

**“Watchful Insecurity”: a grounded theory to explain  
the meaning of recovery after a heart attack.**

***Volume 1***

**By**

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*“Occasionally illness, bereavement, redundancy and accidents impose on people and bring them up short with a shock of recognition that, however hard they try, nothing can be permanently safe”.*

(Simpson, 1994:119)

*“When God closes a window, she opens a door”*

(Frank, 2002:156)

# **“Watchful Insecurity”: a grounded theory to explain the meaning of recovery after a heart attack.**

## **Abstract**

A heart attack can be devastating. If recovery is not well managed, such an event can seriously impair quality of life. However, recovery is a relatively unexplored concept in research. This study aimed to generate a theory to explain the meaning of heart attack recovery from the perspective of those who have encountered a heart attack. The theory of “Watchful Insecurity” was developed.

The study used a modified constructivist grounded theory methodology, incorporating qualitative methods and grounded theory analysis techniques.

The sample included i) twenty four cardiac support group members who attended one of four group interviews ii) 10 patients six to eight months following their heart attack who participated in individual interviews iii) 10 informal interviews with people with “expert” conceptual knowledge.

The theory of Watchful Insecurity emerged from the participants’ stories and their perception that they were a different person after their heart attack. Watchful Insecurity is identified as an enduring state that dominates the process of recovery. Recovery is understood as a social process through which people come to live with and manage Watchful Insecurity. The

triggers of Watchful Insecurity after a heart attack are identified. Different types and levels of “watchful insecurity” become apparent. The theory of Watchful Insecurity challenges the assumption that recovery follows a linear trajectory. Instead, recovery is experienced as a series of “peaks and troughs”. Watchful Insecurity is a core category that applies to all, but the overall trajectory of recovery is unique for each individual. Tools that participants used in order to learn to deal with Watchful Insecurity are discussed.

This study illuminates heart attack recovery by exploring it as a concept and a process. This understanding can be used in developing acceptable and accessible services to support recovery.

## Table of contents

<b>ACKNOWLEDGEMENTS</b>	1
<b>QUOTATIONS</b>	2
<b>ABSTRACT</b>	3
<b>TABLE OF CONTENTS</b>	5
List of boxes	12
List of tables	13
List of diagrams	13
List of appendices	13
<b>PREFACE</b>	14
<b>CHAPTER 1: INTRODUCTION TO THE STUDY</b>	22
1.1 Introduction	22
1.2 A heart attack and its impact	23
1.3 Different perspectives on recovery	24
1.3.1 <i>Health professionals</i>	24
1.3.2 <i>Health services research</i>	25
1.3.3 <i>Social science research</i>	26
1.4 The preliminary research study	28
1.5 Refining the research question	29
1.6 The structure of the thesis	31
<b>CHAPTER 2: EXPLORING THE CONTEXT OF A HEART ATTACK</b>	33
2.1 Introduction	33
2.2 Searching the literature	35
2.3 What is a heart attack?	46
2.3.1 <i>The nature and prevalence of heart attacks</i>	46
2.3.2 <i>Heart attack interventions</i>	47
2.3.3 <i>Social, cultural and economic influences</i>	49
2.4 How can a heart attack impact upon people?	51
2.4.1 <i>Heart attack impact and quantitative inquiry</i>	51
2.4.2 <i>Limitations of quantitative methods to explore illness impact</i>	55
2.4.3 <i>The emotional impact of a heart attack</i>	68
2.4.4 <i>The social impact of a heart attack</i>	72
2.5 Cardiac rehabilitation services	75

2.5.1	<i>A definition of cardiac rehabilitation</i>	75
2.5.2	<i>The content and quality of cardiac rehabilitation in the UK</i>	76
2.5.3	<i>Access to cardiac rehabilitation</i>	79
2.6	<b>Conclusion</b>	82
<b>CHAPTER 3: LITERATURE REVIEW: ILLNESS EXPERIENCE AND RECOVERY</b>		<b>85</b>
3.1	<b>Introduction</b>	85
3.2	<b>Definition of terms</b>	86
3.3	<b>Illness experience</b>	87
3.3.1	<i>The contribution of research to illness experience</i>	87
3.3.2	<i>Biographical disruption</i>	89
3.3.3	<i>Control</i>	96
3.3.4	<i>Women's experience of illness</i>	99
3.3.5	<i>The limitations of the research on illness experience</i>	104
3.4	<b>Researching recovery from illness</b>	106
3.4.1	<i>Theories related to recovery</i>	106
3.4.2	<i>Definitions of adaptation and adjustment</i>	107
3.4.3	<i>Adjustment</i>	108
3.4.4	<i>Coping</i>	113
3.4.5	<i>Loss and change</i>	118
3.4.5.1	<i>Post-traumatic stress disorder</i>	119
3.4.5.2	<i>Grief</i>	120
3.4.5.3	<i>Loss</i>	121
3.5	<b>Justification for the study</b>	124
<b>CHAPTER 4: ESTABLISHING THE RESEARCH PARADIGM</b>		<b>128</b>
4.1	<b>Introduction</b>	128
4.2	<b>Research dimensions</b>	129
4.2.1	<i>Social and cultural influences</i>	130
4.2.2	<i>Variation and similarities in experience</i>	130
4.2.3	<i>Recovery as process</i>	131
4.2.4	<i>Second level truth</i>	131
4.3	<b>Research paradigms</b>	132
4.3.1	<i>Positivism</i>	132
4.3.2	<i>Interpretive inquiry</i>	133
4.4	<b>The limitations of positivist research</b>	134
4.4.1	<i>Biomedical research</i>	134
4.4.1.1	<i>Mechanism and reductionism</i>	134
4.4.1.2	<i>Limitations of biomedical research</i>	136
4.4.2	<i>Quality of life research</i>	138

4.4.2.1	<i>Measurement of quality of life</i>	138
4.4.2.2	<i>Inconsistent definition and application</i>	139
4.4.2.3	<i>Conceptual integrity</i>	140
4.4.2.4	<i>Complexity and capacity</i>	141
4.4.2.5	<i>Sensitivity of measurement tools</i>	142
4.4.3	<b>Summary</b>	143
4.5	<b>The interpretive paradigm and qualitative inquiry</b>	144
4.5.1	<i>Interpretivism versus positivism</i>	144
4.5.2	<i>Idealism versus realism</i>	146
4.5.3	<i>Naturalism versus artificiality</i>	149
4.5.4	<b>Summary</b>	151
4.6	<b>The limitation of the two-paradigm approach</b>	151
4.7	<b>Ontology</b>	153
4.7.1	<i>Adopting an ontology</i>	153
4.7.2	<i>Critical realism</i>	154
4.8	<b>Epistemology</b>	155
4.8.1	<i>Selecting an epistemology</i>	155
4.8.2	<i>Symbolic interactionism</i>	156
4.8.3	<i>Social model of health</i>	158
4.9	<b>Methodology</b>	161
4.9.1	<i>Selecting a methodology</i>	161
4.9.2	<i>Grounded theory</i>	162
4.9.3	<i>Grounded theory versus other qualitative methodologies</i>	162
4.9.4	<i>Discourse analysis</i>	163
4.9.5	<i>Selecting grounded theory</i>	164
4.9.6	<i>Grounded theory</i>	166
4.9.6.1	<i>The development of grounded theory</i>	166
4.9.6.2	<i>Grounded theory techniques</i>	167
4.9.6.3	<i>Criticisms of grounded theory</i>	168
4.9.6.4	<i>Constructivist grounded theory</i>	171
4.9.7	<b>Summary</b>	174
4.10	<b>Ethics</b>	175
4.10.1	<i>Rigour</i>	175
4.10.2	<i>Trustworthiness</i>	176
4.10.2.1	<i>Trustworthiness criteria</i>	176
4.10.2.2	<i>Reflexivity</i>	176
4.10.3	<i>Glaser's criteria of "fit"</i>	179
4.11	<b>Conclusion</b>	180
<b>CHAPTER 5: METHODS</b>		<b>182</b>
5.1	<b>Introduction</b>	182
5.2	<b>Aim</b>	184
5.3	<b>Research questions</b>	184
5.4	<b>Objectives</b>	184



5.5	<b>Methodology</b>	185
5.6	<b>Design</b>	185
5.7	<b>Ethical approval</b>	185
5.8	<b>Setting</b>	186
5.9	<b>Sampling and recruitment</b>	186
5.9.1	<i>Group interviews</i>	186
5.9.2	<i>Individual interviews</i>	190
5.9.3	<i>Informal interviews</i>	193
5.10	<b>Data collection</b>	196
5.10.1	<i>Group interviews</i>	196
5.10.2	<i>Individual interviews</i>	198
5.10.3	<i>Informal interviews</i>	199
5.11	<b>Data analysis</b>	202
5.11.1	<b><i>Grounded theory techniques</i></b>	203
5.11.1.1	<i>Theoretical sensitivity</i>	203
5.11.1.2	<i>Theoretical sampling</i>	204
5.11.1.3	<i>Analytical induction</i>	205
5.11.1.4	<i>Coding</i>	207
5.11.1.5	<i>Using the literature</i>	209
5.11.1.6	<i>Constant comparison</i>	209
5.11.1.7	<i>Memos and sorting</i>	210
5.11.1.8	<i>Qualitative data software</i>	211
5.11.2	<b><i>Doing grounded theory</i></b>	211
5.11.2.1	<i>Undertaking analytical induction</i>	211
5.11.2.2	<i>Validating analytical induction</i>	214
5.11.2.3	<i>Prior knowledge and rigour</i>	217
5.11.2.4	<i>Focusing on the phenomenon not the person</i>	218
5.11.2.5	<i>Thinking conceptually</i>	219
5.11.2.6	<i>Sorting and talking</i>	222
5.11.3	<b><i>A reflexive account</i></b>	224
5.11.3.1	<i>Tolerating confusion and regression</i>	224
5.11.3.2	<i>Being able to conceptualise not describe</i>	225
5.11.3.3	<i>Data collection</i>	226
5.12	<b>Conclusion</b>	228
 <b>CHAPTER 6: THE EXPERIENCE OF HAVING A HEART ATTACK</b>		 230
6.1	<b>Introduction</b>	230
6.2	<b>The heart attack experience</b>	232
6.2.1	<b><i>The nature of a heart attack</i></b>	232
6.2.1.1	<i>Predictability</i>	233
6.2.1.2	<i>Physical distress</i>	235
6.2.1.3	<i>Understanding</i>	237
6.2.2	<b><i>Emotional response to the heart attack</i></b>	238
6.2.2.1	<i>Fear and vulnerability</i>	238

<b>CHAPTER 7:</b>	<b>WATCHFUL INSECURITY: A GROUNDED THEORY TO EXPLAIN THE MEANING OF RECOVERY AFTER A HEART ATTACK</b>	<b>242</b>
7.1	Introduction	242
7.2	Watchful Insecurity as a core concept	242
7.2.1	<i>Watchful Insecurity</i>	242
7.2.2	<i>Watchfulness</i>	243
7.2.3	<i>Insecurity</i>	244
7.3	The theory of Watchful Insecurity	245
7.3.1	<i>Theory description</i>	245
<b>CHAPTER 8:</b>	<b>ELUCIDATING THE THEORY OF WATCHFUL INSECURITY</b>	<b>249</b>
8.1	Introduction	249
8.2	Being a different person	250
8.2.1	<i>The concept of difference</i>	250
8.2.2	<i>The nature of difference</i>	251
8.2.3	<i>The impact of difference</i>	252
8.3	Experience of the state of Watchful Insecurity	255
8.4	Characteristics of Watchful Insecurity	257
8.4.1	<i>Lack of trust</i>	257
8.4.2	<i>Awareness of difference</i>	258
8.4.3	<i>A sense of loss</i>	258
8.4.4	<i>Aspects of life prior to the heart attack are preferred and desired</i>	259
8.4.5	<i>Feeling preoccupied and watchful</i>	259
8.4.6	<i>Learning to live with and manage Watchful Insecurity</i>	261
8.5	Theoretical components of Watchful Insecurity	261
8.5.1	<i>Triggers</i>	262
8.5.1.1	<i>Meanings ascribed to the heart</i>	264
8.5.1.2	<i>Range of symptoms</i>	268
8.5.1.3	<i>Illness trajectory</i>	269
8.5.1.4	<i>The meaning of activity after a heart attack</i>	270
8.5.1.5	<i>The balance of internal and external threat</i>	271
8.6	Types of Watchful Insecurity	274
8.6.1	<i>Stable Watchful Insecurity</i>	275
8.6.1.1	<i>Subliminal Watchful Insecurity</i>	275
8.6.1.2	<i>Affirming Watchful Insecurity</i>	277
8.6.2	<i>Aggravated Watchful Insecurity</i>	279
8.6.3	<i>Routine Watchful Insecurity</i>	282
8.6.4	<i>Proxy Watchful Insecurity</i>	285
8.7	Trajectories of Watchful Insecurity	290
8.7.1	<i>The undulating nature of recovery</i>	290

8.7.2	<b>The trajectories</b>	292
8.7.2.1	<i>Ascending Watchful Insecurity</i>	292
8.7.2.2	<i>Spiralling Watchful Insecurity</i>	294
8.7.2.3	<i>Declining Watchful Insecurity</i>	297
8.7.2.4	<i>Stable Watchful Insecurity</i>	298
8.8	<b>Tools to manage Watchful Insecurity</b>	300
8.8.1	<b>Taking control</b>	301
8.8.1.2	<i>Avoiding / keeping safe</i>	301
8.8.1.3	<i>Getting information</i>	302
8.8.1.4	<i>Getting on with it / resuming activities</i>	303
8.8.2.	<b>Challenging Watchful Insecurity</b>	305
8.8.3	<b>Generating meaning</b>	307
8.8.3.1	<i>Attribution</i>	308
8.8.3.2	<i>Seeking explanations</i>	309
8.8.3.3	<i>Comparing</i>	310
8.8.4	<b>Redefining</b>	311
8.8.4.1	<i>Resetting limits</i>	311
8.8.4.2	<i>Reprioritising</i>	312
8.8.4.3	<i>Setting new targets and goals</i>	313
8.9	<b>Conclusion</b>	315
<b>CHAPTER 9: DISCUSSION</b>		317
9.1.	<b>Introduction</b>	317
9.2.	<b>Watchful Insecurity: theoretical contribution</b>	318
9.2.1.	<b>Conceptual links</b>	318
9.2.1.1.	<i>The nature and impact of the heart attack experience</i>	320
9.2.1.2.	<i>Threat and Disruption</i>	320
9.2.1.3.	<i>Threat to coherence</i>	321
9.2.1.4.	<i>Control</i>	322
9.2.1.5.	<i>Loss</i>	323
9.2.2.	<b>Theoretical contribution of Watchful Insecurity</b>	324
9.2.2.1.	<i>Difference and Watchful Insecurity</i>	325
9.2.2.2.	<i>Recovery as an enduring state</i>	328
9.2.2.3.	<i>The undulating nature of the recovery pathway</i>	331
9.2.2.4.	<i>Tools to manage Watchful Insecurity.</i>	332
9.2.3.	<b>Theoretical dualities</b>	335
9.2.3.1.	<i>Physical and mental distress</i>	335
9.2.3.2.	<i>Stable and aggravated Watchful Insecurity</i>	336
9.2.3.3.	<i>Acute and chronic</i>	337
9.2.3.4.	<i>Control and coping</i>	337
9.2.3.5.	<i>Loss and gain</i>	338
9.2.3.6.	<i>Self as subject and object</i>	338
9.2.3.7.	<i>Patient and partner</i>	339

<b>9.3.</b>	<b>Reflection on the research paradigm and process</b>	<b>340</b>
<b>9.3.1.</b>	<b><i>Reflections on the research process</i></b>	<b>341</b>
<b>9.3.1.1.</b>	<i>The serendipitous nature of “real world” research</i>	<b>342</b>
<b>9.3.1.2.</b>	<i>Explaining the intangible in qualitative research analysis</i>	<b>346</b>
<b>9.3.2.</b>	<b><i>Reflections on the ontology and epistemology</i></b>	<b>348</b>
<b>9.3.2.1.</b>	<i>Social influences and Individual variations</i>	<b>348</b>
<b>9.3.2.2.</b>	<i>Generating theory about recovery as a process</i>	<b>351</b>
<b>9.3.3.</b>	<b><i>Reflections on the methodology and methods.</i></b>	<b>355</b>
<b>9.3.3.1.</b>	<i>Group interviews</i>	<b>356</b>
<b>9.3.3.2.</b>	<i>Semi-structured interviews</i>	<b>358</b>
<b>9.3.3.3.</b>	<i>Interrelated jobs of theory</i>	<b>359</b>
<b>9.4.</b>	<b>Recommendations for future research and health care</b>	<b>361</b>
<b>9.4.1.</b>	<b><i>Implications for future research</i></b>	<b>361</b>
<b>9.4.1.1.</b>	<i>Developing a formative theory</i>	<b>361</b>
<b>9.4.1.2.</b>	<i>Characteristics influencing Watchful Insecurity</i>	<b>364</b>
<b>9.4.1.3.</b>	<i>Quantitative measurement</i>	<b>365</b>
<b>9.4.2.</b>	<b><i>Recommendations for health care</i></b>	<b>367</b>
<b>9.5.</b>	<b>Conclusion</b>	<b>371</b>
<b>CHAPTER 10: CONCLUSION</b>		<b>372</b>
<b>10.1.</b>	<b>Introduction</b>	<b>372</b>
<b>10.2.</b>	<b>The research findings</b>	<b>372</b>
<b>10.3.</b>	<b>The research paradigm</b>	<b>373</b>
<b>10.4.</b>	<b>Recommendations</b>	<b>374</b>
<b>REFERENCES</b>		<b>375</b>
<b>LIST OF BOXES</b>		
<b>Box 1.</b>	<b>Phases of Cardiac Rehabilitation</b>	<b>78</b>
<b>Box 2.</b>	<b>Stages of regaining control</b>	<b>98</b>
<b>Box 3.</b>	<b>Aspects of coping</b>	<b>115</b>
<b>Box 4.</b>	<b>Positivist and naturalist axioms</b>	<b>150</b>
<b>Box 5.</b>	<b>Methodological and epistemological differences between Glaser and Strauss &amp; Corbin’s.</b>	<b>170</b>
<b>Box 6.</b>	<b>Establishing “Trustworthiness”</b>	<b>178</b>
<b>Box 7.</b>	<b>Example of codes used for theoretical sampling of text</b>	<b>192</b>
<b>Box 8.</b>	<b>Case study 1.</b>	<b>240</b>
<b>Box 9.</b>	<b>The theory of Watchful Insecurity</b>	<b>247</b>
<b>Box 10.</b>	<b>The components of Watchful Insecurity</b>	<b>263</b>
<b>Box 11.</b>	<b>Case study 2</b>	<b>267</b>
<b>Box 12.</b>	<b>Case study 3</b>	<b>277</b>
<b>Box 13.</b>	<b>Case study 4</b>	<b>284</b>
<b>Box 14.</b>	<b>Case study 5</b>	<b>293</b>

