential in determining attendance at cardiac rehabilitation, adapted during the biographical disruption phase and then remained relatively fixed. Those in the consequence and control domains adapted in the months following their heart attack and provided enlightenment as to why some individuals did not participate in cardiac rehabilitation. These findings offer information on the timing of interventions designed to support the adaptation of specific illness beliefs.

The theory also offers ways of developing new interventions aimed at making cardiac rehabilitation relevant and accessible for those who do not feel it is currently relevant for them. This study acknowledged that cardiac rehabilitation does support those who can effect health-related behaviour change and increase their ability to self-manage their condition. However, although it is promoted as an individualised approach, cardiac rehabilitation is not as accessible to those who are struggling to self-manage their condition. This limitation may account for some of the poor uptake of the programmes and other initiatives aimed at improving self-management of chronic illness. There are opportunities to improve this by acknowledging the value of narrative knowledge and using it to inform the development of such programmes. The current value afforded knowledge from the medical narrative in the development of these programmes and initiatives limits their applicability to those in whom chronic illness is a continual and unpredictable intrusion into daily life.

The theory of biographical restorying brought to light the different ways in which individuals engage with health care professionals. Medical staff remain central figures in the provision of information to patients and for the most part doctors retain their privileged respected position with patients. However, their failure to discuss the patient's understanding of the information they have provided did lead to later concerns. Participants interpretations were

challenged as they increased their own knowledge giving rise to conflict with other health care professionals they encountered in their journey.

The study highlighted the on-going tension between medical and narrative, or lay, knowledge in the management of chronic illness. Specifically, individuals increased their lay-knowledge to find meaning and create a narrative around the identity, causes, consequences and controllability of their condition. Interpretation and labelling of illness perceptions of those experiencing a heart attack were different to those of medicine.

They interpreted this information and developed lay beliefs incorporating it into the biographical restorying undertaken after their heart attack. This involved developing self-management strategies perceived as important in the management of chronic illness. This altered their traditional relationship with health care professionals as they assumed responsibility for aspects of their care previously in the medical domain. Relationships with health care professionals appeared better where there was an acknowledgement of the impact of their condition on their social world.

Responsibility for supporting those with long term conditions is increasingly being handed over to allied health professionals (Dennis, et al., 2008; Rogers, et al., 2011). These professionals have embraced a biopsychosocial model, which values narrative knowledge, more fully than the traditional systems based medicine model with its emphasis on diagnosis and cure. The biopsychosocial model may also be more appropriate for supporting those with long term conditions where a degree of adapted self-management is expected.

The participants relied on health care professionals to provide or signpost them to specialist information about their condition. No-one adapted their previous means of finding information on health-related matters as a consequence of their heart attack. Internet usage appeared low in this group which may be related to their age, personality or not having 'grown up' with the internet. This was a surprise and the extent to which this finding would be found in a different cohort of patients would be interesting.

The theory of biographical restorying after a heart attack proposes that beliefs and health related concepts are informed, adapted and reinforced in response to physical sensations experienced. The theory provides insight into the means by which illness beliefs adapt following a heart attack supplementing the substantial body of quantitative work already undertaken in this field. This study provides an explanation for some of these previous findings and adds qualitative experiential data to the body of knowledge.

## **7 Reflection**

Seven years is long time to spend on one project. I would suggest it is difficult for anyone to undertake a qualitative study and it not make a dent in aspects of life other than their academic world. I am going to reflect on the study, the impact of the study on my role as senior specialist nurse working in the specialty I have researched, and the impact on me as a person. The factor that has made the biggest change is the focus on matters of epistemology and ontology in qualitative research; these were concerns I never had prior to commencing this PhD and concerns to which those undertaking research in the quantitative paradigm pay minimal attention. I did not appreciate that the decisions I would need to make in these issues would be anything other than an academic exercise.

### **Reflection on the academic me**

In reading qualitative studies prior to commencing this programme I was aware of the ontological and epistemological declarations at the start of most reports. However, the relevance of this to the way in which the research would have been undertaken and the findings presented was missing. I am now aware that I was probably unable to critique these studies appropriately.

In considering how I would manage methodological and research method conundrums I made a pragmatic decision to stick with specific core texts when planning and undertaking the study. In this way guidance on grounded theory was most frequently sought from Charmaz's, (2014) core text with further reading on specific concepts such as theoretical sensitivity and abstracting out of the data from Glaser, (1978;1992; 2011) whilst undertaking the component parts of constant comparative analysis. The limited involvement with other grounded theory authors' approaches to the constant comparative

method may have reduced the ability to critique this approach but as a novice researcher I was 'reading and learning' in the grounded theory tradition of Strauss, whose advice to his students was 'watch and learn'. In a similar vein I sourced a range of texts on interviewing and selected two to use as key texts.

Within the study what it means to construct knowledge has developed as the data accumulated. Learning to recognise cues for further exploration developed my listening skills as I strived to listen for the meaning behind the words. When the theory began to develop and the findings chapter evolved I realised how much of it was dependent on the data provided by the participants. The written word conveys meaning but pulling together the final document has been exhausting; trying to mould what has been one huge intertwined project to then distil data, reading and thinking into a linear document such as a thesis diminishes some of the passion I have had for this project. The whole is definitely greater than the sum of the parts for this thesis.