<b>Box 15.</b>	Case study 6	296
<b>Box 16.</b>	Case study 7	299

### **LIST OF TABLES**

<b>Table 1.</b>	Psychological impact of a heart attack: key literature	41
<b>Table 2.</b>	Psychosocial and emotional impact of a heart attack: key literature	62
<b>Table 3.</b>	Factors influencing access and uptake of cardiac rehabilitation	81
<b>Table 4.</b>	Women's experience after a heart attack	100
<b>Table 5:</b>	Group interview participants	188
<b>Table 6:</b>	Individual interviews participants	191
<b>Table 7:</b>	Informal interview participants	195
<b>Table 8.</b>	Heart attack experience	233
<b>Table 9.</b>	Theories on response to threat	333

### **DIAGRAMS**

<b>Diagram 1:</b>	Modes of adjustment to chronic illness	110
<b>Diagram 2:</b>	Living with the change of a myocardial infarction	122
<b>Diagram 3:</b>	The social model of health	161
<b>Diagram 4:</b>	Presentation of the study results	231
<b>Diagram 5:</b>	Ascending and Spiralling Watchful Insecurity	293
<b>Diagram 6:</b>	Declining and Stable Watchful Insecurity	297

### **APPENDICES**

		i
<b>Appendix 1.</b>	List of publications and conferences arising from this study	ii
<b>Appendix 2.</b>	Publications associated with the study	xxii
<b>Appendix 3.</b>	Summary of ethical issues and Ethics Committee approval letters	xxiv
<b>Appendix 4.</b>	Participant documentation for group interviews	xxx
	<ul style="list-style-type: none"> <li>• Information sheet</li> <li>• Consent form</li> <li>• Cardiac history form</li> <li>• Interview schedule</li> </ul>	
<b>Appendix 5.</b>	Example of a group interview summary	xxvi
<b>Appendix 6.</b>	Participant documentation for individual interviews	xl
	<ul style="list-style-type: none"> <li>• Information sheet</li> <li>• Consent form</li> <li>• Interview schedule</li> </ul>	
<b>Appendix 7.</b>	Recovery paradigm model	xliv
<b>Appendix 8.</b>	Examples of codes, categories and analysis techniques.	xlviii
<b>Appendix 9.</b>	Analytical induction process	lix
<b>Appendix 10.</b>	Memos made during selective coding	lxxiv

## **PREFACE**

*“I think you start from a different place don’t you, after a heart attack .... in terms of getting back on your feet and recovering”?* (Group participant P3.2)

The aim of this research is to develop a theory to explain the experience and meaning of heart attack recovery from the perspective of patients. This preface provides a personal reflection of my clinical experiences and the intellectual journey that led me to the research presented here.

### **Personal experience**

For twenty years I have been listening to people’s accounts of their experiences during and after a heart attack. This has been in the capacity of both nurse and researcher. As a nurse I had worked on a coronary care unit and as a cardiac rehabilitation nurse specialist. In this clinical role I witnessed people’s immediate experiences of distress and disorientation after the sudden, frightening and bewildering acute cardiac event. As a rehabilitation nurse I observed people displaying a spectrum of emotional and psychological responses over the months and years following a heart attack. At this time there was an increasing volume of patient education literature aimed at supporting rehabilitation after a heart attack. This literature implied recovery was about regaining aspects of life and health and, in other words, “returning to normal”. However, my observation of the many patients and research participants I had encountered over the years

suggested that people's ability to "return to normal" varied enormously. This raises a number of questions that are fundamental to the research presented in this thesis; what exactly is meant by recovery after a heart attack, how is it defined and how do patients themselves perceive and characterize it?

### **The literature**

Having moved into a research environment I reviewed the relevant literature in more depth. I began to develop a number of concerns. The experiences as described by patients that I had met clinically did not appear to be captured in the research. As a cardiac rehabilitation nurse I had observed the range of different responses to a heart attack and how these changed and varied over time. The ability to resume life and "be oneself again" after a heart attack seemed to depend on a complex interrelation of a variety of social, individual and cultural factors, in addition to clinical influences. Neither the nature nor complexity of this scenario was portrayed in the literature. This left unanswered questions. What was the focus of recovery for patients and how was recovery mediated by various factors, for example, social and environmental influences?

### **Biomedical research**

Research emerging from health related disciplines was predominately biomedical in nature and positivist in epistemological orientation. My

interpretation of this literature was that recovery was deemed to be improvement in clinical outcomes such as physical function, psychological profiles, for example, anxiety and depression, health status and health related quality of life. When social factors were considered it was in relation to the achievement of tangible social goals such as return to work. Objective physiological and psychological measurement tools are used in this research to evaluate people's progress after a heart attack. Scores derived from such measurement are taken as an indication of recovery. One increasingly common example of such an objective measurement tool is that of health related quality of life (HRQoL) (Rapley, 2003). I questioned whether improvements on these objective scores directly equated to recovery from the patient perspective. It seemed to me that it was by no means certain that the domains encompassed in HRQoL tools actually reflect what patients understand by recovery. I was, therefore, unable to answer the following questions; how did people's individual subjective experience of heart attack recovery compare with one another? In what way were they similar and different? How did people characterize recovery after a heart attack and was there a point at which patients thought of themselves as recovered?

### **Social science research**

From reviewing the literature and reflecting on my clinical and research practice it became clear that much research referred to recovery as a goal



after a heart attack. However, there was very little understanding of what the term meant and what patients' experiences of the recovery period were. As mentioned, the biomedical literature used physical and emotional outcomes as proxy indicators. In contrast, the social science literature does explore some issues related to recovery, but this knowledge was limited in being able to address the emerging questions about the nature of heart attack recovery. The social science disciplines under consideration here are psychology and sociology.

### ***Psychology***

In the psychology research literature I found a number of theories explaining concepts such as adjustment, coping and adaptation after illness. These concepts potentially related to recovery. However, the tradition of psychology research lies in the quantitative methods of measurement and experimentation, for example detecting correlations between psychological variables and human behaviour. This scientific tradition mimics, mirrors and legitimates that of biomedical research and does little to help understand individual, subjective experience of illness, and recovery, and the associated complexity and variation. The subject of heart attack recovery exemplified to me the limitations of the positivist convention in psychology research. According to this paradigm, adjustment, coping and adaptation theories are used to generate dimensions for psychological outcome measures. An improvement in scores using such measures is assumed to indicate

recovery. Recovery is assumed to be positive progression over time, indicated by improved scores. However, it was by no means certain to me whether the dimensions of the tools match patient's recovery definitions.

More recent evolution of critical health psychology challenges the positivist scientific psychology academic citadel (Gough & McFadden, 2001). This has prompted some qualitative investigation of individual patient experience of illness. However, no research emerging from this new school of psychology asks patients after a heart attack directly what they mean by recovery and what experiences dominate and dictate recovery. Without this information it appeared impossible to understand what people were pursuing during the recovery phase after an illness like a heart attack and by what criteria they judged whether they had recovered or not. It is this requirement for knowledge that led me to the fundamental questions that influenced the development of this study. What do patients mean by recovery after a heart attack? How do they conceptualise recovery and what do these conceptualisations mean in terms of recovery?

### ***Sociology***

Sociology is a discipline that explores norms and values in society and culture. The research tradition here is in more naturalistic and qualitative research. It was, therefore, with some optimism that I turned to this literature for information on heart attack recovery. Ethnographic and

narrative methodologies have been used to develop and test theories that explain ways in which society and culture influence and interact with illness experience and impact. Whilst sociological inquiry has the advantage of moving away from quantitative measurement and more towards exploring subjective experience, once again the literature was limited in the area I required. The concept of recovery is not an explicit focus of this research. Rather than exploring the social and cultural meaning of heart attack recovery, the focus has been on the social and cultural implications or impact of illness in general. Some studies did use a heart attack as a vehicle to explore or test illness theories. Theories posited in the literature suggest how this illness might disrupt or alter the social pathways or goals. These theories may have some resonance and relevance when seeking to understand what recovery is. However, the extent to which this is true remains speculative without further research. The existing published work therefore has little to contribute in relation to the central question asked here; what does recovery mean to people who have experienced a heart attack?

### **Nursing research**

The definition of nursing research is adopted here, that is, research conducted by nurses or conducted for the purpose of informing and influencing nursing care. Nursing research has often demonstrated an affiliation to qualitative lines of inquiry. It was unsurprising then that a small

body of qualitative research was uncovered that looked at heart attack experience, life after a heart attack and the emotional impact of the heart attack.

A number of concepts reoccurred in these few studies. These concepts were identified as central to the impact and experience of a heart attack. They were control, confidence, loss, meaning and understanding. This research and the concepts they discussed resonated with my own clinical experience to some extent. However, once again it was illness experience and impact rather than recovery that was the explicit focus of this research. Whilst interesting, and anecdotally relevant, it was not clear the extent to which the concepts overlapped or integrated with patient's own experience of recovery. I was still unclear about what patients meant by recovery after a heart attack and what tools and mechanisms they needed to employ in order to facilitate recovery.

## **Conclusion**

From my clinical and academic experience I saw again and again that a heart attack could be a life-altering event and one that was, for many, a devastating one. As my interest in the subject of heart attack recovery increased the concept appeared increasingly complex and variable, according to individual experience and perceptions. Visiting the literature from various health-related disciplines did little to inform me about heart

attack recovery from the patient perspective. It seemed important to me that more empirical research was conducted in order to increase our academic understanding of recovery as a concept but also to inform clinical practice. More knowledge about how recovery is experienced is necessary for appropriate services and care to be developed and delivered and for recovery to be facilitated. I was therefore motivated to focus my doctoral research on this subject.

The research that emerged, and that is presented here, is a study that generated a grounded theory to explain the patients' experience and meaning of recovery after a heart attack. I have termed the theory that was generated, "Watchful Insecurity".

## **CHAPTER 1: Introduction to the study**

*“I was physically and mentally lost”.* (Group participant P1.1)

*“I couldn’t cope with it emotionally, I got really emotional, I used to cry”!* (Group participant P3.1)

*“You’re so afraid, let’s face it, you’re afraid”.* (Group participant P2.1)

*“You think you’re infallible until then”.* (Group participant C2.2)

### **1.1. Introduction**

This chapter builds on the points made in the preface. It begins to build a justification for this study and provides an overview of the thesis. The study presented here examines the world of patients after they have experienced a heart attack. The research concentrates on the concept of recovery. The primary aim is to explore the subjective experiences of patients recovering from a heart attack in order to understand what they mean by recovery. The purpose is to develop a grounded theory that will help explain recovery from the patient’s perspective and so comprehend what influences recovery and how health services can better facilitate recovery. The theory to emerge from this study is referred to as “Watchful Insecurity”.

The questions underpinning the research are intricate and complex questions to answer. They prompt an additional challenge in relation to this

study. What are the most appropriate research methods and techniques required to capture patient experience?

In order to introduce the study, this chapter addressed questions raised in the preface by briefly considering why it is important to explore the experience and meaning of recovery. The impact of a heart attack is first discussed. Different perspectives on the concept of recovery are then considered. This is followed by a short account of a research project that created the platform for the study presented here. The study explored access to cardiac rehabilitation after a heart attack. How this initial study helped refine the research question is then described. The chapter ends with a description of the thesis structure.

## **1.2. A heart attack and its impact**

As illustrated by the quotes above, having a heart attack can have a devastating effect. In addition to a heart attack being a sudden, life-threatening event, often there is no prior warning. The acute cardiac event may be the first indication that a person has the underlying chronic condition, coronary heart disease (CHD). A heart attack can hurl those who experience it into a state of crisis, characterized by various degrees of distress and disorientation (Cossette, Frasure-Smith & Lespérance, 2002; Johnson & Morse, 1990; Levy, 1981). As an unexpected event it can impact upon a person's ability to perform existing roles and responsibilities and

bring to a halt any aspirations and goals (Thompson & Stokes, 2002). The potential physical, psychological and social impacts of a heart attack are therefore wide-ranging and complex. As with other illness, the acute and chronic experience of CHD can have a profound effect on a person's sense of identity.

This devastation prompts the questions central to the research presented here. These questions are:

- How do people experience recovery after a heart attack?
- What do people mean by recovery after a heart attack?

Implicit in these questions is the intention to pursue understanding of how people move away from and overcome the distress described. In addition, there is a need to understand how people reconcile the difference described between the person they were before and after the heart attack. The overall aim of the study is, therefore, to develop a theory that explains the experience of recovery from the perspective of those who have experienced a heart attack.

### **1.3. Different perspectives on recovery**

#### ***1.3.1 Health professionals***

There is an implicit assumption that the purpose of much health care is to elicit or facilitate recovery. That this is true is supported by the ubiquitous



use of the term “recovery” in patient education literature. In relation to heart attacks there is a selection of leaflets, booklets and websites entitled “recovery from a heart attack” (Health net, 2004; Macnair, 2004). Couched in the content of these resources is the notion that if people follow certain instructions and resume certain activities they will achieve recovery. The terms recovery and rehabilitation are used synonymously. Both are mainly affiliated to improvements in physical function and to a lesser extent to psychological and social improvement (Petrie et al, 1996; Weinrauch, 1996). It remains uncertain the extent to which this interpretation of recovery reflects the concerns of health professionals, rather than patients.

### ***1.3.2. Health services research***

Considering this emphasis on recovery, it is surprising to discover that so little attention has been paid to what is actually meant by recovery within the body of research into health services. Recovery from the perspective of patients is unexplored. This may in part be due to the predominance of biomedical, positivist scientific traditions in health services research.

Health services research is a broad church. Its scope includes a variety of activities ranging from provision, use, organisation and quality of services as well as the evaluation of attitudes of users, access and equity issues (Crombie & Davies, 1996 p 10). With such a broad remit it is inevitable that health services research will adopt a variety of research methodologies,

methods and techniques. Health services research does not, however, have a strong tradition of qualitative inquiry and remains embedded in the world of biomedical approaches to research.

Biomedical studies conducted with people after a heart attack have an unsophisticated understanding of recovery as a concept. Research of this nature focuses upon *“the investigation and symptomatic treatment of heart disease”* (Weatherall, 1995, p96). In these studies recovery is considered in terms of the objective measurement of quantitative outcomes relating to physical and psychological symptoms. From this research, it remains unclear what patients themselves mean by recovery and what they consider important to achieve in order to recover. In addition, it is far from certain whether the outcomes measured in the quantitative studies bear any relation to the characteristics of recovery considered important by patients themselves.

### **1.3.3. Social science research**

The social sciences cover a variety of disciplines relating in some way to society and culture, including sociology, psychology, anthropology and social policy. In relation to life after a heart attack, there is a body of social science research that resorts to quantitative evaluation of psychological outcomes in line with the natural science traditions of psychology and sociology (Frasure-Smith, Lespérance & Talajic, 1995; Hoffman *et al.* 1995;

Frasure-Smith, Lespérance & Talajic, 1993; Ruberman *et al*, 1984; Philip *et al*. 1979; Mayou, Foster & Williamson, 1978). These studies also add little understanding of the subjective patient experience of recovery.

Some social science research, alongside research conducted by nurse researchers, has explored the impact of illness on people's lives, as well as coping and readjustment (Johnson & Morse, 1990; Levy, 1981). This qualitative research aimed to uncover the depth, density and diversity of patients' experience of illness but the work did not have recovery as its main focus. Whilst this adds to our knowledge of related concepts, for example readjustment, it does not provide information on the meaning of recovery after a heart attack from the perspective of those who have been through the process.

This current study challenges the stance taken by previous biomedical research that interprets recovery as achievement of certain professionally selected outcomes measured via objective, quantitative methods, for example anxiety and depression scales or health related quality of life (HRQoL). It also challenges the assumption that the outcomes used in these studies adequately reflect or capture the complexity of recovery as a concept. The study adopts an interpretive perspective that acknowledges that there will be multiple individual subjective experiences of recovery. It

rejects the notion that recovery experience can be reduced down to measurement of, often dichotomous, variables (Jenkinson *et al* 2002).

#### **1.4. The preliminary research study**

The research presented here evolved from another project. The preliminary study aimed to explore factors influencing access to cardiac rehabilitation services in the South Yorkshire Coalfields. It was carried out as part of a programme of qualitative research exploring barriers to accessing heart health services (Tod & Lacey, 2004; Tod, 2003; Tod, Lacey, McNeill, 2002; Tod, Read, Lacey, Abbott, 2001). The South Yorkshire Coalfields Health Action Zone funded this research.

In the preliminary research 20 patients participated in semi-structured interviews, six to eight months after their heart attack. More detail of the methods and results of this study are available elsewhere (Tod *et al*, 2002, Appendix 2).

From the initial study, there was an emerging sense from the data that people saw themselves as a different person after the heart attack than the one they were before. The participants reported that the accumulative effect of various impacts of the heart attack created a sense of change. During the preliminary study it became clear to me that this notion of difference required further investigation if recovery was to be better understood. More

information was required on the nature of this difference and the bearing it has on people's meaning of recovery and their ability to recover.

### **1.5. Refining the research question**

The initial study therefore served four vital functions as a precursor to the research presented here. First it provided me with an opportunity to obtain initial data on patients' heart attack and recovery experience. This provided further insight into the distress that a heart attack can create. In turn, this contributed to my theoretical sensitivity regarding the subject of heart attack recovery (Glaser & Strauss, 1967).

Second, it assisted greatly in refining my doctoral research question. The first study raised the notion of difference in someone before and after a heart attack. This prompted a number of queries. Health professionals and biomedical research interpret recovery as "returning to normal" and resuming certain activity after a heart attack. However, if people feel fundamentally different after a heart attack, to what extent is this possible? The primary research question therefore emerges. What is the meaning of heart attack recovery from the perspective of patients themselves?

The third contribution of the earlier study was that data from ten of the individual patient interviews were selected for use in the doctoral research. Using theoretical sampling, this data was employed to test the emerging

theoretical propositions generated from group interview data. The use of the individual interviews in the PhD study was included in the Ethical Committee approval. It was justified methodologically because it was from this data that the notion of difference, and the primary research question, initially emerged. Integrating this data into the analysis provided an opportunity to test the emerging theory for fit, work, relevance and modifiability (Charmaz, 2003; Glaser 1978a).