The research process highlighted a perseverance I never knew I had both in terms of the number of years and the struggling through sections of the work such as abstracting out of the data and critiquing of other works. Becoming reflexive is a journey in progress and I still have a tendency to self-criticise rather than be self-critical, the latter being a more positive personal experience than the former. The difference lies in examining the ways in which the social world has impacted on the views and assumptions developed over the years. It is not about beating yourself up but about learning how you have arrived at this stage on the journey. This does not absolve the personal responsibility but it does offer a means acknowledging and adapting that self-criticising lacks.

The grounded theory research process is totally absorbing and I attribute that to being the correct methodology for the phenomenon I wanted a greater understanding of. It was already a methodology I was familiar with due to the frequency with which this methodology appears

in qualitative health research so I felt relieved when it had 'fit' with my question. At a later stage in my ontological journey there was a time, when I was struggling with abstraction of the data, when I did wonder if I had chosen it because of its positivist tendencies, but I trusted in the process and my earlier rationale for choosing it and ploughed on.

The process of moving in and out of the data to the literature and musing over the range of possibilities as to the meaning participants had made of the data was completely absorbing. Although slightly less tangential reading might have sped the process up slightly, overall it augmented the final theory. I have many years of reading stored on my hard drive.

As I became more familiar with a constructive framework I had to find a voice in which I was comfortable writing; use of the personal 'I' took time. It also required a consideration of the way in which participants are given their voice as this research was a co-construction of their original data, a joint interpretation and my authorship. The aim was to make my voice strongest in the 'I' form in the methods and methodology with the participant voice strongest in the findings where their words tell the story and provide the evidence for the theory.

The development of a model to illustrate the developing theory re-awakened my difficulty with computer-generated models. The challenge to reduce a complex interactional theory to a two-dimensional drawing was immense, reflecting my challenges with technology but also the way in which I view the world. In considering my difficulties in this area I realised that I have no great interest in the drawn medium, I have no interest in visiting art galleries and I have no interest in which pictures adorn the walls of my home but I enjoy theatre and admire landscapes whilst out walking. The three-dimensional, living element of this is the difference and I believe this contributed to some of my challenges in this area.

Academic beliefs and uncertainties have crept into my work and social life. It has proved impossible to box it all but life as a relativist is one of living with multiple realities. Life within a symbolic interactionist world is social and multi-faceted so I just go with it. Generally I can tolerate uncertainty a bit better now.

### **Reflection on the clinical me**

As an individual who had functioned within the world of science for my whole career I had always accepted that we needed 'facts' to enable us to provide the evidence-based medicine that is now part of our being. There is a frustration that the randomised controlled trial (RCT) remains the gold standard evidence and all other studies are graded lower by national and international bodies such as NICE and Cochrane Institute. I work in an area where the situated life of the patient impacts heavily on outcomes, and is generally not suitable for RCT. Research in this area tends to consist of cohort or qualitative studies meaning that good studies do not reach the criteria for grade 1 evidence. In today's cash-strapped NHS this can be sufficient reason to close services. As a member of a NICE guideline development group during these seven years I have experienced first-hand the low regard in which qualitative research is held. This is due to the dominance of science and the search for truth. There is a lack of concern with matters ontological and epistemological, and minimal comprehension of the context of these qualitative studies and why the numbers within a study are so small. This awareness and a level of frustration over this has grown in line with my understanding of the fundamental differences between the paradigms. A small glimmer of hope may be a call for a more heterogeneous trial population within RCTs through an increase in the numbers of individuals with co-existing conditions to the one under study. This is still science driven but perhaps in discovering the difficulties there are in controlling additional variables, science will look for another way to understand what is happening in their data. This is

most probably the voice of hope over experience and rather too much theoretical consideration of all the possible outcomes of an action!

In practice my perceptions have adapted and I now consider that we continually trial medicines every time we give one to a patient for the first time. That is a trial within the context of the individual's life and we then have to alter for that individual as we see the true effect of interaction physiologically and socially. When you consider the impact of medication such as diuretics, which entail staying near a toilet for four to six hours after taking them, I am much more aware of the lifeworld of the patient since undertaking my PhD and strive to incorporate it into clinical work.

At some points during the last seven years I have felt isolated clinically as I wrestled with academia / practice tensions. This was often as a result of my own uncertainty with the issue and not feeling confident enough in my knowledge base to explain my thoughts to colleagues. It was in reflecting on these issues that reflection seemed more about self-criticism. I now have a greater understanding which I can share with colleagues. Additionally colleagues undertaking the dissertation component of an education programme have an insight into ontological and epistemological concerns giving some common topics for discussion. However, clinical practice remains rooted in the scientific paradigm with our terminology: we *prescribe* exercise for those attending cardiac rehab – within the definition of the word, this is correct but the use of an overtly medical term mystifies the process for our patients. Whilst the allied health professionals who undertake this role can claim legitimate membership of the discourse of medicine as they can prescribe, a role traditionally the remit of doctors, I wonder what sense our patients make of it.

The underpinning of my life with the mantra of the scientific paradigm and its privileged position was a revelation in the early part of the course and as I reconciled a means of working constructively within the paradigm rather than fighting against it part of the answer is to ensure

the findings of this work are disseminated and discussed at every opportunity.

### **Reflection on the personal me**

Within my personal life the impact has been on the time spent in this study away from the hub of the family. My children have grown into adulthood with this study as they have all undertaken state exams and headed off to university. A 'we are all in this together' mentality was my rationale for starting the Prof Doc programme at the time I did, when my youngest child was starting secondary school, thinking we could all be studying together! I am easily accessible in my office and being around the home at this time has, I believe, enhanced our family bonds.

The ontological question intruded into home life as I looked at the relationship I have with religion. I have attended church for many years and believing in a higher spiritual being, named God, has been an important part of being able to undertake some of the more emotionally demanding aspects of my role and family life over the years. The time afforded to prayer and the manner in which I undertake it is a form of mindfulness and rooting myself in the real world. Although I have maintained my personal relationship with this higher being I have reduced my involvement in the established Church. I now need to explore the reasons for this as I can no longer use the excuse of writing up my PhD for my increasingly erratic attendance.

Am I the better for undertaking a PhD? Certainly, academically, the ability to undertake a research project and then distil it into a thesis would suggest so. As for the other worlds, I have grown more sure of myself at work and am now looking for opportunities that will enable me to combine research and practice. In the reality of home, this would be best assessed by the family and friends who have supported me over the last seven years. This support has involved debates around the meaning of life, a chance to escape from the study, the provision of wine, help with childcare and so much more.





## 8 References

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## 9 Appendices

### 9.1 Example of a literature search criteria

Run on Cinahl, PsychInfo and Medline.

1. myocardial infarction.mp. [mp=ti, ab, tx, ct, sh, hw, tn, ot, dm, mf, nm, an, hn, ui, tc, id]
2. common sense.mp. [mp=ti, ab, tx, ct, sh, hw, tn, ot, dm, mf, nm, an, hn, ui, tc, id]
3. 1 and 2
4. risk behaviour.mp. [mp=ti, ab, tx, ct, sh, hw, tn, ot, dm, mf, nm, an, hn, ui, tc, id]
5. 1 and 4
6. lay beliefs.mp. [mp=ti, ab, tx, ct, sh, hw, tn, ot, dm, mf, nm, an, hn, ui, tc, id]
7. attribution.mp. [mp=ti, ab, tx, ct, sh, hw, tn, ot, dm, mf, nm, an, hn, ui, tc, id]
8. representation.mp. [mp=ti, ab, tx, ct, sh, hw, tn, ot, dm, mf, nm, an, hn, ui, tc, id]
9. causal explanation.mp. [mp=ti, ab, tx, ct, sh, hw, tn, ot, dm, mf, nm, an, hn, ui, tc, id]
10. subjective perception.mp. [mp=ti, ab, tx, ct, sh, hw, tn, ot, dm, mf, nm, an, hn, ui, tc, id]
11. perceived cause.mp. [mp=ti, ab, tx, ct, sh, hw, tn, ot, dm, mf, nm, an, hn, ui, tc, id]
12. health beliefs.mp. [mp=ti, ab, tx, ct, sh, hw, tn, ot, dm, mf, nm, an, hn, ui, tc, id]
13. cognitive structure.mp. [mp=ti, ab, tx, ct, sh, hw, tn, ot, dm, mf, nm, an, hn, ui, tc, id]
14. perceived risk.mp. [mp=ti, ab, tx, ct, sh, hw, tn, ot, dm, mf, nm, an, hn, ui, tc, id]
15. perceived etiology.mp. [mp=ti, ab, tx, ct, sh, hw, tn, ot, dm, mf, nm, an, hn, ui, tc, id]
16. 1 and 6
17. 1 and 7
18. 1 and 8
19. 1 and 9
20. 1 and 10

21. 1 and 11

22. 1 and 12

23. 1 and 13

24. 1 and 14

## 9.2 Participant Information Sheet



**University of Brighton**

### **Information sheet for participants: October 2012**

#### **Increasing understanding of the development of illness beliefs following a myocardial infarction.**

You are being invited to take part in a research study. Before you decide whether or not to take part in this study, it is important that you understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Do contact me if there is anything that is not clear or if you would like more information

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

This study is designed to discover more about the experiences of those who have a heart attack.

- What do people know about heart attacks before they experience one?
- What and who influences beliefs about heart disease after you have had a heart attack?
- What part do the health care professionals caring for you have in influencing these beliefs?
- What part do these beliefs play in deciding whether you change any aspects of your lifestyle following your heart attack?
- What part do these beliefs play in deciding whether you attend a cardiac rehabilitation programme?

The study will provide information on patients' perspective of their beliefs related to a heart attack complementing the studies already undertaken from a health care professional's perspective. It will provide health care professionals in cardiac rehabilitation with information which will inform the development of interventions designed to support patients as they change their health related behaviour following a heart attack.

#### **Why have I been chosen?**

You, along with up to 20 other patients with a heart attack admitted to hospital under the care of a consultant cardiologist will be invited to participate in this study

### **Do I have to take part?**

No, you do not have to take part in this study; it is entirely up to you to decide whether or not to take part.

If, after careful consideration, you do decide to take part, you will be asked to sign a consent form. You will be then sent a copy of your signed consent form to keep with this information sheet. Even if you do decide to take part and return the consent form, you are still free to withdraw from the study at any time and you do not need to give a reason. Please be assured that the decision not to take part or a decision to withdraw from the study at any time during the research will not affect the standard of care that you receive.

### **What will happen to me if I take part?**

If you do decide to take part, I will contact you a day or so after you have been discharged to arrange a day and time that suits you to come to talk with you. The meeting will last between 45 and 60 minutes, and I will ask you to talk about your thoughts about having had a heart attack. With your permission, I would like to tape record our conversation to ensure I have an accurate record of our meeting. After the interview I will make a written copy of our conversation and analyse it alongside those of the other participants.