The fourth and final function of the preliminary study was to highlight the importance of social and cultural context on response to and impact of illness. Both studies were conducted in the South Yorkshire Coalfields. People from this area experience health inequalities that epitomise those present in the UK (Acheson, 1998; Chapple & Gatrell, 1998; Beattie *et al*, 1993; Townsend, Phillimore & Beattie, 1986; Black *et al*, 1984; Townsend & Davidson, 1982). Some of the highest national CHD death rates are experienced in this region. High CHD levels are linked to the deprivation in these and other communities. The health of people in the area had been further affected by the impact of traditional industries on health and subsequent unemployment since the demise of coal and steel production. The results of the initial study indicate that roles and responsibilities, socio-economic influences and stoical culture all had an impact on access to cardiac rehabilitation services. A theoretical proposition arising from this

data was that these factors would also impact upon recovery in terms of goals and pathways.

The underlying research problem emerging from this initial study was that there is currently an insufficient conceptual or theoretical understanding of what patients mean by recovery after a heart attack. This doctoral study therefore aimed to develop a theory to explain the meaning of heart attack recovery.

As previously stated, the fundamental research questions are:

- How do people experience recovery after a heart attack?
- What do people mean by recovery after a heart attack?

## **1.6. The structure of the thesis**

The following chapter (Chapter 2) presents those aspects of the literature necessary to establish the research context in terms of what a heart attack is and its impact. It also presents detail on literature related to health services for people after a heart attack and heart attack recovery. The subsequent chapter (Chapter 3) discusses various theories that relate to and may be applied to the concept of recovery. This will incorporate a discussion on the limitations of biomedical dominance in the related research and the limitations of the current orthodoxy of evidence based practice in informing us about patient's experience of health, illness and recovery (Williams & Garner, 2002). Chapter 4 describes the research

paradigm underpinning the study and influencing the choice of methods. These methods are outlined in Chapter 5. The results of the study are presented in Chapters 6, 7 and 8. The grounded theory that was developed from this study data, Watchful Insecurity, is outlined in these chapters with reference to illustrative quotes. This is followed by a discussion of the implications of the theory, conceptually, theoretically, methodologically and in terms of future health care and research (Chapter 9).

The following chapter therefore aims to provide a background to the study by providing an overview of literature relevant to heart attack experience and related health services.



## **CHAPTER 2: Exploring the context of a heart attack**

*“You never think of the mental side until it happens to you. And although you actually suffer the pain when you have the heart attack, I think the mental side of it is worse”. (Individual interview 2)*

*“Well you don’t actually know what you’re doing sometimes.... you get cross with somebody for no reason whatsoever”. (Group participant 3.3)*

*“I’d always been the breadwinner, you know, what me wife earned were pin money. Now roles have changed and it hurt, it was really alien to me and now, I’m getting to accept it now, we joke about it now” (Group participant 4.3)*

### **2.1. Introduction**

This chapter adds to the context and background of the study with reference to the literature on what a heart attack is, its potential impact on life and what health services are currently available to support people after a heart attack.

A heart attack can be a devastating, distressing and disorientating event (Dixon *et al* 2000). In addition, for many people it is only when they have a heart attack that they realise that they do not know what one is. Often, people are uninformed regarding the causes of a heart attack, what impact it will have and what they need to do to recover. This lack of knowledge, added to the shock of the heart attack, can make the world a bewildering place. Life after a heart attack may become unfamiliar and incomprehensible.

This sense of bewilderment raises important questions. How do people understand the heart attack experience? What do they understand to be the implications of the heart attack, socially and emotionally, as well as physically? What do people mean by recovery and what do they need in order to achieve recovery? This thesis addresses these questions by exploring the experience and meaning of recovery from the perspective of those who have had a heart attack.

This chapter examines pre-existing knowledge and literature that provides contextual information about the nature and impact of a heart attack. This is done from three perspectives. First, the nature and causes of a heart attack are examined. Second, evidence is presented on the ways that a heart attack can have a damaging impact upon people. The adequacy of the different research methodologies and designs to provide information on the influence of a heart attack on various aspects of people's lives is reviewed and critiqued. Finally, the provision of existing services to address the impact of a heart attack is examined. The chapter concludes by summarizing key issues raised that support conducting a study to explore the meaning of recovery.

## **2.2. Searching the literature**

The aim of this stage of the research was to conduct a selective but comprehensive review of the relevant literature. In order to achieve this, the literature was drawn from a variety of disciplines and fields of knowledge ranging from medicine and nursing to psychology and sociology. The rationale for the review was to provide a contextual and theoretical understanding of previous research and theoretical study that related to the field of recovery after a heart attack. The goal was to identify any work that was relevant, identify gaps in knowledge in existing published literature and develop understanding for the study that was conducted and is now presented here.

The literature review presented a number of challenges, which included the following:

- The area of study was a conceptual one, i.e. the meaning of recovery, as experienced after a heart attack. This provides a very different requirement to a literature search conducted to inform an interventional study. In the latter case it is possible to develop a clear and structured search question related to the relevant intervention, population and outcomes. In searching the literature for this study it was not possible to generate such a defined question.
- It was necessary to search a number of databases in order to ensure relevant articles from the range of appropriate disciplines were

incorporated. This included psychology, sociology, medicine and nursing.

- There was also a requirement to include seminal theoretical literature that was quite old, as well as more recent academic studies that developed the original work.

A number of different electronic databases were used. These included: MEDLINE 1966 – 2003, CINAHL 1982-2003, Social Science Citation Index 1981-2003, PsychINFO 1967-2003 and the Cochrane Library. Keywords used for the search were selected on the basis that they would capture theoretical and clinical research relating to the patient experience after a heart attack, recovery period and recovery as a concept. The keywords included patient experience, recovery, adjustment, adaptation, coping, coronary heart disease, myocardial infarction (heart attack), quality of life, patient satisfaction and cardiac rehabilitation. The focus of the search was not evidence on clinical interventions after a heart attack. Keywords related to these were not included. The only exception to this was cardiac rehabilitation, as this is the health service dedicated to facilitating recovery.

Because of the lack of research explicitly focusing on the concept of heart attack recovery a broad approach was taken to inclusion in terms of methods and design. In addition, relevant articles related to experience, adjustment and adaptation in conditions, other than heart disease, were

included. All types of studies were included, systematic reviews, randomised controlled trials, surveys, observational studies, theoretical / conceptual papers and discussion / descriptive studies. After limiting to English language articles, 420 articles were retrieved. Additional articles were identified after the initial search. These were identified in relation to emerging concepts from the analysis. This literature is incorporated into the thesis discussion (Chapter 9).

Abstracts and executive summaries of the 420 retrieved articles were examined. Those articles that related to the impact of a heart attack, concepts related to recovery, and rehabilitation services were retained. Seminal theoretical papers related to recovery conditions other than heart disease were also included. As the concept of recovery is an under researched area, initially studies were included purely on the basis of perceived relevance. There was a concern that if literature was filtered too early, an article that raised an important issue or question may be lost. This resulted in 204 articles to be kept for appraisal.

In addition, relevant health policy documents are also included.

Professional documents were identified from the websites and publication lists of relevant organisations, for example the British Heart Foundation (BHF) and British Association of Cardiac Rehabilitation (BACR). Clinical

texts and articles were identified for clinical reference and to provide information regarding health service provision and routine clinical care.

The 204 articles retained for inclusion in this initial literature review included articles using all types of study design. After an initial reading of the articles, they were categorised according to subject and method. The selection of the categories was dictated by the search results. The following categories were used:

- Psychological impact of a heart attack
  - Biomedical, quantitative
  - Psychological, quantitative
  - Psychological, qualitative
- Emotional impact of a heart attack
- Social impact of a heart attack
- Cardiac rehabilitation
- Illness experience
  - Biography and narratives
  - Control
  - Women's experience of heart attack
- Recovery experience
  - Coping
  - Adjustment
  - Loss and change

The articles were critically appraised to assess relevance, contribution to the research topic and aim, and to judge methodological rigour. Again, because of the lack of material in the area of heart attack recovery, it was important to be as inclusive as possible. None of the articles were rejected but some were identified as more relevant and rigorous than others. These were selected for inclusion in this review chapter. Those less relevant, lacking in rigour and those that were theoretical or descriptive were kept for reference and to reflect on during the analysis.

The critical appraisal of the studies was guided by Greenhalgh (1997), who provides questions to examine the relevance and methodological quality for studies adopting a range of methods from randomised controlled trials to qualitative studies. Three simple questions are asked first to become familiar with the articles:

- Why was the study done and what was the research aim / question/ hypothesis?
- What type of study was done i.e. what was the design and methods?
- Was the design appropriate and capable of answering the question?

Having asked these questions a more detailed appraisal was conducted using method specific appraisal frameworks for studies of varying methods Greenhalgh (1997). A brief summary of the study was written and a

judgement made of its quality and strength of evidence. This judgement was based on the following questions:

- Was the study original and relevant to the study?
- Who was the study about? (i.e. who is included/excluded, sampling method and size.
- Were the design and methods sensible and appropriate?
- How was bias addressed or minimized?
- Was the analysis clearly described, justified and the results rigorous / credible?

In line with grounded theory methodology, additional research was incrementally identified, appraised and incorporated as the study progressed. This literature was related to emerging analysis and concepts identified during the analysis.

The key references on the psychological impact of a heart attack are detailed in Table 1 (page 40). The most important and relevant references relating to the psychosocial and emotional impact of a heart attack are summarized on Table 2 (Page 61). Theoretical papers and sociological articles, where little information is available about the underlying empirical work the theory is based upon, are not included in the tables.



**Table 1. Psychological impact of a heart attack: Key literature**

*Abbreviations: AX = Spielberger Anger Expression Scale, BDI = The Beck Depression Inventory, CBT = Cognitive Behavioural Therapy, DSM IV = Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, GHQ = General Health Questionnaire, HAD = Hospital Anxiety and Depression Scale, M&M = mortality and morbidity, PSSS = Perceived Social Support Scale, RCT = Randomised Controlled Trial, SAI = Spielberger State-Trait Anxiety Inventory, SF-36 = Short Form 36 Health Survey, SSRI = Selective Serotonin Reuptake Inhibitor, US = United States*

<b>Author, Year, Journal</b>	<b>Purpose Design</b>	<b>Sample Setting</b>	<b>Outcomes</b>	<b>Results</b>	<b>Comments</b>
Frasure-Smith N, Lesperance F.  2003 60: 627-636 Archive of General Psychiatry	To examine the relative importance of depression, anxiety, anger and social support on 5-year mortality after a heart attack.  Cohort study	896 people (232 women) who experienced a heart attack.  Age 24-88yrs  Montreal, Canada	Self report questionnaire at hospitalisation and 5 years. SAI, BDI, AX, GHQ, PSSS,	BDI, SAI, GHQ all related to 5-year mortality. BDI predictive value of cardiac M&M. 2.	Not able to explain why social support not linked to cardiac morbidity.  Authors forced to speculate about other results e.g. why intervention has short-term benefit.
Berkman L. et al/ for the writing committee of the ENRICHD study  2003 289(23): 3106-3116 JAMA	Measure impact of CBT & SSRI on cardiac M&M after a heart attack.  RCT, 5 year follow up.  8 clinical Centres in the US	2481 people (1084 women) post heart attack with depression	DSM IV = Depression BDI – depression PSSS – social support ESSI = social support tool developed by ENRICHD	Improvement in outcomes at 6 months favoured intervention but no difference between groups at 27 months.	a) Intervention not successful. Conflicts with expectations. b) Study can't provide reasons to explain results. c) Don't know whether outcomes as measured are important to patients.

**Table 1. (continued)**

<b>Author, Year, Journal</b>	<b>Purpose Design</b>	<b>Sample Setting</b>	<b>Outcome Measurement</b>	<b>Results</b>	<b>Comments</b>
Frasure-Smith et al/2002 64 (4) 571-579 Psychosomatic Medicine	Measure differences in 5-year survival according to sex, anxiety and coping.  Cohort study located within RCT of psychological intervention (M-HART, 1997)	1376 (473 women) patients post heart attack  Montreal, Canada	Self report questionnaire at hospitalisation and 5 years. SAI, BDI, AX, GHQ, PSSS, Cardiac M&M, Marlow-Crowne Social Desirability Scale	Highly anxious men did better at follow-up. Repressive copers in both sexes had worse survival and higher benzodiazapine prescription	Psychological intervention of M-HART may have increased distress of repressive copers, but only speculation. Indicates complexity of interaction of variables but doesn't explain them.
Cossette S, Frasure-Smith N, Lesperance F. 2002 39:479-494 Int. Journal of Nursing Studies	Examine patient – nurse interaction associated with reduction of psychological distress in M-HART.  Cohort study within RCT (as above)	431 (146 women) post heart attack patients from M-HART intervention group  Montreal, Canada	Patient-nurse intervention measured on grid developed for study  GHQ after 2 nurse visits	3 types of approaches linked to reducing distress. Approaches varied according to patient concerns. Gender differences in approaches used.	Secondary analysis. Variation and complexity obstructs application of results. Indicates supportive interactions not always helpful but not clear which are.
Dobbels et al/2002 1:45-55 European Journal of Cardiovascular Nursing	To provide an evidence-based framework to understand depression after cardiovascular disease (CVD)  Comprehensive review	Selective, not systematic review.  Belgium	Depressive disorder (DD) (DSM IV)	Major DD present in 2-9% general population, 30-45% in CVD population. DD is a risk factor for poorer outcomes in CVD. Self report scales e.g. BDI sensitive to presence of DD	Not a systematic review. No search strategy.  Don't know if relationship is direct or indirect. Can't tell if scale scored due to somatic or psychological factors

**Table 1. (continued)**

<b>Author, Year, Journal</b>	<b>Purpose Design</b>	<b>Sample Setting</b>	<b>Outcomes</b>	<b>Results</b>	<b>Comments</b>
Mayou <i>et al</i> 2000 62(2): 212-219	Describe prevalence, course of anxiety and depression after heart attack and associations with pre-hospital status  Cohort study within larger Oxford MI Incidence Study.	347 (93 women) heart attack patients.  Oxford	Survey tool at baseline, 3 and 12 month follow up. Clinical and demographic data HAD and SF-36	Anxiety and depression <i>probably</i> present in 15%.  Anxiety and depression predict poor outcome on SF-36, chest pain and lifestyle change at 1 year	Presentation of results lack conviction. Link to pre-hospital status not clear.  Not all outcome measures given or explained. High loss to follow up.
Frasure-Smith <i>et al</i> 1997 350: 473-479  Lancet	To evaluate impact of home nursing intervention for heart attack patients in psychological distress. M-HART  RCT	1376 (473 women) patients after heart attack.  Montreal, Canada	Self report questionnaire at hospitalisation, 6 and 12 months. SAI, BDI, AX, GHQ, PSSS, Cardiac M&M	No positive impact of intervention. No reduction in medical events. Women did worse, including cardiac and all cause morbidity	Rigorous RCT but illustrates how the design doesn't always explain results.
Cay EL 1982 Feb 159-170  Hospital Update	Overview of psychological implications of heart attack, using evidence from own studies (1972) and others	Not a systematic review.	Self reported anxiety, emotional disturbance and activities e.g. sex, leisure, work.	Inverse relationship between severe emotional disturbance and return to work.  Anxiety highest at ward transfer and 6-8 days after heart attack	Many details of study design and samples not given. Reasons for outcomes and measures used not given. Data from 1972 not applicable because of changes in care.

**Table 1. (continued)**

<b>Author, Year, Journal</b>	<b>Purpose Design</b>	<b>Sample Setting</b>	<b>Outcomes</b>	<b>Results</b>	<b>Comments</b>
Mayou R. 1979 13(2):103-105 Journal of the Royal College of Physicians	Describe heart attack patient activity and psychological outcomes  Cohort study	100 first heart attack patients.  Oxford	Psychological status and activity measured at 2 and 12 months in semi- structured interview. Researcher developed scales e.g. psychological status mild / moderate / severe	50% reported moderate or severe depression at 2 and 12 months Leisure, sex activity decreased in 25%. Relationships deteriorated in 19%	No information on sample age / gender No justification or explanation of sample strategy or size. No information on psychometric properties of the tools used.
Mayou R. Foster A. Williamson B. 1979 23: 23-26  Journal fo Psychosomatic Research	Describe medical care after a heart attack i.e. advice, consultations, detection of psychological problems.  Cohort Study	100 first heart attack patients	Self reported scales administered in interviews. Medical note review	52% received advice but few retained information. Consultation not linked to medical or social problems Doctors underestimated psychological morbidity	As above. Difficult to validate interpretation of results from data provided.  Don't know if the same cohort as previous and subsequent studies.
Philip AE. Cay EL. Vetter NJ. Stuckey NA. (1979) 23: 277- 280  Journal of Psychosomatic Research	Determine fluctuations in anxiety in hospital after heart attack  Cohort study	131 male patients with heart attack admitted to CCU  Edinburgh	Cattell 8-Parallel Form Anxiety Battery administered day 1,4,7,10 after admission.  55 completed all tests	Anxiety highest on ward transfer and lowest 1 day pre- discharge	Highlights anxiety fluctuates but may be confounders. Sample size and method not justified. High non-completion Hospital care now much shorter. Anxiety at discharge may be high.

**Table 1. (continued)**

<b>Author, Year, Journal</b>	<b>Purpose Design</b>	<b>Sample Setting</b>	<b>Outcomes</b>	<b>Results</b>	<b>Comments</b>
Mayou R. Williamson B. Foster A. (1978) 22: 439-445 Journal of Psychosomatic Research	Determine physical and psychological outcomes at 2 months after a heart attack. Cohort study	100 patients and their spouses Oxford	Psychological status and physical symptoms at 2 interviews using researcher developed scales	53% described mild to moderate psychological distress at 2 months and substantial disability. 90% less active after heart attack. 25% returned to work	Disability demonstrated but unsure how applicable to current day due to changes in medical care.  No justification or rationale for sample or details of outcome measures.
Mayou R. Foster A. Williamson A. (1978) 22: 447-453 Journal of Psychosomatic Research	Describe psychological and social outcome in heart attack patients after one year. Cohort study	100 heart attack patients 29 – 69 years Oxford	As above. Interviews at 2 and 12 months	3 deaths, 8 readmission and 14 still outpatients. Two thirds had at least one symptom 32% marked and 32% moderate depression. Marked reduction in leisure activity.	Authors admit patterns of interrelation between factors so various difficult to generalize. Criticisms as for previous Mayou studies.
Mayou R. Foster A. Williamson A. (1978) 1: 699-701 Journal of Psychosomatic Research	Describe psychological and social effects of a heart attack on wives of patients. Cohort study	82 wives of male heart attack patients Oxford	As above. Interviews at 2 and 12 months.	Heart attack had impact on work, leisure and social life of wives. They had persistent psychological symptoms. Pre-morbid status influenced adjustment.	Impact on wives highlighted but lack of evidence of representative sample or psychometrically tested tools.