Approximately five months later I will contact you to ask if you wish to remain involved in the study and if so arrange a second interview. This will follow the same format as the first interview. I will ask similar questions and also follow up on your responses from the first interview to identify how your thoughts and feelings might have changed over time.

I will be happy to meet with you in a private room in a local community centre or, if you would prefer, at your own home. If you would prefer that we meet outside of your home, then we will pay your travel expenses. Irrespective of our meeting place I have to leave details of the venue and expected duration of the meeting at my work base. I will also be expected to contact that base at the start and end of the interview.

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

It is possible that, during our conversation, you may become distressed. If that were to happen, then if you wish we will not continue and the tape recorder will be switched off. If, during or following our meeting, you feel that you would like to talk to someone else about how you are feeling, you will be given details of someone whom you can contact.

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

You, along with other people taking part in this research study, will have an opportunity to provide information about your thoughts and experiences following your heart attack. This will allow the researcher to evaluate the data, and make suggestions as to how best health care professionals can support patients as they recover and attempt to change their health related behaviour following a heart attack.

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

Your hospital medical team and GP will be informed you are participating but they will not have access to the information you give as part of the study.

Although, with your permission, the conversation will be recorded, only members of the research team will have access to the tape recording and transcripts of your recording. These will be kept on an encrypted computer storage device and will be destroyed at the end of the research study, once the report has been written. No-one will be able to identify who has or has not taken part in the research from the final report. Your own names will not be used and no personal information about yourself will be given in the final report.

It is possible that you may provide information during the interview which it is important I share with other individuals. It may be related to your treatment or the health care professionals providing your care. If this is necessary I will discuss this with you and explain why it is necessary to share this information. Please be assured that if this is necessary it will not affect the care that you receive.

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

The results of the research study will be collected together and a report written. This will form the thesis for my Professional Doctorate in Nursing at the University of Brighton. If you wish I can send you a summary of the final report.

Results from the research will be published in professional medical and nursing journals, and will also be presented at professional conferences, in order that more people will be able to learn from the results.

### **Who has reviewed the study?**

This research study has been reviewed by the Faculty Research and Ethics Governance Committee at the University of Brighton, the Social Care Research Ethics Committee and the Research and Development Committee of Cambridge University Hospitals Foundation Trust

### **About the researcher**

I am undertaking this study as a part-time doctoral student at the University of Brighton. I have a permanent post within the Hospital as a Cardiac Rehabilitation Lead Nurse and will be working for this service during the study period. If you participate in this study your cardiac rehabilitation programme will be provided by other members of the team, should I require to be involved in providing your cardiac rehabilitation you would not be able to participate further in the study.

### **Contact for Further Information**

If you have any further questions or wish further information, then please contact me:

Mrs Kathryn Carver on telephone number (specific number for this study to be obtained) or by e-mail to [e.k.carver@brighton.ac.uk](mailto:e.k.carver@brighton.ac.uk)

If you have any concerns regarding the way this study is being conducted you may contact the PALS service at the Trust or Dr Nikki Petty, Principal Lecturer, Clinical Research Centre for Health Professions, 209 Aldro Building, Darley Road, Eastbourne, BN20 7UR

Telephone 01273 641806

Email [n.j.petty@brighton.ac.uk](mailto:n.j.petty@brighton.ac.uk)

I would like to take this opportunity to thank you for taking the time to read this information sheet and, whether or not you decide to take part in the research, to thank you for considering it.

### 9.3 Consent Forms



**University of Brighton**

#### **Consent Form for interview 1**

Research Project Title: **The development of illness beliefs following a myocardial infarction.**

Principal Investigator: **Kathryn Carver**

I confirm that I have read and understood the information sheet dated 30<sup>th</sup> October 2012

for the above study and have had the opportunity to ask questions.

I agree to take part in the first interview for this study within the next three weeks.

I agree to the researcher contacting me approximately five months later to confirm that

I wish to remain involved in the study.

I understand that the interviews will be recorded and then transcribed by the principal investigator.

I understand that the information I provide will be anonymised in the final report.

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

I accept that a copy of this form will be placed in my hospital medical notes and my GP will be informed that I am participating in a research study.

Name of patient participant \_\_\_\_\_

Signature of patient participant \_\_\_\_\_

Date \_\_\_\_\_

Signature of principal investigator \_\_\_\_\_



**University of Brighton**

Consent Form for interview 2

Research Project Title: **The development of illness beliefs following a myocardial infarction.**

Principal Investigator: **Kathryn Carver**

I confirm that I have re-read and understood the information sheet dated 30th October 2012

for the above study and have had the opportunity to ask questions.

I agree to take part in the second interview for this study within the next three weeks.

I understand that the interviews will be recorded and then transcribed by the principal investigator.

I understand that the information I provide will be anonymised in the final report.

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

I accept that a copy of this form will be placed in my hospital medical notes

and my GP will be informed that I am participating in a research study.

Name of patient participant \_\_\_\_\_

Signature of patient participant \_\_\_\_\_

Date \_\_\_\_\_

Signature of principal investigator \_\_\_\_\_

## **9.4 Interview Structure and Guiding Questions Initial Interviews 2013**

### **Guiding questions for interview.**

#### **Opening**

- General comfort issues: seating, drink available, microphone / Dictaphone positioning
- Review general aims of the project and reaffirm consent to continue
- Agree time available for interview today
- “Icebreaker” discussion

#### **Research Questions / Prompts**

Can I take you back to the time before you had your heart attack – what if anything did you know about heart attacks at that time? Where did this information come from?

Tell me about your thoughts and feelings when you learned you had had a heart attack?

What changes have occurred in your life since that day? (This question will explore both positive and negative changes and why the changes have occurred)

What do you now know about heart attacks? And where did this information come from?

How, if at all have your thoughts and feelings about having a heart attack changed in the few weeks since that day?

Who or what has been important in supporting you since you came out of hospital? In what way?

Who or what is helping you manage your recovery? In what way?

What, if any, difficulties or problems have you encountered since coming out of hospital?

Where do you see yourself in the next few weeks / six months time? (Two year time frame for interview 2)

Where do you hope to be by then in comparison to where you are now? (Ask same question for nearer/further into the future depending on the initial response)

Is there anything else you think I should know to help me understand better how having a heart attack has affected you?

Is there anything you would like to ask me?

### **Conclusion**

- Confirm when and how next contact will be arranged
- Discuss what will happen to the information collected today
- Ensure participant has contact information for me.
- Thank participant for their time and sharing their thoughts with me.

Interview 2 will use the same framework but will relate to the specific comments offered in interview one and explore changes over time.

Additionally it will explore:

Have you changed in any way as a person since having a heart attack? Who or what has influenced these changes most?

What advice, if any, would you give to someone who has just been told they have had a heart attack?

## 9.5 Interview Structure and Guiding Questions Interview 2 2014

### Thoughts on directions for interview 2

- General info on how been
  - Ask about pace in early days and how it felt – where are they now?
  - Was it unnecessarily restricted?
  - Do they think about doing too much / overdoing it at all now?
  - Have they resumed past life or do they have a new self and life.
  - Discuss time pre and post event – is it faster / slower more precious/ more aware of etc.
- Emotional security
  - Have they noticed a change in their emotional / psychological response
  - How have they coped
  - Vulnerability increased or decreased since previous interview
- Health care professionals as source of information
  - In looking at the information from medical staff and the life in limbo this gives participants I need to identify if they were given answers at clinic and their response to that answer.
  - Does the medical staff provide the clarity?
  - If yes how did the answer impact. On looking back did they hold back on life until that event?
  - If answers not supplied what do they do about the missing information? How did they react how has it impacted since then?
- Awareness of messages in media
  - Do they notice them more or less
  - How do they react to them
  - Use of internet general and specific to health
- Social world and awareness of MI
  - Family / friends do they make allowances for MI
  - Do they try to limit in any way
  - Any others with MI positive or negative effect on your recovery
- Andrew & Frank: diabetes v MI chronic v acute explore
- How did you learn to be a survivor?

## 9.6 Interview Structure and Guiding Questions 2015

### Interview 2

- **Biographical Fracture**
  - Meaning making
    - Pre admission / early symptoms
    - Medical story
  - Place
    - Hospital routine of CCU / loss of independence
    - Witnessing death
    - Impact of readmission
  - Time
    - Witnessing death – impact on own biographical timeline
    - Life in limbo
  - Dialogical self
    - Thoughts, impressions, meaning making in hospital
    - Disturbance to previous life on discharge
- **Narrative Re-storying**
  - Impact of diagnosis
  - Impact of changed diagnosis
  - Re-story life and roles
  - Re-story life and expectations re longevity
  - Re-story life and symptoms real or potential
- **General info on how been**
  - Ask about pace in early days and how it felt then and now?
  - Is the caution learned in hospital and carried outside or does the diagnosis alone make you cautious.
  - Do they think about doing too much / overdoing it at all now?
  - Have they resumed past life or do they have a new self and life.
  - Is their life useful

- Discuss time pre and post event – is it faster / slower more precious/ more aware of etc.
- **Emotional security**
  - Have they noticed a change in their emotional / psychological response
  - How have they coped
  - Vulnerability increased or decreased since previous interview
- **Health care professionals as source of information**
  - were they given answers at clinic and their response to that answer.
  - If yes how did the answer impact. On looking back did they hold back on life until that event?
  - If answers not supplied what do they do about the missing information? How did they react how has it impacted since then?
- **Awareness of messages in media**
  - Do they notice them more or less
  - How do they react to them
  - Use of internet general and specific to health
- **Social world and awareness of MI**
  - Family / friends do they make allowances for MI
  - Do they try to limit in any way
  - Any others with MI positive or negative effect on your recovery
- **Impact of any other illness**
- **Risk factor modification**
  - Medical story of secondary prevention
  - Where do they view its role
  - How much importance do they place on it for future length and quality of life