## **2.3. What is a heart attack?**

### ***2.3.1. The nature and prevalence of heart attacks***

A heart attack is one of the most common manifestations of coronary heart disease (CHD). Despite some reduction in death rates from CHD in recent years, rates still remain high (British Heart Foundation, 2003). CHD is the most common cause of mortality in the UK. In 2001 it was thought to be responsible for 120,891 deaths. Twenty three percent of premature deaths (under 75) in men and 14% of premature deaths in women are due to CHD (British Heart Foundation, 2004, British Heart Foundation, 2003). This is equivalent to one in four premature deaths in men and one in six deaths in women (British Heart Foundation, 2003).

CHD is a chronic condition that involves the gradual build up of atheroma, a fatty deposit, on the walls of the coronary arteries. The resultant narrowing of the arteries means the blood supply to the heart muscle is compromised. Two of the main problems resulting from CHD are angina and a myocardial infarction (Schofield, 2000). Angina is chest pain that occurs when the narrowed arteries cannot provide the increased blood supply required by the heart during exercise. A myocardial infarction, or heart attack, occurs when an artery becomes blocked, usually due to formation of a blood clot. A heart attack is a sudden event, characterised by a number of symptoms, the most common being severe central chest pain, breathlessness and nausea. Symptoms can vary enormously between individuals in terms of nature and

intensity. This is evidenced by research exploring factors influencing delay in reporting symptoms in a heart attack (Chen *et al.* 2005; Pattenden *et al.* 2002). Variation in symptom presentation is one of the reasons given for not recognising symptoms as a heart attack (Dracup *et al.* 1995). This means that people's experience of a heart attack may not match their expectations (Perry *et al.*, 2001; Horne *et al.*, 2000). For many, a heart attack may be the first sign that they have a chronic condition, that is, heart disease. This means recovery involves addressing not only the frightening acute event of a heart attack, but also the implications of living with a chronic disease.

It is estimated that a total of 275,000 people (151,000 men and 124,000 women) have a heart attack every year in the UK (British Heart Foundation, 2004, British Heart Foundation, 2003). Of these, almost half die (Volmink *et al.*, 1998). The high prevalence of a heart attack means that many people will know someone who has had or died from a heart attack, prior to experiencing their own. This vicarious experience may contribute to their perceptions, beliefs and expectations of what life and recovery will be after a heart attack.

### **2.3.2. Heart attack interventions**

Survival rates after a heart attack have, however, greatly improved in recent years due to the advent of more effective treatments (Hatchett & Thompson, 2002; Schofield, 2000). Examples of new interventions include

thrombolysis, “clot busting” drugs (Baigent *et al*, 1998). The welcome improvement in survival means that there is an ever-increasing population of people surviving a heart attack who have to find a way to recover and adapt to life after the event.

The medical term for a heart attack is myocardial infarction. Myocardial infarction means death of heart muscle (Hatchett & Thompson, 2002). Due to the cessation of blood supply during a heart attack, those who survive experience damage to the heart in the form of the death of an area of heart muscle. This damage can leave the patient with various symptoms with different degrees of severity. Some resume full physical function. Others are left with residual problems such as angina, amongst other symptoms. The physical damage, in addition to the psychological, and social impact of the event, creates challenges in recovering from the event (Hatchett & Thompson, 2002).

Medical treatment received in hospital or in primary care is aimed at controlling any symptoms that are experienced, maximizing physical functioning and reducing the risk of further cardiac events. This is achieved by a combination of drug and interventional therapy (Cosmi *et al*, 2003). The main forms of intervention are referred to as revascularisations, where narrowed arteries are bypassed by surgery or widened using a technique called an angioplasty. Increasingly, the latter less invasive option is used.



The presence or threat of enduring symptoms or further interventions may well have implications for recovery (Lewin, 1997).

Due to improvements in medical care available to people after a heart attack, the length of stay in hospital is now only five or six days. In 1997, the average length of stay in hospital was 11.7 days. It is now 5.9 (Frederick & Spencer, 2004; Schofield, 2000). This provides patients with only a short time to take in what has happened to them before they are discharged home. In hospital they can only begin the physical healing required. In addition, hospital provides little time to understand what has happened to them, and start to address some of the psychological and social implications of a heart attack. As a result people can feel very vulnerable and have numerous information and support needs upon discharge home in order to facilitate rehabilitation (Lewin, 1997; Thompson, 1990).

### ***2.3.3. Social, cultural and economic influences***

One of the problems with CHD, and a reason why it is so difficult for people to understand, is the complexity and inconsistency of its epidemiology. It is known that certain lifestyle factors and behaviours exert an influence over CHD risk (British Heart Foundation, 2004; British Heart Foundation, 2003). However, this risk is not spread evenly across populations in the UK. Environmental, social, cultural and economic factors appear to moderate a person's risk of developing or dying from heart disease (Department of

Health, 2002; Lacey, 2000; Department of Health, 1999; Davey-Smith, Shipley & Rose, 1990; Marmot & Theorell, 1990; Marmot, 1983). Death rates from CHD are highest in Scotland and the North of England. The lowest rates are found in the South of England (British Heart Foundation, 2004; British Heart Foundation, 2003). The chance of a Scottish man dying prematurely from CHD is almost twice that of his equivalent in the South of England. Disease rates are also higher in areas of deprivation (Tod *et al*, 2001; Goddard & Smith, 1998; Payne & Saul, 1997). CHD deaths are 58% higher in manual workers when compared to professional groups (British Heart Foundation, 2004).

Socio-economic factors would, therefore, appear to play a part in explaining the geographical variations, not just in the incidence of heart disease but on the ability to recover. Some of the highest national coronary heart disease death rates are experienced in the South Yorkshire Coalfields. In the UK, in 2001, age standardized death rates per 100,100 population were 213 for men and 68 for women. In the Yorkshire and Humberside region they were 245 and 87 respectively (British Heart Foundation, 2004). The differences within the UK are illustrated by a comparison between Richmond upon Thames in Surrey and the South Yorkshire Coalfields. The number of annual male deaths under 65 years (1998/2000) in Richmond was 61. In Barnsley Doncaster and Rotherham the equivalent numbers were 215, 251 and 247 respectively (British Heart Foundation, 2004). The health of these

communities has been affected by long-term deprivation and exacerbated by the continuing decline in the traditional local coal and steel industries (South Yorkshire Coalfields Health Action Zone, 2000; Rotherham Health Authority, 1998). Research on heart attack recovery therefore needs to explore social and cultural influences. The perspectives of those at highest risk should be included. This study meets these needs.

#### **2.4. How can a heart attack impact upon people?**

The emerging picture suggests that a heart attack has the potential to impact upon people in a variety of ways. The effectiveness of different research methodologies, from various academic and health disciplines, to capture this impact is now appraised.

##### ***2.4.1. Heart attack impact and quantitative inquiry***

This component of the literature review will focus primarily upon psychological and epidemiological surveys, correlation studies, and experimental trials. It does not address the adequacy of quality of life as an outcome to evaluate illness impact and recovery after a heart attack. This debate is discussed in relation to methodological issues in Chapter 4.

Research into the impact of a heart attack has traditionally been dominated by evaluations of functional and biological implications (Weatherall, 1998). Quantitative and experimental research designs have been used to

investigate the impact of a heart attack and associated interventions. The perspectives of health professionals and biomedical research have dominated this body of work (Clark, 2003). Biomedical research is defined as bringing together:

*“fundamental aspects of biology and medicine with the ultimate aim of contributing to the improvement of human health” (Caron-Flinterman et al, 2005. p2576)*

There is an expanding literature, within the biomedical, tradition, that tries to address the range and extent of psychological and social implications of a heart attack. In his formative work Mayou *et al* (1979, 1978a, 1976) began to examine the social and psychological impact of a heart attack (Table 1). He conducted research in which adverse outcomes of patients were detected after a heart attack. High rates of psychological distress were indicated. In a sample of 100 heart attack patients followed up one year after the event, 32% reported moderate symptoms and a further 32% marked symptoms. Predominant symptoms were anxiety, depression and fatigue (Mayou, Foster & Williamson, 1978a). Between a quarter and a third of the respondents reported being dissatisfied or very dissatisfied with work and leisure outcomes and changes in sexual activity (Mayou, Foster & Williamson, 1978a).

This research also started to explore the impact of the illness on families. Examples of issues raised include, relationship strain, over protectiveness of

spouses, being wary of quarrelling despite irritation and a lack of confidence in and a reduction in sexual activity (Mayou, Foster & Williamson, 1978b).

An important finding from this programme of work was that physical and psychological improvement was not always related to the size and nature of the heart attack (Mayou, Foster & Williamson, 1978a). However, as the authors admit, the extent of the variations in individual progress trajectories mean that these studies are unlikely to be generalizable (Mayou, Foster & Williamson, 1978a).

This and other work by Mayou and colleagues was influential. It succeeded in raising the research profile of the social and psychological consequences of an acute illness event, such as a heart attack. It also began to demonstrate the complexity of the issue. For example, that different patients may prioritise different outcomes, and that the range and nature of the heart attack impact also differs:

*“For most patients there is no single measure of psychosocial outcome and it is evident that individual patterns of disability vary widely”* (Mayou, Foster & Williamson, 1978a, p451).

Some participants of this study indicated reduced activity and decreased satisfaction related to this, whilst for others the reported experience was very different, and the situation improved.

*“For those families the crisis of infarction seems to have proved the opportunity and stimulus for greater understanding and occasionally for constructive rethinking and planning”* (Mayou, Foster & Williamson, 1978a, p453).

So, whilst many reported impaired physical, psychological and social functioning, the experience of others was more positive. This research made the important step of establishing that the impact of a heart attack had a psychological as well as physical component.

The research of Cay and colleagues (Philip *et al*, 1979, Dellipiani *et al*, 1976; Cay, 1982; Cay *et al*, 1972) used similar methods to demonstrate successfully the presence of anxiety after a heart attack (Table 1). They generated evidence that anxiety fluctuates at different time points from the heart attack. This research implies that a recovery pathway exists with differing levels of anxiety risk at different times after the acute event.

However, because of the nature of the methods used in these studies the results raise more questions than answers (Table 1). The studies do not have the capacity to explain the difference of impact experience between participants. This issue is taken up in the following section. The limitations of the studies are now explored.

#### **2.4.2. Limitations of quantitative methods to explore illness impact**

The biomedical orientation of this research has three important limitations.

First, whilst some people may experience a good physical and functional recovery, others are left with enduring symptoms of heart disease and heart failure. This denotes that the impact of a heart attack can vary significantly between individuals. Biomedical research, using quantitative methods, can detect variations in, for example, HRQoL scores. However, what this variation in scores means in terms of individual life experience is difficult to determine using quantitative methods that focus on statistical probability.

Second, the nature and extent of variation does not just apply to physical impact, but to a range of psychological and social effects of the illness event. The complexity and variation of psychological and social impacts of illness are difficult to encapsulate using standard quantitative measurement tools.

The final limitation is that it is not certain whether biomedical research always reflects the priorities or perspectives of patients. This is illustrated by the views of a patient research participant who was a member of consumer-orientated organisations (Caron-Flinterman *et al.* 2005):

*“The problem with biomedical research is that research questions are often relevant from a scientific perspective, but this does not imply that they are also relevant from the perspective of patients. Biomedical science is very*

*reductionist. This leads to useful knowledge and innovation, but the broader context – the overarching ‘system’ - is ignored. Patients have specific knowledge about what it is like to live with one or more ailments. By not involving patients, biomedical research is overlooking an important source of knowledge” (Caron-Flinterman et al, 2005. p2576):*

A number of additional methodological limitations also arise from the studies, as cited in Table 1.

Using quantitative methods, the researchers mentioned above looked for correlations between patient outcomes and certain behaviours or characteristics (Mayou, 2000). In the research of Mayou *et al* (2000, 1979, 1978a, 1976), psychological well being was linked to reports of over-protectiveness, relationship problems and sexual activity. Using these correlations the researchers ascribe the differences in patients’ psychological profiles to the level of supportive and encouraging attitudes within families. This assumption is problematic and illustrates the limitations of the design. This research indicates how aspects of the interpretation of survey results are merely speculative. The basic inadequacy in quantitative methods to understand the impact of an illness event such as a heart attack is, therefore, unveiled.

It is true that patients who reported better psychological profiles also report more positive experiences related to their families (Mayou *et al* 2000, 1979, 1978a). This does indicate a potential correlation. However, the study



design offers little capacity to explore the issues in more detail. As a result questions remain unanswered. First, are the outcomes used appropriate? The authors do not justify or demonstrate the relevance of the outcomes selected. The researchers themselves developed many of the outcome measures used, with little information provided of their psychometric properties (Table 1). Were the outcomes selected as they reflect professional or patient priorities?

Second, is the correlation a causal one? It is possible that other factors are at play here that are not considered by the researcher or addressed by the outcomes used. For example, does socio-economic status bear any impact upon incidence of psychological distress or family support? It is possible that overprotectiveness or reduction in sexual activity is a proxy outcome for some factor not considered in the research design. In addition, in the case of some outcome measurement scales it is difficult to tell if certain scale scores are due to somatic, medical or psychological factors. This question is identified and discussed in the selective review presented by Dobbels *et al* (2002).

In addition, it is also impossible to demonstrate from these studies how, why or in which way any correlation operates. Do people who are depressed report being overprotective? Or do people who are overprotected report

being depressed? This research raised the questions but lacks the capacity to inform us of the answers.

Further, Mayou *et al* (1979, 1978a, 1976) provide little information to describe or justify the nature and size of the sample or to demonstrate the psychometric properties of the outcome measures used. It is therefore difficult to make claims that the sample was representative. The external validity of the studies must therefore be questioned.

In summary, this seminal body of research was important in emphasising that a heart attack does have psychological and social impacts. However, when trying to understand impact of illness and recovery mechanisms, it raises a fundamental problem in terms of bio-medically driven, quantitative inquiry. It is not possible to gain understanding of or information on the dynamics and reasons for any proposed correlations from such survey based studies.

When examining the impact of a heart attack, the emphasis in these studies was on the measurement of a narrow range of clinical outcomes reflecting an orientation to the biomedical model. Whilst valuable and informative, the research leaves unexplored patient's subjective experience of illness and therefore does little to illuminate the impact from the patient's perspective. The focus is on outcomes selected as important to health professionals and

researchers rather than patients. Knowledge of the individual experience is required to gain an understanding of the range and variation of ways a heart attack can impact upon a person's life. Information of a more qualitative nature is required in order to understand illness and recovery experience from a patient's perspective.

More recent studies exploring the incidence and treatment of the psychological repercussions of a heart attack has followed that of Mayou and Cay (Berkman *et al.* 2003; Frasure-Smith, Lespérance, 2003; Hoffman *et al.* 1995; Frasure-Smith, Lespérance & Talajic, 1993; Ruberman *et al.*, 1984; Philip *et al.* 1981). Much of this work further explores the incidence of psychological problems after a heart attack, but also evaluates the effectiveness of interventions (Table 1). This research further illustrates some limitations of quantitative methods in understanding the impact of a heart attack.

This later research has established that, in patients with CHD, the prevalence of major depression is 20% and minor depression up to 27%. Depression has been identified as a risk factor for mortality after a heart attack (Berkman *et al.*, 2003). In response to this, projects such as the Montreal Heart Attack Readjustment Trial (M-HART) sought to develop and evaluate health care interventions in order to reduce anxiety and improve coping in people after a heart attack (Frasure-Smith & Lesperance, 2003;

Frasure-Smith *et al*, 2002; Frasure-Smith *et al*, 1997). The limited lens and scope of information provided by such biomedical studies is adequately demonstrated by this work.

Despite the methodological problems present in some research (Table 2), the fact that psychological distress exists after a heart attack is no longer in doubt (Lewin, 1997). High levels of anxiety and depression are consistently demonstrated in people who have had a heart attack and have been reported to be significant predictors of mortality (Dixon, 2000). The rationale behind the M-HART study was an obvious response to this evidence on psychological distress. The researchers' hypothesis was that patients randomised to a home based supportive intervention would score better on a range of psychological, social and quality of life indicators than a control group. The intervention was monthly telephone monitoring of psychological distress and home nursing visits. However, by their own admission, the researchers found the results disappointing and rather bewildering. At one year the intervention made no impact on survival or psychological outcomes (Frasure-Smith & Lesperance, 2003; Frasure-Smith *et al*, 1997). In fact, all cause and cardiac related mortality actually increased in the women in the intervention group. This trend was maintained in a five-year follow up study (Frasure-Smith *et al*, 2002). The researchers were left wondering what caused people who received additional health services and support to do worse.

Whilst quantitative and experimental studies are the gold standard for judging the effectiveness of an intervention, the example of the M-HART study demonstrates very well what such studies do not tell us about a range of factors relating to heart attack impact. These include, for example, the involved and convoluted ways that illness interacts with individuals as social and cultural beings, how it affects their sense of self and the dynamics between them, their family and social group. Research that acknowledges these factors is required if illness impact and recovery are to be truly understood and appropriate and accessible interventions developed.

**Table 2. Psychosocial and emotional impact of heart attack: Key literature**

Abbreviations: AIQ = Adjustment to Illness Questionnaire, EPQ = Eynsenck Personality Questionnaire, HLS = Health and Lifestyles Survey, HPQ = Health Perceptions Questionnaire, IPQ = Illness Perceptions Questionnaire, JCS = Jalowiec Coping Scale, MHI = Mental Health Index, MAAC = Multiple Affect Adjective Checklist, Psychosocial Adjustment to Illness Questionnaire, SIP = Sickness Impact Profile, SFS = Sexual Function Scale,

Author, Year, Journal	Purpose Design	Sample Setting	Outcomes	Results	Comments
Frazier et al/ 2002 31(6): 411-420 Heart & Lung	Describe pharmacological and non-pharmacological management after a heart attack.  Descriptive correlational survey	101 (47 women) heart attack patients. 93% White  Mid West US.	SAI measured 48 hours after admission  Medical note review after discharge.	45 notes documented anxiety assessment. 47% of them were in highest 2 quartiles for anxiety. 72 had anxiety management documented but no association between SAI score and management	Only one time measure of anxiety but anxiety levels fluctuate.  Don't discuss the demographic limitation of the sample.
Dixon et al/ 2000 31(6): 1368-1375 Journal of Advanced Nursing	Report nature, incidence and severity of psychosocial problems after heart attack and explore age and gender differences.  Cross sectional postal survey located within longitudinal cohort study.	2071 emergency cardiac patients (36% women). Included heart attack, angina and heart failure  1124 completed.  Australia	Questionnaire containing McNew Quality of Life tool posted 4 months post discharge.	Patients reported problems physically (70%), emotionally (79%), with family and friends (63%). In heart attack patients greater proportion of women and over 65s had more problems	Don't know how problems interrelate or the influence of pre-hospital psychosocial state.  Not sure if there is a sampling bias. Who were the non-responders?