## 9.7 Example of interview transcript and coding

	Initial Coding	Early category and analysis
<p>Barbara is a 79 year old widow who lives with her widowed daughter and grandchild. She had a previous MI and is a retired nurse.</p> <p><b><i>Can I take you back to before you had your heart attack and can you tell me what if anything you knew about heart attacks at that time?</i></b></p> <p>Well I knew that it was caused by a clot blocking the blood supply to part of your heart which caused the muscle to die, it was dangerous you know, to life, and it was important to get help fairly quickly if you suspected that you had. It was caused by chest pain or the symptom is chest pain which is a sort of a feeling of heaviness in your chest a squeezing sort of pain. Also it can occur at any time in adult life you know even young people or older people if you have got someone in the family who has had a heart attack it is always wise to realise that you have got more of a tendency probably towards one and try and do everything you can to help prevent one. Important to follow the 5 a day rule which I think everyone knows about these days, not to have too much fatty fried food, smoking is very bad because often the clot is caused by the artery getting clogged up and you know the clot is then formed that will stop the blood getting through.</p>	<p>Elderly widowed female, previous MI, retired nurse</p> <p>Knowing what causes MI Muscle dying Dangerous to life Help needed quickly Symptom is chest pain</p> <p>Can occur at any time</p> <p>Affecting young and old Increased chance if family history present You can try and prevent it</p> <p>Eating 5 fruit and veg daily Not eating fatty food Stopping smoking Smoking clogs arteries Blood clot stops blood flow</p>	<p><i>Keen to let me know she was a retired nurse. Had made notes as a prompt prior to the interview based on patient information sheet.</i></p> <p><i>Relates knowledge to training as a nurse and not to prior heart attack. However age suggests she had retired from nursing prior to much of her knowledge being current. Very polished rendition of cause and read from notes</i></p> <p><i>Demonstrating knowledge of healthy lifestyle activities</i></p>

<p><b><i>So you have a lot of information there, where did this information come from?</i></b></p> <p><b><i>Were you conscious of where it came from and how you gathered it?</i></b></p> <p>Well partly because of being a trained nurse I did know quite a bit about it anyway. But I think recently much more publicity has been around the five a day rule everybody knows that is a healthy thing to do to try and prevent sort of things like heart attacks and strokes. Mostly I knew it before I had the heart attack because of being a nurse really.</p> <p><b><i>When you got the discomfort what made you think you had to do something about it?</i></b></p> <p>Really I did think, because I had one 10 years ago, (a heart attack), and it was a similar sort of pain and underneath I really thought that it might be but I was hoping it wasn't. So I tried things like gaviscon to see if it made a difference which it didn't and there was all sorts of things went through my mind because it went into my shoulder blade and I thought maybe I have got a gallstone or something but I think that underneath it all I think I did realise it might be a heart attack. But I wasn't short of breath or anything it was just the pain. It was really my daughter who nagged me and said come on I am going to take you to casualty and it was a good job she did.</p>	<p>Being a nurse provided current knowledge</p> <p>Publicity around healthy eating</p> <p>Admitting to previous MI</p> <p>Experiencing similar symptoms Not wanting to acknowledge it may be another MI Hoping it wasn't another MI Considering alternative diagnosis</p> <p>Knowing it was another MI Symptoms not experienced Daughter nagging to take action Daughter initiating action Acknowledging daughter did the right thing</p> <p>Liking the medical staff</p>	<p>Demonstrating knowledge from previous situation and experience</p> <p>Information out there for reading not necessarily picking up a personal message – subliminal or contemplation information in cycle of change behaviour</p> <p>Acknowledging previous history of IHD</p> <p>Hoping it was not another MI despite same presentation</p> <p>Seeking a cause for symptoms Unwilling / afraid to consider recurrent MI as diagnosis</p> <p>Escalating need for support to health care professionals</p> <p>Waiting for a diagnosis</p>
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<p><b>Who actually told you you had had a heart attack?</b></p> <p>It was in casualty, we went to casualty and a very nice young doctor there explained that they would have to wait for the result of the blood test before they could decide definitely because I having got a pacemaker the ecg didn't show probably all the thing that it might have done. Anyway I did know that and ecg doesn't always show until quite a while after you have had it so and then she said well I am sorry you will have to stay in until we get the result of the blood test because we need to do another one 12 since the onset of pain which made it ten o'clock at night so they admitted me. Then the doctor from casualty came up and told me the blood test had come back showing that I had indeed had a heart attack. She was lovely she was, we had excellent care couldn't complain about the treatment we had. We were seen straight away by the triage nurse, straight into a cubicle, straight away a doctor you know it was a really excellent service.</p>	<p>Waiting for a diagnosis</p> <p>Tests not conclusive</p> <p>Having to stay in hospital Awaiting the result of tests</p> <p>Test showed that it was a heart attack</p> <p>Excellent care Seen straight away</p>	<p>Appreciative of medical care</p>
<p><b>When he did confirm what you had.....</b></p> <p>Yes and then the consultant when he came round the next morning he said yes, because I said to the doctor will the second blood test show maybe differently and she said no definitely not but when he came round he said as well that it was definitely a heart attack.</p>	<p>Consultant confirmed diagnosis</p> <p>Seeking affirmation of diagnosis Hoping it would not be heart attack</p>	<p>Diagnosis confirmed</p> <p>Seeking additional confirmation of diagnosis / seeking refutation of diagnosis</p>
<p><b>What were thought your thoughts when the diagnosis was confirmed?</b></p>	<p>Upset at diagnosis What would it stop me doing Very active driving</p>	<p>Disruption to life</p>