**Table 2. (continued)**

<b>Author, Year, Journal</b>	<b>Purpose Design</b>	<b>Sample Setting</b>	<b>Outcomes</b>	<b>Results</b>	<b>Comments</b>
Chalfont L. Bennett P. 1999 3: 110-116 Coronary Health Care	Explore relationship between hostility, hardiness and coping with mood and behaviour.  Cross sectional survey	100 men 3 and 12 months post heart attack  Wales	HAD, coping (COPE), hostility (Cooke-Medley Scale), Hardiness (Personal Views Survey), health behaviour.	Hardiness a useful predictor of coping. Hostility, some coping variables and commitment associated with affect. Commitment negatively associated with alcohol.	Cross sectional so limited in claims of causality.  Most outcome measures valid and reliable. Some problems with hardiness measures.  Authors acknowledge limits of small sample – only 59 completed.
Petrie et al 1996 312: 1191-1194  BMJ	Explore role of patients' views on return to work after a heart attack  Longitudinal survey	143 (19 women) patients post heart attack surveyed in hospital and at 3 and 6 months 104 completed.  New Zealand	Attendance at cardiac rehabilitation, MHI, IPQ, SF-36, illness severity (hospital notes), return to work, SIP, SFS	Cardiac rehabilitation attendance related to perception that illness could be cured or controlled. Return to work predicted by perception illness time limited. Disability linked to beliefs of serious consequences	Loss to follow up accounted for. The authors speculate but don't know if perceptions due to illness or information they had before or after heart attack. Don't know how constant perceptions are.

**Table 2. (continued)**

<b>Author, Year, Journal</b>	<b>Purpose Design</b>	<b>Sample Setting</b>	<b>Outcomes</b>	<b>Results</b>	<b>Comments</b>
Radley <i>et al</i> 1996 Report to NHS R&D Directorate CVD and Stroke Programme & 1998 2(4): 202-209 Coronary Health Care	Establish if women experience more and different problems than men after a heart attack. Identify what accounts for difference  Cross sectional study interview study	120 (60 women) post heart attack patients interviewed at 6 months  Leicester	Questionnaire administered in interview on symptoms post hospital experience and validated instruments: GQH, AIQ, HLS, Sex Role Inventory	Women had poorer background (older, live alone, lower socio-economic group), more symptoms and health, lifestyle problems, especially young women with manual background	Implied recovery period has endpoint.  Conflicting information on design.  "Lifestyle problems" non-specific and broad category
Moser & Dracup 1995 24(4) 273-280  Heart & Lung	Determine relationship between feelings of control after acute cardiac event and psychosocial recovery  Longitudinal comparative survey	228 patients with heart attack, heart surgery or both. 176 (25 women) completed.  California, US	Questionnaire at 3 months and 6 months after. Researcher developed control attitude scale plus MAAC, PAIS	Link between high control and low anxiety, depression and hostility and better adjustment. No sex related differences (but only 25 women) Social variance did not impact on variance	Measurement time points confusing e.g. baseline is 3 months post admission not on admission. Loss to follow up accounted for. Suggest measuring perceived control in clinical setting
Riegel & Goeka 1995 24: 457-466  Heart & Lung	Compare adjustment, function and return to work in men and women post heart attack  Longitudinal comparative survey	32 men and 32 women 1 and 4 months after a heart attack  6 hospitals in California	Validated self esteem, mood, social support dependency scales and HPQ, EPQ. Clinical data	Men and women improved psychological function at 4 months Return to work comparable. Woman received and gave more support	Authors acknowledge limits of small sample. Not representative. Not clear what accounts for differences in social support accessed.



**Table 2. (continued)**

<b>Author, Year, Journal</b>	<b>Purpose Design</b>	<b>Sample Setting</b>	<b>Outcomes</b>	<b>Results</b>	<b>Comments</b>
Mackenzie G. 1993 4(2): 9-15 Canadian Journal of Cardiovascular Nursing	Examine role enactment and emotional responses 4-6 weeks after discharge with CVD  Descriptive correlation survey	19 women in cardiac units with heart attack (13) angina (5), coronary insufficiency (1)  Canada	Researcher administered questionnaire pre-discharge and 4-6 weeks after.  Role enactment and symptoms and well being - researcher developed questionnaire	Homemaker and family role a priority for heart attack patients -also new role as heart patient. Heart attack patients decreased role enactment. Loss of independence a fear. Patients test themselves with activity and adapt	Small, varied non-random sample. Questionnaire developed by researcher - no evidence of psychometric testing Some results not explained.
Hilbert GA. 1993 22: 200-205 Heart & Lung	Determine affect of heart attack patient and spouse, correlation with family functioning and satisfaction.  Initial baseline measurement of longitudinal study	35 men with heart attack and 35 spouses.  5 hospitals in US	Questionnaire completed in hospital measuring family function (Family APGAR) and affect (Affects Balance Scale). Demographic and clinical data	Considerable distress and affect below norm. Correlation between patient and spouse for positive affect (PA) and between PA, family function and time married	Psychometric properties of outcome scales demonstrated. Non-probability sample, limited generalizability, possible sampling bias.
Scherck KA. 1992 21: 327-324	Examine how heart attack patients cope 4-5 days after the event.  Descriptive exploratory study using qualitative and quantitative methods	30 (6women) with heart attack. 38-70 years  2 regional centres in US	Open ended interview on appraisal of heart attack and perceptions of risk and stress.  Jalowiec Coping Scale	Varied coping strategies, Didn't recognise symptom of heart attack. Fear of death and invalidity. Heart attack viewed as challenge. Positive coping strategies include self reliance	Non-random sample Limited external validity  Sampling strategy and size not explained or justified.

**Table 2. (continued)**

<b>Author, Year, Journal</b>	<b>Purpose Design</b>	<b>Sample Setting</b>	<b>Outcomes</b>	<b>Results</b>	<b>Comments</b>
Riegel & Dracup 1992 21: 529-535 Heart & Lung	Determine contribution of overprotection on cardiac invalidism Longitudinal survey	120 heart attack patients, 111 completed. 74% male	Validated self esteem, mood, dependency scales and HPQ, EPQ. Clinical data	Overprotected patients had lower anxiety, depression, anger, confusion, higher self-esteem	High non-completion Problems with definition of overprotection
Johnson & Morse 1990 19: 126-135 Heart & Lung	Examine the process of adjustment after a heart attack Grounded theory study using unstructured interviews	14 (7women) people post heart attack, 26 interviews Canada	Qualitative data used to generate theory of adjustment after heart attack "Regaining Control"	Theory claims 4 stages in regaining control (see Box 2)	Interviews range from 1 to 45 months post heart attack Sample limited to those attending cardiac rehabilitation theory may not apply to those who don't or can't attend. Claim "theoretical generalizability" but don't say whether saturation was reached.
Ben-Sira & Elizer 1990 30(5) 523-536 Social Science and Medicine	Elucidate factors enhancing or impeding psychosocial adjustment after heart attack Cross sectional correlation study	72 married men 3-24 months after heart attack Israel	Researcher developed tool measuring distress and readjustment, function and spouse support	Framework developed to explain readjustment. Demands impede self-controlled resources enhance adjustment. Spouse has crucial role.	Non-random sample at different time points to heart attack – not explained. Psychometric testing explained. No demographic data / variables discussed.

**Table 2. (continued)**

<b>Author, Year, Journal</b>	<b>Purpose Design</b>	<b>Sample Setting</b>	<b>Outcomes</b>	<b>Results</b>	<b>Comments</b>
Radley & Green 1985 20(5) 461-472  Social Science and Medicine	Examine how patients employ adjustment styles according to experiences.  Cross sectional descriptive survey	1. 40 patients pre-cardiac surgery 2. 40 patients 11 months after surgery  Leicester	1. Adjustment style, expectations of surgery, activity pattern 2. Recovery course, activity pattern, adjustment style.  Researcher developed tool	Different adjustment styles pre and post surgery. Conceptual theory developed (see Diagram 1). Adjustment influenced by expectations and changes in activity. "accommodation" style most successful	Not given gender split in sample. Tool piloted but no full validity testing. Qualitative data coded and analysed quantitatively. May have lost some meaning about why different styles adopted.
Levy SM. 1981 12: 153-171  Phenomenological Psychology	Examine 1) essential components of heart attack experience 2) compare those who do and don't reconstruct their past	28 men post heart attack. 50% with first heart attack  US	Qualitative perceptions of heart attack experience  "Reconstruct past" rated as success / failure and "Plans to cope and adapt" as clear / vague by 2 independent researchers	Heart attack seen as loss of vital energy. Attempt to normalise heart attack experience. Those who reconstruct have tendency to report motivation to cope and adapt.	Limited sample size not adequately discussed. Can only claim trends, not statistical significance. More questions than answers about why and how people reconstruct. No demographics – don't know is homogenous or not.

#### **2.4.4. The emotional impact of a heart attack**

There is a body of literature that reports research that has made a contribution to understanding the emotional impact of a heart attack (Frazier *et al*, 2002; Moser & Dracup, 1995; MacKenzie, 1993). This work has highlighted a range of concepts of potential importance when considering recovery experience (Table 2). Nurse researchers were responsible for a large quotient of these studies. It is possible that this is a reflection of the traditional affiliation of nurses to conduct research that relates to clinical problems that are meaningful to patients (Field & Morse, 1985)

Hilbert (1993) conducted a study to expand upon descriptive psychological studies and to measure correlation between emotional distress and its impact on family functioning. The study involved 35 couples where the man had had a heart attack. Prior to discharge substantial levels of emotional distress were revealed in both patients and spouses. Patients and spouses with low levels of satisfaction regarding family functioning were seen to be at greater risk of emotional distress.

MacKenzie (1993) followed up the findings of Hilbert (1993). Her study examined role enactment and emotional response in women four to six weeks after hospitalisation for heart disease. The study demonstrated that women experience poorer outcomes than men following a heart attack, a finding supported by others (Cochrane, 1992; Boogaard, 1984; Stern, Pascale &

Ackerman, 1977). The study does indicate that emotional distress in her sample was raised in the first four to six weeks post discharge. It also emphasises the importance for women in being able to re-enact and resume their home-making and family roles. However, the research is compromised by the small sample size of 19 women. In addition the data was collected using a tool developed by the researcher that had not been piloted or subject to psychometric testing. The generalizability of the results must therefore be questioned (Table 2).

Moser and Dracup (1995) explored the role of perceived control on psychosocial impact of outcomes following a heart attack. Perceived control is described as the self-belief that a person can influence the “adversiveness” of an event. This study involved 228 patients who had had a heart attack or heart surgery. The sample completed a validated questionnaire 3 months after the cardiac event and six months later. Of the initial sample, 176 completed the study. At the six month follow up, participants with high levels of control were seen to be less anxious, less depressed, less hostile and with better psychosocial adjustment (Table 2).

Loss of control is cited as an influential impact of the heart attack. Resuming control therefore becomes crucial afterwards. Reigel & Dracup (1992) investigated psychosocial adjustment, cardiac invalidism and social support in 111 heart attack patients. *Cardiac invalidism* is a concept associated with low

self-esteem, negative health perceptions, dependency and lack of control after an illness (Reigel, 1993). Using a combination of validated instruments this study revealed that overprotected patients were less anxious and had higher self-esteem. The follow-up period in this study was only four months, suggesting that in the short term, overprotection may be beneficial. The question remains, however, about what the long-term impact of overprotection on self-esteem and ability to regain control (Table 2). The indication from this study, and a subsequent study (Reigel, 2003) was that those who were overprotected had less negative feelings, higher self-esteem and were better able to regain control of their lives, make the readjustment and avoid the adoption of the "sick role".

In a small Canadian qualitative study with 14 heart attack patients, Johnson & Morse (1990) also identify loss of control as an important impact of the heart attack. Using grounded theory methods, the authors explicitly identify regaining control to be central to recovery. Regaining control is described as having a sense of mastery, when tasks of life were completed without undue worry and effort. The process of regaining control is suggested as staged and linear in nature.

The study by Johnson & Morse (1990) reinforces the fact that a heart attack can have a profound psychological impact on a person and his or her family. It has also raised some concepts that could be potentially important in terms of

recovery, for example control and self-esteem. The study is however open to criticism due to its small sample size, as discussed below.

Qualitative studies may have justifiably small sample sizes. The aim in qualitative research is to explore the range and nature of experience of a phenomenon (Bowling, 1997). The goal is to generate information that represents participants' experience, rather than data that is representative of a wider population (Charmaz, 2003; Bowling, 1997). Researchers using grounded theory use theoretical sampling, where the theoretical concepts and principles identified in the analysis direct the sampling (Strauss & Corbin, 1990). When no new concepts emerge, sampling will cease (Bowling, 1997). A small sample may therefore be warranted. However, Johnson & Morse (1990), and some of the other research cited in Table 4, do not provide the detail necessary to establish the adequacy of the sample size. There is no discussion or evidence that theoretical saturation was reached or whether the sample size was directed by convenience rather than analysis.

Those using qualitative methods are bound by the same methodological limitations as the biomedical studies discussed above. A number of concerns arise. First, as illustrated by Table 2, the authors do not always explain, justify and provide a rationale for the sample size and method. The external validity of the qualitative studies is therefore in doubt.

Much of the research cited here on the emotional impact of a heart attack was conducted outside Britain. It is difficult to assume the results are transferable to a UK context in general, or more specifically to the population in the South Yorkshire Coalfields. Demographic and socio-economic information about the participants is often lacking, thus preventing the ability to make a judgement about the wider application of the results outside of the study area. Finally, psychological and emotional factors are considered in the studies alongside some social issues, such as social support. However, more detailed exploration of health inequalities, and the influence of cultural and socio-economic factors are not addressed in this body of literature.

#### ***2.4.4. The social impact of a heart attack***

The work of Reigel (1993), Reigel & Dracup (1992) and Johnson & Morse (1990) makes reference to the social impact of a heart attack. The fact that a sudden unplanned illness has occurred, with potential health consequences, can have an impact on the physical psychological and social ability of someone to function, within and outside of the family. Sociological research has expanded knowledge on the social impact of a heart attack and raised other questions that may potentially relate to recovery.

Blaxter (1979) explored the processes and experience of disability of people with a range of conditions, including a heart attack. Using discursive, unstructured interviews, her study revealed the extent to which problems



encountered after an illness or disability, are social as much as clinical. The impact and issues to deal with will depend on the context of the social, financial and occupational circumstances of each individual. The positive influence of the social support received from a spouse was discussed.

*“It was only to be expected that people living with their spouses should have fewest problems, and those living alone the most. There is some likelihood of a couple being able to offer each other practical help and social support, and people living alone are particularly likely to be in a financial need. The difference between married and single people and ‘others’ (widowed, separated, divorced) was striking (Blaxter, 1979, p44).*

Whilst living with a partner may provide support in illness, the illness can also create stress and put strain on relationships. Blaxter (1979) identified that in the immediate period after an illness, the main problems encountered related to money, work and daily living. Eventually problems with marital and family relationships and social life loom large. This may in part be due to the stigma of an illness or condition or the fact that, in the case of a heart attack, it challenges a person's sense of identity. For example, the impression that “I'm not the man I used to be” may well impact upon the ability or willingness to interact socially and sexually (Drory, Kravetz & Weingarten, 1999; Arino-Norris, 1997). The social disruption after a heart attack impacts on family and relationships with partners (Hilgenberg *et al*, 1992; Thompson, 1990). How these issues integrate with the meaning recovery has for a person needs to be further explored.

Blaxter (1979) proposes that more strain can be put on relationships by a husband's illness. She discusses this in terms of illness in general, but using a heart attack as an illustration. Possible explanations offered were that a woman was more likely to talk about her illness. Also, in traditional homes where the woman kept house, her illness was less likely to cause a complete change in a family's way of life. Her disability did not mean a change in occupation. Even if restricted in mobility or being housebound, the women in Blaxter's sample were more able to keep occupied and maintain social networks with neighbours, relatives and daughters. In contrast, where the man was the wage earner a more radical change was reported, impacting upon ability to adapt and adjust. He may have to give up work, change jobs, be around the house more and lose previous social contacts. This led to irritation and tension in the household and relationship. This was particularly true when disability was unexpected, for example after a heart attack. The wife of a man provided one example after a heart attack.

*"Another young wife with four toddlers, vividly expressed the strain of living with a husband whose heart condition permitted only intermittent work: 'He gets attacks of rage – I know its only because he's worried – but the red begins to rise in his neck and I get the shakes when I see it. His illness is making me ill – I can't sleep either – it's the children that suffer'" (Blaxter, 1979, p204).*

Radley (1997) proposes that there are three main areas of concern in relation to the social impact of a heart attack. His claims are based on his empirical work, summarized in Table 2 (Radley *et al*, 1996; Radley & Green, 1985). These

areas of concern are, return to work, relationships with families (especially spouse) and relationships with others (especially friends and confidants). The complexity of these issues lies in their interrelation with one another, with broader social and environmental context and with physical and psychological impacts of the heart attack. This myriad of potential interrelations also indicates the many and varied experiences people may have in response to a heart attack. The range and complex nature of heart attack impact justifies the further exploration of the subjective experience of recovery from the perspective of patients themselves.

## **2.5. Cardiac rehabilitation services**

### **2.5.1. A definition of cardiac rehabilitation**

From the above review of the impact of a heart attack it is clear that the event can have physical, emotional and social consequences. One intervention, which aims to benefit patients and relatives and improve quality of life after a heart attack, is cardiac rehabilitation. The World Health Organisation (WHO) defined cardiac rehabilitation as:

*“The sum of activities required to influence favourably the underlying cause of the disease, as well as to ensure the patients the best possible physical, mental and social conditions so that they may, by their own efforts, preserve, or resume when lost, as normal a place as possible in the life of the community. Rehabilitation cannot be regarded as an isolated form of therapy, but must be integrated with the whole treatment, of which it forms only one facet”* (World Health Organisation, 1993, p5)

Chau and Lipkin (1993) suggest that cardiac rehabilitation aims to improve function, relieve symptoms and enhance quality of life. However, the WHO's broad definition also implies that the person and their recovery, should not just be viewed from a biomedical perspective, but as placed in their community context.