<p>Obviously I was upset, although all I could think through my mind was what it was going to stop me doing because up until that point I been very active driving and I help my daughter with her daughter for school, take her to school, pick her up from school look after her every day from school. To be honest that is all I could think about was the disruption it was going to make to my life and to the help people needed. So yes I think that was the biggest thing so I was quite upset about it yes.</p>	<p>Help daughter with family</p> <p>Considering the disruption to life and the help needed by daughter</p>	
<p><b><i>When in hospital were the other people around you admitted with similar things?</i></b> <b><i>Did you talk much about medical things?</i></b></p>	<p>Awaiting pacemakers so no heart attacks</p> <p>Not conversing with room mates</p>	<p>Other patients awaiting pacemakers but did not see that as a link and thread, they did not have MI's therefore were different and no common situation to discuss.</p>
<p>It was in the cardiac ward but in our little 4 bedded ward the other three were waiting to have pacemakers inserted so none of them had actually had heart attacks. So I didn't really no I don't think I did speak to anybody about it.</p>	<p>Information given at time of previous MI</p>	<p>Accepts information on MI given at time of previous event but relates this knowledge to that gained during time as nurse.</p>
<p><b><i>When you had previous heart attack did you get a lot of information at that time?</i></b></p> <p>Yes quite a lot I was in coronary care then, in <i>hospital</i>. So I was sent to Papworth for an angiogram then and that did show that my arteries were absolutely fine and this time the same thing happened. You know the doctors said well you have to go and have one because time has moved on ten years but again they were fine so they are a bit puzzled as to why I have had this heart attack. I am going back to the clinic and I have just had the appointment with the vascular risk clinic to see if they</p>	<p>Seeking information from medical staff</p> <p>Wanting to know why MI occurred</p>	<p>Medical staff as a source of knowledge</p> <p>Seeking cause of MI</p>

<p>can decide you know why. Because when I had the one 10 years ago they thought it was because my heart had gone really really slow and had been deprived of blood and that might have caused it but since then I have had the pacemaker so that should guard me and I thought I was very well protected and they put me on warfarin as well and I you know and I honestly was quite surprised by this. I was quite taken aback and I didn't want it to happen at all I had done so well in those 10 years. but there you go</p>	<p>Thought protected from further MI</p>	<p>Surprised at recurrent MI</p>
<p><b><i>In the 10 years had you thought much about having another one?</i></b></p>	<p>Not dwelled on prospect of another MI</p>	<p>Not dwelled on prospect of another MI</p>
<p>Not really because I say I was you know well on the way to having another one prevented because of what they had said. But the first one I think even then they were a bit mystified because it was not the usual cause of a heart attack with the arteries clogged up so we will see. That was another reason why I didn't know if it would be different to talk to you because it was a different cause</p>	<p>Not usual cause of an MI</p>	<p>Seeking cause of MI</p>
<p><b><i>You talked about what it would stop you doing - how has that transpired? How are those feelings now?</i></b></p>	<p>Accepting the disruption to life</p>	
<p>Just the same really. Well I can accept it now because there is nothing much I can do about it now it has happened.</p>		
<p><b><i>Do you see yourself getting back to these things?</i></b></p>	<p>MI causing a loss of confidence</p>	<p>Loss of confidence</p>
	<p>Coming out of the blue</p>	

<p>Hopefully but I think my confidence has definitely been affected because of having one, because it just came out of the blue. I hadn't been doing anything that you know extraordinary, a certain amount of heavy lifting or anything where I had over exerted myself I had just done all the normal things and so it came out of the blue.</p> <p><b><i>Since you came home have you specifically gone looking for more information on heart attacks?</i></b></p> <p>No when I came out they gave me a leaflet informing me of everything I needed to do and what I must not do and how you know how to graduate myself for exercise. I have followed that very carefully because obviously I am doing my best to get back to what I was before. I am very anxious to do and I have found this extremely useful even as far as how many times to go upstairs and things like that and what not to do.</p> <p><b><i>Are you an internet user or a reader of newspapers?</i></b></p> <p>No we have internet in the house but I don't actually do it.</p> <p><b><i>What about your family - have they been offering advice / information?</i></b></p> <p>Well I think they know, unfortunately my daughters husband unexpectedly died of a heart attack at 4. So then she wanted to know then quite a lot about it and I was able to help her with it. So when I had mine my little granddaughter who is 11 said she didn't like her mummy saying I had had a heart attack you know because of her</p>	<p>Not doing anything to cause the MI</p> <p>Provided with information from hospital.</p> <p>Not seeking further information</p> <p>Followed information leaflet very carefully</p> <p>Wanting to return to previous activities Written information extremely useful Detailed information given</p> <p>Non user of internet</p> <p>Previous family experience as a source of knowledge</p> <p>Previous family experience as a source of fear for grand child Requesting to change terminology due to fear</p>	<p>Trigger factors</p> <p>Information from hospital as a source of knowledge</p> <p>Information from hospital meeting all needs</p> <p>Prescriptive information useful</p> <p>Acknowledging that MI can be fatal Rationalizing the concern of others Impact of younger family members of diagnosis</p>
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<p>dad. She said I don't like you saying that so we had to say something different. She was frightened to be honest because he died unfortunately. He had a massive one at 43 a young fit healthy man so that made me realise that it could happen to anybody really.</p>	<p>Granddaughter frightened of potential death of grandmother from MI</p>	
<p><b><i>What else has been useful and supportive since coming out of hospital?</i></b> Well while I was in hospital quite a few people were helpful then. I had the cardiac specialist nurse come round telling me all about the rehabilitation thing I could go to afterwards. I had a dietitian come round just to check on what I was eating and whether my diet was considered healthy and if I needed to change anything. Apart from that really just the doctors who every day I saw a doctor.</p>	<p>Health care professionals in hospital provided support Rehabilitation as a form of support  Dietitian as a form of support  Doctor as a form of support</p>	<p>Support from health care professionals helpful Followed this information very prescriptively and did not seek any other form of support. Control given to health care professionals</p>
<p><b><i>Looking forward where would you like to see yourself in the next few weeks?</i></b> Back driving again. Which I think to be honest it has shattered my confidence a bit about taking, as I did before, my taking my granddaughter to school and everything. I will have to see how I feel about it. You know hopefully if I am given a clean bill of health you know I don't suffer from angina or anything hopefully I will be back driving and I will have restored a bit of confidence again. Certainly I will be driving myself even if I don't take the little ones and doing all the things that I used to do. I couldn't do any heavy digging or anything well I didn't you know because apart from anything my age but I just love pottering about in the garden. I shall</p>	<p>Resuming driving important to regaining confidence  Hoping for a clean bill of health No angina seen as a clean bill of health  Aiming to drive, potter in the garden and light housework as return to normality</p>	<p>Specific activities count towards making a good recovery  Seeking a clean bill of health</p>