Core service components of cardiac rehabilitation are medical treatment, education, risk factor modification, exercise training, counselling (for example, vocational and sexual counselling) and secondary prevention (Bethell *et al*, 2001; Bethell, 2000; Thompson & Bowman, 1997). Cardiac rehabilitation is, therefore a multi-faceted activity requiring a range of health professionals to bring together the skills required.

### ***2.5.2. The content and quality of cardiac rehabilitation in the UK***

There is an ever-increasing body of evidence to demonstrate the benefit of cardiac rehabilitation, for example, a reduction in mortality of as much as 20% to 25% has been indicated (Pell, 1997; O'Connor *et al*, 1989; Oldridge *et al*, 1988; Bobbio 1989). Additional proven benefits include improved exercise tolerance, improved symptoms, and reduction in stress, reduction in smoking and improved psychosocial profiles (NHS Centre for Reviews and Dissemination, 1998; Thompson & Stokes, 2002).

In order to provide adequate and timely services, the use of a structured framework has been recommended (Thompson & Stokes, 2002). Many programmes in the UK use a framework that divides cardiac rehabilitation into four phases (Coats *et al*, 1995). These are described in Box 1.

Frameworks of this nature imply that rehabilitation, and therefore recovery, is a linear process. Over time the damaged heart muscle is healed, other recovery goals are achieved, including social and emotional aims, until the focus is on maintenance.

## **Box 1. Phases of Cardiac Rehabilitation**

### **Phase One**

In-patient cardiac rehabilitation, from admission to discharge.

Issues to consider include:

- Reassurance
- Information
- Risk factor assessment
- Education
- Mobilization
- Discharge planning
- Involvement and support of partner/family.

### **Phase Two**

Immediate post discharge, up to for to six weeks.

Largely focused on education and resumption of physical activity.

The stage often neglected by programmes in Britain.

Various models of delivery have been adopted, including:

- Telephone follow up
- Telephone helplines
- Home visits by hospital based specialists or community nurses
- Individual appointments in hospital or primary care
- Group sessions.

### **Phase Three**

Intermediate post-discharge.

Advised to start anytime from four weeks post discharge.

Often dominated by exercise interventions, in hospital-based groups. Effort has been made recently to emphasise other aspects of the service, including education, behaviour and lifestyle changes, vocational counselling and psychological interventions. Attention has also been paid to alternative locations in the community.

### **Phase Four**

Long term maintenance.

Two main components are:

- Support in maintaining individual, long term cardiac rehabilitation goals
- Monitoring and follow up of progress

It is advised that this should be provided in close liaison with primary care and secondary prevention services for coronary heart disease.

*From: Jones & West, 1995; Stokes, Turner & Farr, 1995*

Despite the adoption of these frameworks a number of challenges in the delivery and evaluation of cardiac rehabilitation have been highlighted (NHS Centre for Reviews and Dissemination, 1998). Allegations regarding inconsistent quality and content of services have been made (Thompson & Bowman, 1997). One reason for the inclusion of cardiac rehabilitation in the National Service Framework for Coronary Heart Disease (Department of Health, 2000a) is the problems and criticisms that services, and those commissioning and providing them, have experienced (Dalal & Evans, 2003). The concern that exists in the UK regarding the provision of cardiac rehabilitation services may in part be due to the fact it is difficult to determine which single component, or combination of components, are most effective. In addition, it is probable that what is effective will be different between individual patients. A “one size fits all” approach to supporting people in rehabilitation will not therefore work.

### **2.5.3. Access to cardiac rehabilitation**

There are also huge questions regarding inequalities in access to cardiac rehabilitation (NHS Centre for Reviews and Dissemination, 1998; Melville *et al*, 1999). Cardiac rehabilitation participation rates range from 15% to 59% (Pell *et al*, 1996). Current services are often hospital based, limited to low risk patients and operate strict exclusion criteria (Bowman, Bryar & Thompson, 1998; Tod, Pearson & McCabe, 1998; Thompson *et al*, 1997). This means that those most likely to benefit are often unable to access cardiac rehabilitation.

*"Most centres tend to restrict access to young, male, white patients who have suffered (usually first, uncomplicated) myocardial infarction. (Thompson and Stokes, 2002, p32)*

There is a limited literature that begins to inform on reasons for low uptake generally and in specific groups. The relevant research is summarised in Table 1, where factors compromising access and uptake are identified. These include socio-economic and psychological issues. No research that adds to the factors identified here has been identified since 2002. More recent studies have focused on interventions to overcome access barriers (Beswick *et al*, 2004; Beswick *et al*, 2005). These resulted in a recommendation for more, good quality research.

There would appear to be a particular problem regarding the uptake of services by women, ethnic minority groups and the elderly (Beswick *et al*, 2004; Conn, Taylor & Abele, 1991). Levels of deprivation and education are also linked to low uptake of services (Melville *et al*, 1999). A notable gap exists regarding research evaluating or recommending interventions to meet the needs of these groups. (Beswick *et al*, 2005). The preliminary study referred to in Chapter 1, did reveal a range of social and structural reasons for the inaccessibility and lack of acceptability of services to women, men and the elderly in the South Yorkshire Communities (Tod, Lacey & McNeill, 2002). These included service location, social roles and responsibilities,



**Table 3. Factors influencing access and uptake of cardiac rehabilitation**

Authors	Journal / Publication Year	Study Focus	Study Design	Factors Influencing Access and Uptake
Hiatt <i>et al</i>	1990, Cardiovascular Nursing	Factors influencing patient entrance	Survey	Living alone, deprivation
Ades <i>et al</i>	1992a, Archives of Internal Medicine	Predictors of participation in older patients	Survey	Being older, perception of physicians recommendation
Ades <i>et al</i>	1992b, American Journal of Cardiology	Referral patterns	Survey	Women not referred
Thomas <i>et al</i>	1996, Journal of cardiopulmonary Rehabilitation	Gender differences in enrolment	Survey	Women not referred, don't attend
Pell <i>et al</i>	BMJ, 1996	Influence of deprivation	Survey	Age limit, deprivation
Melville <i>et al</i>	1999, Heart	Uptake of cardiac rehabilitation	Cohort	Low educational level, deprivation
Cooper <i>et al</i>	1999, Heart	Attendance at cardiac rehabilitation	Survey	Being older, unemployed, belief that the disease is controllable or in a lifestyle cause
Halm <i>et al</i>	1999, Journal of Cardiovascular Nursing	Compliance in women	Cohort	Access to transport, insurance, exercise at home
Schulz & McBurney	2000, Coronary Health Care	Factors influencing attendance	Survey	Being older, living further away, living alone, no access to own transport
Evenson & Fleury	2000, Journal of Cardiopulmonary Rehabilitation	Barriers to participation	Survey	Finance, work commitments, motivation
King <i>et al</i>	2001, Heart	Psychosocial component of attendance	Cohort	Role resumption, low self-efficacy
Daly <i>et al</i>	2002, Progress in Cardiovascular Nursing	Barriers to participation	Systematic review	Lack of referral, illness, self-efficacy/concept, social support, motivation, family, occupation

cultural pressure to be stoical and “put a brave face on things” and a belief that services were for others, not themselves (Tod, Lacey & McNeill, 2002).

What begins to emerge from the literature is a picture where an individual’s rehabilitation needs may be complex and varied. Services do not have the flexibility or capacity to respond to these in an accessible and acceptable way (Tod, Pearson & McCabe, 1998). However, little research is available to help develop understanding of what patients mean by recovery after a heart attack. Such research would be of potential use in delivering more appropriate services. Certain questions arise from this lack of knowledge. For example, how do patients describe their experience of recovery, including those who currently don’t access rehabilitation services? What is the conceptual overlap between rehabilitation and recovery? Is recovery a linear process like that suggested for rehabilitation? It is this gap in knowledge that the study outlined here aims to fill.

## **2.6. Conclusion**

Recovery from a heart attack is complex in nature and demands further research. The nature of the heart attack itself is an issue. It is a sudden and therefore frightening event that many consider life threatening. A heart attack is not just an acute event but involves a diagnosis of a chronic condition as well. Variable physical symptoms may be experienced after a heart attack. The reality or threat of these may well impact upon recovery.

Existing research identifies that psychological and social, as well as physical impacts are experienced after a heart attack that can challenge life as it was experienced before the heart attack. However, research exploring this experience is lacking. There is also an absence of work to link what is known about the impact of a heart attack to recovery.

Despite the severity, variation and complexity of the impact of a heart attack, service provision to support rehabilitation is patchy and of inconsistent quality. Cardiac rehabilitation services have poor attendance and high attrition rates. In order to inform the development of accessible and acceptable services more research is required on the subjective patient experience of a heart attack and recovery.

Recovery as a concept is not explained in the biomedical, rehabilitation or other literature. There is an implication in existing research that recovery equals the resumption of certain activities or attainment of clinically derived outcomes. It is also assumed that rehabilitation is the same as recovery. Both these assumptions need to be challenged in more qualitative research of good quality. It is important to understand the perspective of the people who have to find a way through the scary and disorientating period following a heart attack.

Research to explore the experience and meaning of recovery from the perspective of people who have had a heart attack is urgently needed. It is also

vital to include the social and cultural issues that contribute to the many and varied psychological and social impacts a heart attack can induce. These goals are central to the research in this thesis.

## **CHAPTER 3: Literature review: illness experience and recovery**

*“You know, theoretically we’ve all had heart attacks but they’re all different” (Group participant P3.3)*

*“It’s an emotional thing and it will affect some people differently, some people might not show emotion. It mattered a lot to me to be able to do things I used to be able to do”. (Group participant P1.3)*

### **3.1. Introduction**

This chapter aims to discuss the various theories that relate to and may be applied to the concept of recovery. The adequacy of the current evidence base in increasing understanding of patient’s experience of health, illness and recovery will be considered.

The above extracts are from study participants. Both emphasise the individual nature and variation in the experience of a heart attack. This research develops a theory to explain the experience and meaning of heart attack recovery, the theory of “Watchful Insecurity”. The theory acknowledges the unique nature of each individual’s experience and encompasses the variations in experience and recognises the subjective nature of the heart attack experience. Conceptually, however, the theory applies to the experience of all. It has conceptual resonance with the meaning that all the participants ascribe to recovery after a heart attack.

As a background to this study, aspects relating to the impact of a heart attack were considered in the previous chapter. The potentially devastating and varied nature of the impact was indicated. In this chapter, attention turns to the theoretical literature relating to illness experience and to recovery. This chapter examines how previous research contributes to a theoretical understanding of the experience and meaning of heart attack recovery. Where possible examples are provided from the literature on heart attacks. In some instances literature drawn from other illness experience will be referred to. The limitations of current knowledge are highlighted. Some of the methodological challenges in researching patient's recovery experience in a meaningful way are discussed along the way. This section of the review concludes by justifying the central research question and the framework for the study.

### **3.2. Definition of terms**

“Experience” and “recovery”, when applied to illness are complex terms. However, little attention is given in the related research to developing a conceptual understanding of them or providing a definition. A working definition of both terms, as used in the research study, is below.

Standard dictionary definitions of and thesaurus entries related to “experience” reveal how the term can be defined and explored from polarized positions. One definition of experience is *“long and varied observation, personal or general”* (Chambers Dictionary, 2003. p527). This interprets experience as an objective

assessment of an occurrence. This would fit with a positivist, realist research approach that concentrates on the measurement and observation of outcomes. In contrast experience is also defined as *“passing through any event or course of events by which one is affected”* or to “meet with”, “suffer”, “feel” or “undergo” an event (Chambers Dictionary, 2003. p527). These concepts capture a more subjective interpretation of experience and highlight the emotional component of the concept. As this study concentrates on exploring patients' subjective individual experience of recovery, and the variations of this, it is the more subjective approach to defining experience that was adopted.

Recovery is similarly unexplored as a concept in medical and social science literature. Dictionary and thesaurus definitions interpret recovery as meaning *“the process, possibility or power of recovering, or state of having recovered”* (Chambers Dictionary, 2003. p1268). To recover is described as *“to regain health or any former state”* (Chambers Dictionary, 2003. p1268). Key concepts of note here are that recovery is understood to be a process and that it relates to in some way pursuing health, or a previously experienced state of health.

### **3.3. Illness experience**

#### **3.3.1. *The contribution of research on illness experience***

Illness experience has been subject to considerable exploration in recent years, resulting in a number of classic texts and theories (Corbin, 2003). These discuss and attempt to explain various issues related to what it means to be ill

and how illness is experienced. For example theoretical propositions are made relating to concepts such as, identity, self, self-image, loss. Theories are presented to explain the way illness influences how people construct and represent themselves, and how they communicate socially (Morse, 1997; Bury 1991; Corbin 2003; Corbin & Strauss, 1987; Charmaz, 1983). Sociology is the discipline that plays a predominant role in producing this knowledge.

Much of the research reviewed here does not explicitly concentrate on the experience of a heart attack; its emphasis is, rather, on chronic illness. A heart attack is both an acute event and an indication of chronic underlying disease. The extent to which this existing chronic illness literature will apply to heart attack recovery experience is therefore uncertain. Despite the fact that the research does not explicitly explore heart attack illness experience, this body of work does use qualitative methods to help elucidate experiences after an illness event. This methodological approach makes it of potential use. The themes, issues and theoretical propositions generated by the qualitative inquiry can potentially be transferred to explain the meaning of heart attack recovery from the patient's perspective. The contribution of such research is therefore explored here.

Drawing upon her own research and that of others, Corbin, (2003) reflects upon the various ways illness can bring about differences for a person. These include differences in time, space, morality, aesthetics, technology, information



and interpersonal relationships. In the introduction, I identified that this current study was in part prompted by the discovery that people referred to themselves as being a different person after a heart attack. Corbin's reflections of difference are therefore of interest and use in helping to direct the literature review. The range of ways Corbin (2003) suggests people experience difference as a result of illness illustrates the diversity of the literature available. In order to keep the literature focused it has been limited to that which, first, is most pertinent to experience of heart attack recovery and second, acknowledges difference in some way. The following subheadings are used to discuss the illness experience literature: biographical disruption, control and confidence, women's experience of illness. The limitations of this literature in relation to the study presented here are then considered.

### **3.3.2. *Biographical disruption***

Corbin discusses how time takes on a different dimension as a result of illness which "*Intrudes into life, disrupting biographical time*" (Corbin, 2003 p259). In this way continuity of life can be threatened or changed. Illness can mean that people struggle to anchor current and future life to that of their past. As a result it is difficult for some to make sense of memories, goals and emotions. The term that has been used to describe this is "biographical disruption" (Bury, 1982; Bury 1991). Proposing that people experience biographical disruption due to illness, prompts the question, how do people understand and make sense of the illness experience?

The need to construct meaning in order to continue life after a sudden frightening event, such as a heart attack, is picked up in the sociological literature. Cowie (1976) initially explored this issue in research that preceded that on biographical disruption. Cowie (1976) interviewed 27 heart attack patients under 60 years of age. The interviews took place 2 days before discharge from a hospital in Scotland. After the initial interview, one or more subsequent interviews took place with the spouse present. The focus of the interview was on the perception and interpretation of the illness. No further information regarding data collection or analysis is provided (Cowie, 1976). Cowie (1976) suggests that patients retrospectively reconstruct their heart attack in order for the event to make sense for them in the future. He called this process "narrative or retrospective reconstruction". This involves finding reasons for the heart attack to happen. That is, people rewrite the past to fit the present. One of the strategies adopted to do this is to compare themselves with other patients. Other strategies involved reference to a previously experienced illness. By reconstructing their biography the participants were seen to reduce the surprise element of the event and normalize it.

In relation to heart attack recovery experience, two points can be extrapolated from this study. First, Cowie (1976) highlights the importance of "making sense" of an event in order to move forward, recover or adjust. Second, there is a link between this argument and Antonovsky's (1979) sense of coherence

model. Antonovsky claimed that people could incorporate adversity into their lives and move forward if they could construct life events as comprehensible, manageable and meaningful. This construction is fundamental to maintaining health. Cowie's (1976) theory of retrospective reconstruction is one suggested way that people manage to do this.

Bury (1982, 1991) developed these ideas further and devised a framework that explicitly considers illness as a biographical disruption. The theory emerged from some empirical work conducted and published in 1982. Bury conducted 30 semi-structured interviews (including five women) with people with a chronic illness, rheumatoid arthritis. The sample was taken from a working class community in the North of England. Little further information on data collection and analysis is provided. The theory of biographical disruption is built on the assumption that people live their lives with, to some extent, an expectation of a certain life trajectory. Illness and other challenging experiences are viewed as possibilities for others, not the self. When illness occurs, travel along this anticipated trajectory is derailed or brought to a halt. Rooted in a social perspective of health, this disruption will be experienced and influenced not just by the interrelation between the illness and the person, but by families and those in wider social networks.

Three aspects of disruption have been suggested in relation to illness (Bury 1982). First, the disruption of taken for granted assumptions and behaviours. In

relation to a heart attack, these assumptions may relate to who is at risk of experiencing one and what the symptoms are. The extent to which experience fits expectation will influence the extent of disruption. An illustration of this is that some view heart disease as a predominantly male disease. For a woman with such views to have a heart attack may then result in biographical disruption. How this is experienced in terms of patients' recovery has not, however been explored empirically.

The second aspect of disruption addresses disruption in explanatory systems and deals with the uncertainty encountered when people are faced with re-thinking their biography. This strongly resonates with the importance Cowie (1976) and Levy (1981) place on the ability to retrospectively reconstruct a heart attack in order to give it meaning for future life. Bury (1982) suggests this disruption is influenced by uncertain knowledge about the condition. In relation to a heart attack, there may, for example, be no clear causal reason for the event in a particular individual. However, interpretive sociology has theorized about the importance of having a cause in order to construct meaning (Bury 1982). This highlights the importance of the provision of sufficient information, relevant to a patient's needs after a heart attack. Without this they will not be able to incorporate the heart attack in a meaningful way into their future biography.

The final aspect of disruption relates to the ability of someone to mobilise resources in order to face an altered situation due to illness. By resources, Bury (1991) is referring to social networks and community involvements. Disruption in social involvement occurs after illness because of both physical limitations and emotional responses. For example, if it was perceived to be embarrassing or carry a stigma, an illness may inhibit someone from social interaction. After a heart attack people may be concerned that others will consider them weak in some way. This was referred to earlier in relation to the research of Blaxter (1979). She reveals how illness can challenge social identity and interaction. In this instance, in order to maintain some control over their biography a person may choose relative social isolation.

In an earlier study on barriers to accessing services for people with angina, the researcher identified examples where this occurred (Tod et al 2001). In the small mining communities where this study was conducted, people tended to know a lot about their neighbour. Participants who were disabled by their angina reported that they would rather not go out, than be seen by their neighbours in an electric chair. This was seen to carry a stigma of disability. Corbin (2003), drawing on her interviews with people with multiple sclerosis, discusses how people may change in appearance, performance or ability as a result of illness. This change can impact upon identity and “can arouse disgust in self and others” (Corbin, 2003. p260). This would severely affect a person's

ability or willingness to mobilize social support and resources to help deal with illness. This exemplifies the social disruption and isolation that can ensue.

Despite the fact that biographical disruption has great potential in helping to understand the experience and meaning of recovery after a heart attack, this has never been explicitly explored. Bury (1982) worked theoretically from the perspective of chronic illness, not an acute event such as a heart attack. His theory does, however, resonate with what we know about the nature and impact of a heart attack (Chapter 2). Bury exemplified this potential application to heart attacks when he commented that chronic illness:

*"... involves a recognition of the worlds of pain and suffering, possibly even death, which are normally only seen as distant possibilities or the plight of others"* (Bury, 1982 p189)

The potential application cannot, however, be assumed. By explicitly exploring the heart attack recovery experience and meaning from the perspective of patients themselves, it will be possible to consider the role of Bury's theory.

Another concern regarding the contribution Bury's theory makes to understanding heart attack experience is that recent research has challenged the idea that biographical disruption occurs to the extent originally claimed (Asbring, 2001; Pound *et al*, 1998). In an exploratory study, Pound *et al* (1998) conducted in-depth interviews with 40 people (19 women) at home, 10 months after a stroke. Their ages ranged from 40 to 87. The purpose of the study was

to explore the response to stroke and the presence of disruption. As with a heart attack, the onset of a stroke is usually acute. That narrative reconstruction occurs in people after an acute stroke is supported, but not biographical disruption (Pound *et al*, 1998). Narrative reconstruction takes the form of normalizing the illness. Perceiving the illness as “not that bad” therefore preserves the continuity of life. One explanation for this is that the stroke study was conducted amongst a particularly stoical, working class community. Expectation and experience of life amongst this community was that life was hard. The stroke was assimilated into these expectations. It is suggested that consideration of social context will impact upon the biographical disruption experienced. This was not originally taken into account by Bury (1982), but will need to be considered in relation to the findings of this study on heart attack recovery.

Asbring (2001) explored how people with chronic fatigue syndrome (CFS) and fibromyalgia suffer from identity loss. She interviewed 25 women with CFS and 12 with fibromyalgia in a study using grounded theory methods. Biographical disruption was reported in the women (Asbring, 2001), but this impact was partial. The women experienced a transformation in identity associated with this but came to terms with the difference in life after illness by developing alternative interests. In this case the biographical disruption was partial and the illness experience had a positive aspect. Loss occurred alongside gain. That biographical disruption can be partial and positive has not been considered in

relation to a heart attack, which again supports the rationale for the research conducted here.

### **3.3.3. Control**

The issue of control is interwoven into the results of much qualitative literature on illness experience. Associated with control are the concepts and sensations of confidence and trust, physical, psychological and social (Corbin, 2002). An important piece of research in this area by Johnson & Morse (1990) was that referred to earlier. This study provided a much-needed qualitative interpretation of the experience of life after a heart attack. They argue that their study gives primacy to patients rather than professional's perspective and to the subjective experience of adjustment after a heart attack.

Using grounded theory methods, 14 people (seven men and seven women) were interviewed up to three years after their heart attack. The aim was to explore illness experiences, increase understanding and so be better equipped in helping patients set realistic rehabilitation goals. The core concept of "regaining control" was seen to be dependent on three things: first, the ability to predict the outcome of actions to promote health and prevent recurrence; second, the ability to make decisions about illness, treatment and lifestyle; and finally, the ability to act on the above decisions.



Four stages of regaining control were identified. Key points related to these are summarized in Box 2. The process of regaining control was portrayed as a linear or staged pathway. That is, people move from a point at which they are out of control to a point at which they have regained control. At various points people described moving back and forwards between stages, for example, if they experienced a setback such as a re-occurrence of a symptoms. A core aspect of regaining control in this work was the balance of needs and support. Social support from partners and families was not always seen as positive but as overprotection. This needed to be challenged in order to regain independence and control.

The work of Johnson & Morse (1990) is important in gaining an understanding of experience after a heart attack (Table 2). They introduce the concepts of control and social support as central. They suggest adjustment after a heart attack is a linear process, thus supporting the notion that recovery may also be a linear process. Johnson & Morse (1990) also emphasise the importance of issues such as self-concept, self esteem, gaining mastery over the illness and resuming tasks and activities.

## Box 2. Stages of regaining control

Stage	Characteristics
Defending oneself	<p>Occurs in the acute phase.</p> <p>Deals with coping with acute symptoms, medical interventions and gaining explanations.</p>
Coming to terms	<p>Lasts up to 8 days, may be revisited.</p> <p>Mortality, future limitations faced and further explanations / causes sought. Lifestyle changes planned.</p> <p>Some positive thoughts and start to regain control others fear death or future disability.</p>
Learning to live	<p>Three stages:</p> <ol style="list-style-type: none"> <li>1. Preserving sense of self e.g. reluctance to give up gender related roles (e.g. housework for women), and adapting or rejecting the sick role.</li> <li>2. Minimising uncertainty by gaining information and reassurance from health professionals.</li> <li>3. Establishing guidelines for living by adopting new lifestyles and listening to their body to judge activity.</li> </ol>
Regaining control or adjustment	<p>Two responses, dichotomous positions of living again (successful adjustment) or abandoning the struggle (unsuccessful adjustment, sick role adopted).</p>

*From: Johnson & Morse (1990)*

#### **3.3.4. Women's experience of illness**

Despite the claim that “*what women experience during recovery from a myocardial infarction (MI) has not been explored in a thorough or systematic way*” (Tobin, 2000 p11), it would seem that women, more than any other group have been subject to qualitative inquiry with regard to life after a heart attack. The focus on women may have been prompted by some research indicating that physical and psychological outcomes are worse for women after a heart attack and that women's adjustment methods differ from men (Reigel & Gocka, 1995, Radley *et al* 1996). The key studies that shed light on women's illness experience after a heart attack are summarised in Table 4.

It is striking how they echo the findings Johnson and Morse (1990). The results mirror one another in the range of conceptual issues raised, for example, control, confidence, loss, change, resuming roles and activities, making sense and regaining mastery over their lives are all key to experience of life after a heart attack. As with Johnson & Morse (1990) the concept of “recovery” is rarely referred to explicitly in the studies on women's experience. Alternative terms are used, for example, healing and adjustment. This indicates that little attention has been paid to understanding what recovery means as a concept to the people who have suffered a heart attack. It is possible, however, to apply the findings of these studies to speculate about the recovery experience of women.

**Table 4. Women's experience after a heart attack**

Author/Journal	Study Focus	Methods	Findings
Kerr & Fothergill-Bourbonnais (2002) <i>Heart &amp; Lung</i>	Recovery experience of women over 65. Canadian	Heidiggerian phenomenology, unstructured interviews, 7 women	"Mosaic of recovery" 4 stages 1. Life is scattered 2. Making sense 3. Learning to live 4. Getting settled Ability to socialize and resuming household work key to recovery.
Fleury, Kimbrell & Kruszewski (1995) <i>Heart &amp; Lung</i>	Women's experience of healing after a heart attack. United States	Grounded Theory, semi-structured interviews, 7 women	Healing involves creating new and positive health patterns. Process has 3 stages: 1. Surviving 2. Originating 3. Patterning balance.
Helpard & Meagher-Stewart (1998) <i>Canadian Journal of Cardiovascular Nursing</i>	Experience of women over 60 living with CHD. Canadian	Grounded Theory, semi-structured interviews, 8 women	Core variables = "finding a voice" & "struggling for a new self". These involve: 1. Living with loss of role and respect 2. Conforming with tradition 3. Striving for respect 4. Blending the gaps.
Tobin B. (2000) <i>Canadian Journal of Cardiovascular Nursing</i>	Women's recovery after a heart attack. Canadian	Grounded Theory, semi-structured interviews, 12 women	Recovery variable, conceptualised as "getting back to normal", 4 stages 1. Accepting 2. Establishing boundaries 3. Making adjustments 4. Re-establishing normality.
Jackson <i>et al</i> (2000) <i>Journal of Advanced Nursing</i>	Women's experience after first M.I. in first three weeks. Australian	Feminist, qualitative, descriptive study. Semi-structured interviews, 10 women	Fear and uncertainty: death, re-occurrence, resuming activity. Exhaustion/anxiety high. Need for reliable information to gain confidence.

A number of points emerge. First, this body of research indicates that experience after the heart attack is dominated by the devastating nature of the event. Strong emotions such as fear, uncertainty and anxiety are experienced (Jackson *et al*, 2000).

In addition, Tobin (2000) identified that the goal of his participants was to “get back to normal”. Four stages were involved in achieving this goal. These were, accepting, establishing boundaries, making adjustments, and re-establishing normality. These four stages are ostensibly simple and straightforward. Upon reflection, however, to achieve these stages requires emotional, cognitive, physical, and social change and adaptation following the illness experience. This hints at the complexity of and potential variation in people’s recovery experience and supports further investigation of this aspect of patient experience.

A third point to emerge from this body of literature on women’s experience of a heart attack is that recovery is depicted as a process. Again the suggestion is that the process is linear. The process starts at the acute stage of making sense of the crisis of the heart attack and resultant fear, anxiety and loss. The process ends with some resolution of being settled, confident, in control and “back to normal”. Although people may move up and down the pathway, the suggestion is that recovery occurs when the end of the pathway is reached. The studies also illustrate the importance of information giving and managing patient

and family expectations as a way of promoting recovery. Finally, although a recovery process is described, all the studies imply a point in time where patients take up one of two dichotomous positions. These are states of recovery or not being recovered. The latter state is probably best described as cardiac invalidism, a concept explored in more depth by Reigel & Dracup (1992) and Ben-Sira & Eliezer (1990).

However, in terms of the study presented in this thesis, it is necessary to consider what this body of work does not tell us. A number of assumptions emerge from the research regarding recovery experience, for example, that recovery is a linear or staged process and that the goal is to return to normal. This view of recovery is just one model, but is there another way of depicting the process? The existing assumptions have not been tested by more in depth exploration of patient's recovery experience and what they mean by the term. It may well be that alternative ways of describing the process may better illustrate the patient experience.

In addition, existing research does little to inform us of the recovery experience of men. Is it the same or different to that of women? All the studies were conducted out of the UK, raising questions regarding transferability. Can results from North American communities be applied to UK populations?

The research also implies some confusion about the meaning of recovery. We know from the results that concepts of control, confidence and dealing with loss are crucial to adjustment and illness experience. However, we do not know if or how they relate to patients' recovery experience. Neither do we know how these concepts contribute to or interact with people's representations and experiences of recovery, nor the meaning recovery has for them after a heart attack.

Similar issues as those raised in the research outlined in Table 4 reoccur in studies examining illness experience in relation to the impact of chronic illness in general (Charmaz, 1983; Wellard, 1998) and other specific conditions, for example spinal cord injury (Carpenter, 1994). Many of the concepts identified are similar; control, confidence, self esteem, meaning and mastery. These studies illustrate how the onset of illness can devastate people's lives and impact on their sense of identity. As Charmaz (1983) observes, illness brings the body beyond the control of the individual, can attack their sense of being autonomous and change their sense of self. The severity, diversity and extent of the impact of illness and patients' experiences as a result of this impact illustrates the importance of exploring in more depth the experience and meaning of recovery. However, once again, the focus of this work was on *illness* experience. Whilst it can be speculated that some of the concepts can be applied to *recovery* experience additional research concerned explicitly with recovery is required.

### **3.3.5. *The limitations of the research on illness experience***

The literature cited here illustrates the value of qualitative methodology in capturing patient experience. The studies do, however, tend to focus on experience in general, rather than an examination of a particular construct or process such as recovery. This limitation in the literature was also noted by Clark (2003) in his examination of the experience of stress after a heart attack.

Therefore, recovery remains relatively unexplored. In addition, some methodological limitations of the illness experience research are noted. As noted earlier, qualitative studies may appropriately comprise a small sample. However, the rationale for the sample size and strategy must be given and the reasons for curtailing the sample provided, for example, theoretical saturation. This information was not available, for example, in Fleury, Kimbrell & Kruszewski (1995), Helpard & Meagher-Stewart (1998), and Johnson & Morse (1990). It is, therefore, not possible to be confident about the capacity of the sample.

Another concern is that participants often comprised motivated individuals, that is, those who attended and had access to support from cardiac rehabilitation services. Assumptions cannot be made that results from these participants would be similar to those that would be obtained from members of communities struggling to access such support. There is also a predominance of North



American and Australian studies. The results of these are not necessarily transferable to an English, National Health Service setting, especially in deprived communities with high levels of disease and poor access to services. These methodological weaknesses and limitations justify further research that explores heart attack recovery experience but raises questions about where and how a study should be conducted.

The work of Charmaz (2003, 1983) was crucial in developing a methodology to address and capture the complexity and variations of illness experience. The merging of grounded theory, social constructionist and symbolic interactionist epistemology and methods provided an interactive, rigorous and responsive approach. The methodological approach adopted by Charmaz (2003) heavily influenced the perspective and design of this study (see Chapter 4).

A deficit has been identified here in relation to research explicitly exploring recovery experience and the meaning of recovery. Much of the research discussed above explores patient experience in relation to either chronic or acute illness. The heart attack experience has the complication of having both acute and chronic elements. With a heart attack someone is diagnosed with not only an acute illness (a heart attack), they are also diagnosed with the chronic condition of heart disease. Consideration of the implications of this dual aspect on heart attack recovery experience and meaning has not been addressed in previous research but is addressed in the study presented here.

The justification for a study exploring heart attack recovery experience and meaning has been made with reference to the contributions and limitations of existing research on illness experience. The studies lack the capacity to capture individual subjective experience. They focus on illness experience and impact rather than recovery and lack methodological strength and transferability. The contribution of current research and theory on recovery will now be discussed.

### **3.4. Researching recovery from illness**

#### **3.4.1. *Theories related to recovery***

The concept of recovery, as suggested, has been rarely explored in health service research. A review of relevant literature into related concepts indicates an assumption that recovery is strongly related to or synonymous with other concepts such as adaptation, adjustment and coping. Theories related to these concepts have been developed to explain responses to and actions during what can be termed “the recovery period”. Sociological and psychological theories explicating adaptation, adjustment and coping include illness representation (Leventhal, Meyer & Nerenz, 1980), sense of coherence (Antonovsky, 1979), post-traumatic stress disorder (PTSD), and loss and change (Marris, 1993). What bearing these theories have on patient’s experience and meaning of recovery has never been overtly investigated. Rather, the assumption prevails that what applies to adaptation, adjustment and coping will apply to recovery.

The study outlined in this thesis contributes to the gap in existing knowledge by exploring the experience and meaning of recovery from the perspective of people who have had a heart attack. A theory that is developed helps to explain recovery from this viewpoint. This section of the literature review therefore aims to harness key findings from the related literature on adaptation, adjustment and coping and theories that relate to recovery. Any similarities, links, and conceptual or theoretical overlap with existing research are examined.

The literature related to adaptation, adjustment, coping and loss addresses questions such as, why do some people stay healthy or resume health after a major life event like a heart attack, whilst others break down or become invalids? As a major stressor and life event, a heart attack can induce crisis and destabilize the way people understand and experience the world. There is, therefore, a theoretical argument that how people adapt, adjust and cope will influence their ability to recover.

#### ***3.4.2. Definitions of adaptation and adjustment***

Adaptation is defined as the process of adapting, where, to adapt means to make fit, to modify or to adjust to new conditions (Chambers Dictionary, 2003). The implication here is that some thing new has been encountered that has necessitated change in some way. The concept is therefore similar to that of adjustment. Adjustment is defined as the process of altering or regulating

oneself in response to an event or stimuli (Chambers Dictionary, 2003). Key issues in both concepts therefore emerge. These are that a process is undergone, that change is required and that this is forced due to an event that is not necessarily sought after or desired, such as an illness. Thus, whilst there is an implicit assumption that adaptation and adjustment are similar to recovery a contradiction emerges. The idea that adaptation requires change seems at odds with the idea, as suggested in patient literature, that recovery requires returning to the same state that existed before the heart attack.

A number of theories and models have been developed to help illustrate strategies and options available to people in undergoing the processes of adaptation and adjustment. In doing this they highlight factors influencing how successful the process is. These theories provide a body of knowledge within which to explore recovery. Some of these are now appraised.

### **3.4.3. Adjustment**

The work of Radley & Green (1985) generates a framework for adjustment developed from the experiences of heart surgery patients (Table 2). This is of potential use in considering recovery. Forty patients on the waiting list for cardiac surgery and 40 patients 11 months post surgery were asked about adjustment styles, activity patterns and expectations or experiences of recovery.

The authors propose that recovery is a function of the style of adjustment. In other words the nature and extent of recovery will be dependent on the style and manner of adjustment. The theory proposes four styles of adjustment that are influenced by Herzlich's (1973) discussions on the interrelation between illness experience and a person's social life:

*Accommodation:* or "illness as occupation". This is described as the acceptance of illness such that it is integrated into the pursuit of modified social goals.

*Secondary gain;* or "illness as liberator". This relates to the constraints of an illness that lead to withdrawal from one aspect of social life to pursue alternative activities.