<p>certainly still do that. All my other things I do are fairly sort of restful, knitting and reading, I read and read so I shall do all these things and a bit of, never did any heavy housework you know because living with my daughter I didn't need to, but I shall be back doing what I did which is I would say is light housework, cooking meals not big heavy meals but sort of light cooking yes.</p> <p><b><i>So do you see yourself having a good recovery?</i></b></p> <p>Oh yes definitely</p> <p><b><i>Have you thought about further into the future and the thought of another heart attack?</i></b></p> <p>Well yes I think that is why my confidence was knocked with this one. I had thought well obviously it is a possibility but I am not going to dwell on it or wait for it. I am going to just do what I did after the last one and just hope that I recover well and that it won't happen again.</p> <p><b><i>You talked about the rehabilitation programme - do you think you will go?</i></b></p> <p>Thinking about it, attending rehab yes, a lot of it depends on getting there for one thing and how it fits in with my... with what I am doing now, with helping with Natasha, with looking after her. So if it fits in with all of that then I will go, I will go yes</p>	<p>Expecting to make a good recovery</p> <p>Not dwelling on the possibility of a further MI</p> <p>Hoping to recover</p> <p>Thinking about attending rehab</p> <p>Fitting in with other commitments</p>	<p>Expecting to make a good recovery</p> <p>Attending rehab not a priority over other roles and responsibilities</p>
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<p><b><i>Is this another way of getting information?</i></b></p> <p>Yes it is and again it is a quite nice way of getting to talk to other people who have had the same thing so I probably will go. I haven't made my mind up definitely because it doesn't happen yet that is a few weeks away.</p> <p><b><i>Do you know of others in the same situation in your social circle?</i></b></p> <p>Well only.... you know we have had unfortunately in our family, my daughters husband died of one at quite an early age and my own husband died of one 16 years ago so yes I suppose the answer is yes. That is why I was so hoping and loathe to you know when I had the one 10 years it was not long after my husband had died and I thought oh no I can't have one as well. I must admit it was something I just didn't want which obviously everybody feels like that don't they. But I mean yes... otherwise there is no one else whom I know just my husband and son-in-law. They were both very sudden and unfortunately they didn't recover - another reason for being a bit frightened I suppose when I had it as well.</p> <p><b><i>I think that is all is there anything else you want to add or expected me to ask?</i></b></p> <p>No I don't think so, not really you have covered most things. I did read all of this and I do understand why you are doing it and what advantages it might be to other people. That is that really.</p>	<p>Rehab for talking to others with MI</p> <p>Husband and son in law died of MI</p> <p>Can't be having one as well</p> <p>Didn't want to have an MI</p> <p>Family deaths from MI increase fear around recovery</p>	<p>Seeking peer support as a source of information</p> <p>Previous family experience as a source of knowledge Applies previous contact with disease condition to give him negative perspective –</p>
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<p>I don't suppose you can tell me about this but unfortunately I should have been on holiday last week. I had booked to go last week only to Scotland but I was really looking forwards to it. The company are really good and look after you but I am hoping they will give me my money back. I took out their insurance and obviously you have to declare pre-existing medical stuff like my pacemaker, the heart attack was too long ago but in the insurance it said that if your holiday is going to be taken completely in the UK you do not need to declare it. So hopefully I will get my money back.</p> <p><b><i>Usually they don't need the information if you are in the UK as the healthcare is completely covered. Are you hoping to take the holiday later?</i></b></p> <p>I am hoping to take my holiday later, it was one particular thing I wanted to do. I have been on those holidays as they have their own hotel. My husband came from Scotland we used to do bed and breakfast around the highlands. So now this is the only way to do it. This one was fort William and I want to go on the stream train out to Mallaig so I am looking for the same holiday and it is the same time next year so I might book that up to look forwards to. I need to book early for the single room I was going on my own as most of my friends still have their husbands to go with and I used to go with Joanne quite a lot because her husband had his own business and he couldn't take as many holidays and she is a bank manager and we used to go on holiday together. Obviously now she has Natasha they are not the sort of holiday you can go on. She has cerebral palsy only her legs are affected but</p>	<p>Seeking information from researcher</p>	
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obviously it wouldn't do her any good to sit in a coach for hours or anything like that.. So really it is don't go or go on my own. I don't mind going, my days of going abroad are over, the airports now Oh my goodness Gatwick – you have miles to walk so I thought Oh no I am quite happy to go up to Scotland or Cornwall or somewhere.

***Is it bus trips you usually select?***

Yes every time I have been it is fine. You sit at tables for dinner and get chatting. Last time I went and two people from Newmarket I knew were there. I didn't know they were going but we met up at the bus but I really enjoy it  
I was upset and thought why did it have to happen this week, but my daughter said thank goodness it did it would have been worse if you have been up there or on the way. Which is true really but it would have been nice if it had happened the week after.