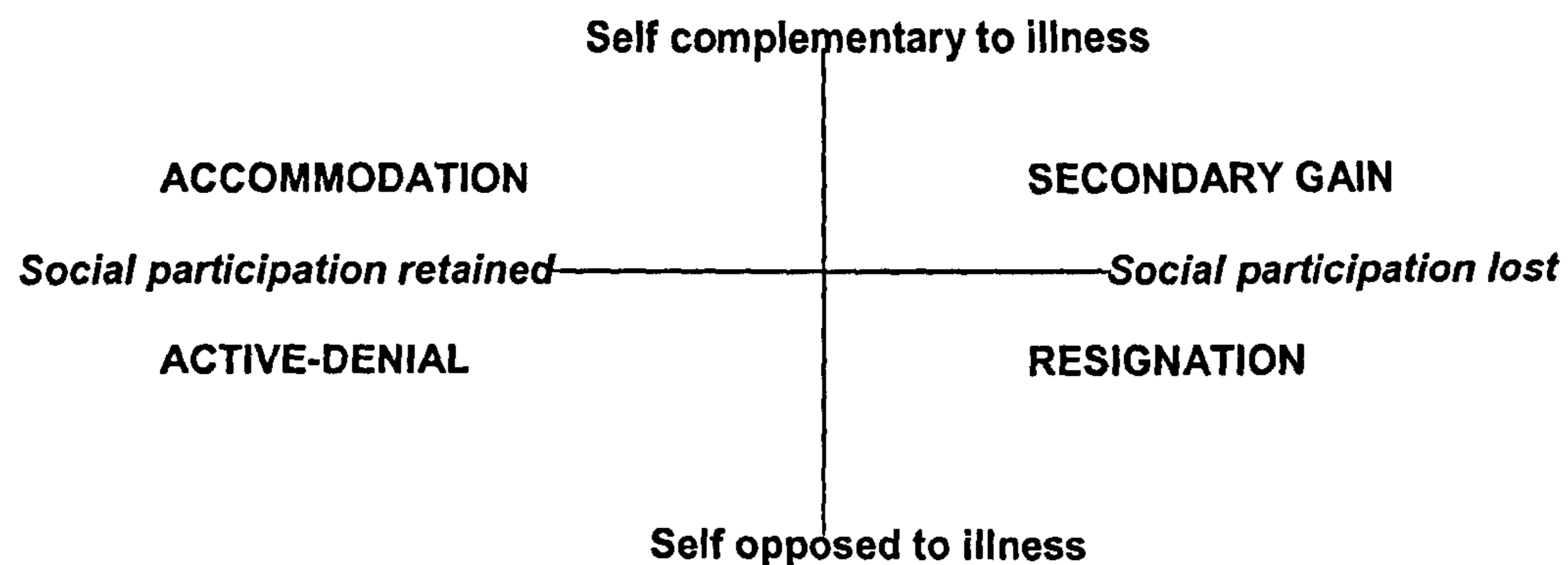
*Active-denial:* This is where someone fights an illness by not making changes and minimizes symptoms and their impact.

*Resignation:* or "illness as destroyer". This is where illness means social loss and a sense of being overwhelmed.

Radley & Green (1985) claim that these four styles can be adopted as mechanisms to aid adjustment and so, recovery. They interrelate with an individual's response and level of acceptance of the illness and also the social impact. All four modes are available to a person. They are not presented as alternatives. The way in which they are adopted will vary, however, according

to the individual and stage of recovery. This is presented diagrammatically in Diagram 1.

### **Diagram 1. Modes of adjustment to chronic illness**



*From Radley & Green 1985. p462*

Different styles are adopted according to different expectations, activity patterns and recovery experiences.

A number of aspects of this framework potentially apply to recovery experience and meaning. First, the importance of social as well as physical influences on illness is emphasised. Second, any individual may adopt a variety of modes of adjustment in variable sequence, indicating the variation in individual subjective experience. This study also provides another way of conceptualising adjustment and does theoretically link this to recovery. What is still lacking, however, is research that overtly examines what patients mean by recovery after a heart attack.

Ben-Sira & Eliezer (1990) created a theoretical “structure” within which to explore adjustment. This structure comprised the following hypothesis:

1. Readjustment after a heart attack is hindered by the perceived seriousness of its demands and consequences.
2. Certain resources facilitate coping with demands and therefore adjustment.
3. Spouse support plays a role by enhancing a person’s resources to cope.
4. The perceived effectiveness of spouse support will depend on their relationship, specifically the ability to have role flexibility, have open communication and co-operate in decision-making.

In their quantitative study of 63 men after a heart attack, Ben-Sira & Elizer (1990) propose a multivariate relationship between the demands of an illness and the resources required to adjust (Table 2). Emotional, behavioural and socio-cultural demands therefore require emotional, functional and cognitive readjustment. Different resources are required for each. For example, instrumental resources such as education and occupation will influence functional adjustment. Emotional adjustment will require affective resources such as self-esteem and a sense of mastery over events. Finally, cognitive adjustment will require cognitive resources such as understanding. The role of the spouse in mobilising these resources and facilitating adjustment is seen to be fundamental. Good communication between patient and spouse is seen to

contribute by providing encouragement, protectiveness and knowledge enhancement.

This study has limitations in terms of its small and select sample. However, it does raise some useful points for consideration when examining recovery. As with previous studies, this research emphasises the importance of social context in restoring meaning, providing recovery resources and restoring predictable order to life after an event like a heart attack. This resonates with Antonovsky's (1979) sense of coherence model. Antonovsky (1979) claimed that the ability to cope with a stressor, such as an illness, is reliant on the psychological and social resources available to cope with them and how manageable, meaningful and comprehensible the event is to a person. Ben-Sira & Elizer (1990) highlight the importance of considering family and partners as a resource in promoting adjustment and, by implication, recovery. They raise the issue that the impact of the illness on the family also should be investigated as this may influence their ability to meet the needs of the person who has experienced the heart attack. That is, families can affect a person's ability to adjust to acute and chronic illness, but may also be affected by it (Van Horn, Fleury & Moore, 2002). Issues relating to the role of partner and family on supporting adjustment after a heart attack have been expounded upon elsewhere in research literature such as that referred to earlier by Blaxter (1979).



Theories and models have been proposed that help to explain adaptation and adjustment after a heart attack. Many of the concepts identified in Chapter 2 as central to illness experience reoccur in the literature related to adaptation and adjustment after a heart attack. Examples include control, uncertainty, living with change and constructing meaning (Sutherland & Jensen, 2000; Levy, 1981). This reoccurrence supports arguments of theoretical and conceptual links to recovery. However, many of the studies were conducted outside of the UK, raising questions regarding the cultural applicability of their findings to a British context. Further research is therefore required that focuses explicitly on heart attack recovery, tests links to existing adjustment and adaptation theory, and acknowledges and explains the variation in experience and the range of influences on recovery.

#### **3.4.4. Coping**

There is a fundamental premise in coping theory that the impact of a stressful event such as a heart attack will be mediated by the ability of a person to mobilize positive coping strategies. These strategies will moderate and influence outcome (Bennet *et al*, 1999; Scharloo *et al*, 1998). Much of the recent research on coping has derived from the seminal theoretical work of Lazarus (Smith & Lazarus, 1993; Lazarus, 1991). Central to Lazarus's theory is an argument that, when faced with a stressful event, an appraisal takes place to reduce negative and maintain positive emotions. The appraisal assesses whether an event is relevant to a person's well being and identifies coping options. A person's emotional response will, therefore, be influenced by these

appraisals. Someone who appraises an event negatively will be pessimistic regarding coping. If one applies this theory to someone responding to a heart attack, it is possible to theorize that a negative appraisal and coping could set a person on the road to cardiac neurosis or invalidism. Conversely, where the appraisal is more positive and coping more optimistic, a more constructive response may occur (Bennett *et al*, 1999).

Lazarus identified two types of coping, these are problem and emotion-focused coping. The former involves strategies that involve acting to alter the situation. The latter, are cognitive strategies to deny, reinterpret or "*redirect attention away from distressing elements of the situation*" (Bennett *et al*, 1999, p193): A theoretical link can again be made to Antonovsky's (1979) sense of coherence theory. The theory suggests people who cope with stressors have a strong sense of coherence and are able to view sudden, stressful events as comprehensible, manageable and meaningful (Antonovsky, 1979). People's ability to do this depends on what are termed Generalised Resistance Resources (GRRs). These resources include a person's characteristics, their intelligence, and religion, social and cultural support. When applied to Lazarus's coping theory it is possible to state that a person's ability and way of appraising and coping will depend, not only on the nature of the event to be dealt with, in this case a heart attack. It will also depend on someone's previous life experience, and their social and cultural context. It could be argued that someone who sees life as meaningful, comprehensible and

manageable would achieve a more positive appraisal and cope in a more constructive and productive way. This could explain why some have suggested that those who coped well with problems before their heart attack are likely to have the resources to cope with the heart attack itself (Cay, 1982).

### **Box 3. Aspects of coping**

Type of Coping	Aspects of Coping
Problem-focused coping	<ul style="list-style-type: none"> <li>• Active coping</li> <li>• Planning</li> <li>• Suppression of competing activities</li> <li>• Restraint coping</li> <li>• Seeking of instrumental social support</li> </ul>
Emotion-focused coping	<ul style="list-style-type: none"> <li>• Seeking of emotional social support</li> <li>• Positive reinterpretation</li> <li>• Acceptance</li> <li>• Denial</li> <li>• Turning to religion</li> </ul>
“Less useful” coping	<ul style="list-style-type: none"> <li>• Focus on and venting of emotions</li> <li>• Behavioural disengagement</li> <li>• Mental disengagement</li> </ul>

*(Carver, Scheier & Weintraub, 1989)*

One goal of coping theory has been to identify and measure coping strategies (Box 3). Measurement tools are available to assess the different ways in which people respond for example the CORE (Carver, Scheier & Weintraub, 1989) and

Jalowiec Coping Scales (Jalowiec, Murphy & Powers, 1984). These tools have been used to explore coping and its influence on mood and behaviour after a heart attack.

For example, Scherck (1992) challenged the previous simplistic assumption that patients predominantly coped by denying their heart attack (Table 2). In her exploratory cross sectional survey, 30 heart attack patients were asked to complete a questionnaire four or five days after hospital admission. The questionnaire included validated tools such as the Jalowiec Coping Scales (Jalowiec, Murphy & Powers, 1984).

Scherck (1992) identified a range of coping behaviours. In the first three days people:

*“engaged in a variety of cognitive and behavioural attempts to reduce, minimize, master and tolerate the demands of the stressful encounter”* (Scherck, 1992, p330).

The most commonly used strategies were optimistic-type categories, for example, trying to think positively, telling yourself things will get better/could be worse, thinking about the good things in life and keeping a sense of humour. Scherck (1992) suggests that having had a heart attack, those who came to view the heart attack as a challenge and something that could be managed had less emotional distress. This perspective can again be explained by Antonovsky's (1979) theory that people with a sense of coherence have the life

experience and resources to interpret stressors as a challenge and not become victims of events. Hardiness, and a history of dealing with adverse events, was positively associated with coping after a heart attack. (Sutherland & Jenson, 2000; Chalfont & Bennett, 1999)

These studies do illustrate a link between coping strategies, mood and behaviour after a heart attack. The utilization of certain problem-focused coping strategies seems to improve certain psychological outcomes (Bennett *et al* 1999). However, the application of this theory is limited in helping to understand recovery experience after a heart attack. The sense of coherence theory does help to add an additional aspect that places coping in the context of life continuum, rather than a response to an isolated event. This implies that certain life experience improves sense of coherence and makes people better equipped to mobilize productive coping strategies. However, this has not been tested and remains a theoretical argument.

Other limitations of coping theory and research in the pursuit of understanding of recovery from a heart attack can be summarized as follows:

- It is possible to measure, using the available tools, the adoption, or not, of certain coping strategies. These responses do not, however, inform us of the reason for the responses, thus limiting our understanding.
- The adoption of coping strategies is considered to be a contextually driven process. However, the questionnaire-based surveys only generate limited

contextual information. It is not, therefore, possible to explain variations and inconsistencies between groups, populations or studies.

- The use or non-use of coping strategies is not put into the context of a person's social and cultural life. Measurement of coping strategies would not provide explanations to unpick complex cultural influences on coping or recovery.

In summary, coping theory makes a contribution to understanding mechanisms adopted after a heart attack and during recovery. However, the contribution is limited and, again, does little to help us understand the subjective experience of recovery and answer questions regarding the meaning the concept has for patients.

The final section of this literature review briefly discusses the literature that relates to loss and change. Links to theories of illness impact, adjustment, adaptation, coping and, therefore, recovery are considered.

#### **3.4.5. *Loss and change***

Any analysis of life after a sudden, stressful and frightening event, such as a heart attack, requires reference to the literature on loss and change. A crisis such as illness prompts change by starting a transition to a new way of life. This in turn creates internal conflict as one is faced with loss as a result of change (Marris, 1993). Having a heart attack has been associated with a

profound sense of physical, psychological and social loss, for example loss of energy, spirit and power, loss of role, loss of self respect and loss of identity (Sutherland & Jensen, 2000; Levy, 2000; Helpard & Meagher-Stewart, 1998).

#### *3.4.5.1. Post-traumatic stress disorder*

A number of theories have been generated in order to explain distress as a result of loss and change. One theory, post-traumatic stress, falls within the bio-medical model as it constitutes a diagnostic state or psychological disorder. The concept of post-traumatic stress disorder (PTSD) has political and socio-economic facets, emerging as it does from the need to assess mental consequences of warfare. More recently, the concept has been applied to other trauma such as illness, most often in relation to diagnosis of cancer (Thulesius, 2003). PTSD is a potential sequel to experiencing an event involving actual or threatened death and that entails a response of fear, loss or helplessness. Experiencing a heart attack could clearly induce PTSD due to the potential loss of control, role and identity experienced. The disorder has been used to explain some of the emotional distress associated with a heart attack, for example the intrusion of flashbacks as people re-experience the trauma, high anxiety states and nervousness, and finally, avoidance of people and places that arouse memories of the trauma.

Fitting with a biomedical approach, PTSD concerns itself with biochemical changes and associated treatment options, including anti-depressive

medication. However, as with other biomedical explanations, PTSD is limited in helping to understand the complexity and individual variations in response to illness, and the loss and change it promotes. It also fails to provide insight into the nature of social and cultural influences on responses to loss and change and how this might relate to illness recovery.

#### *3.4.5.2. Grief*

Conceptual analysis of loss is interwoven with that of bereavement and grief (Robinson & McKenna, 1998). Grief is seen as a consequence of loss. In the context of this study it is depicted as an evolving process that would unfold following loss affecting the physical or embodied self, as a result of illness. One predominant grief theory presents the experience as a process, where a predictable sequence is followed. This involves denial, anger, bargaining, depression and acceptance (Kubler-Ross, 1970). As noted previously, the implication is that recovery is a linear or staged process. Whilst Kubler-Ross (1970) recognised that people may get stuck in a stage, the implication is that if acceptance isn't achieved, neither is recovery. It is tempting therefore to overlay grief theory upon heart attack recovery in order to conceptualise and understand those aspects related to loss. However, the stage theory depicted by Kubler-Ross (1970) appears too ordered and neat. It does not have the capacity to embrace the complex and varied experiences associated with loss and recovery after a heart attack.

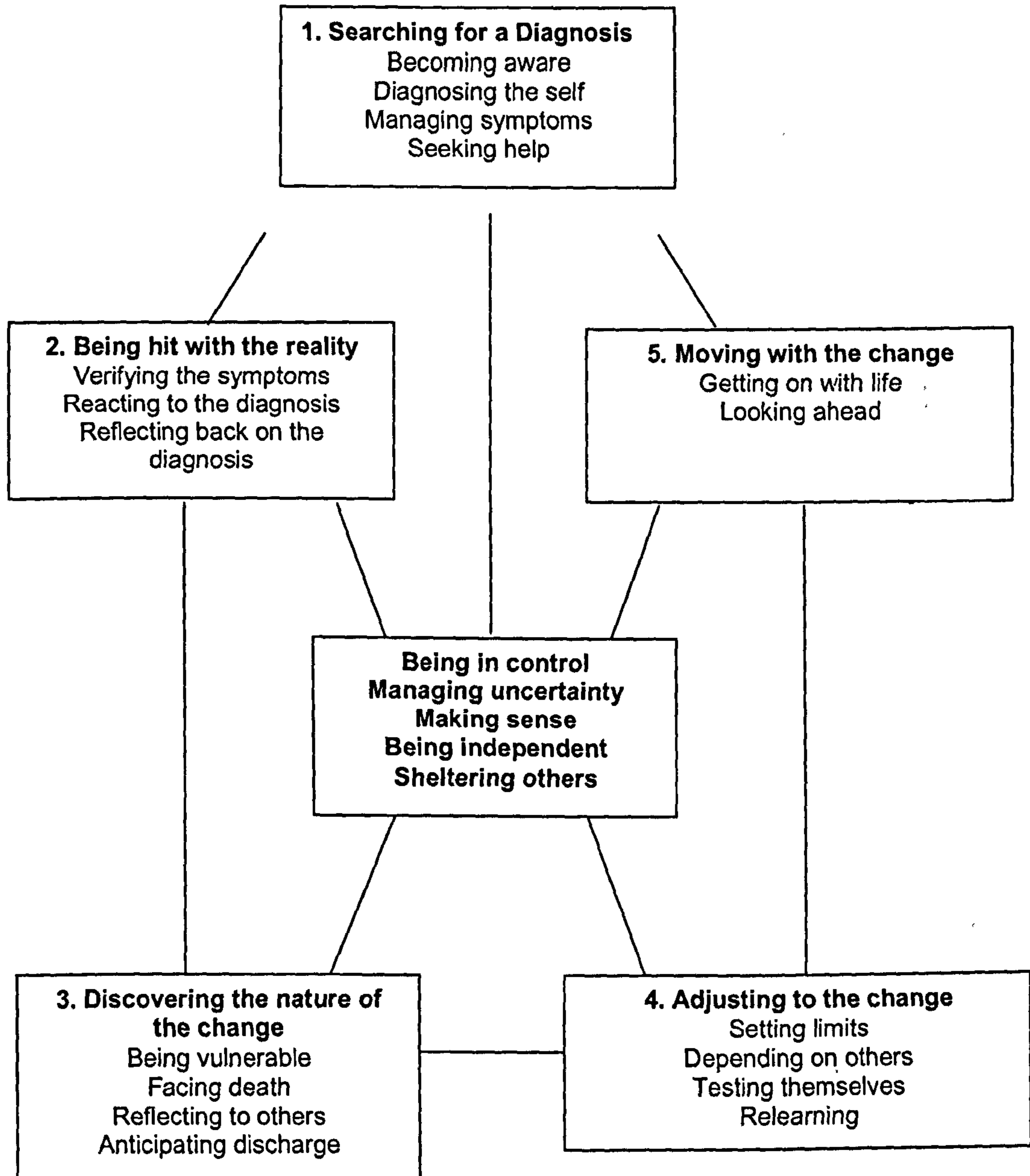


#### 3.4.5.3. Loss

Sutherland & Jensen (2000) illustrate, how elderly women dealt with this loss after a heart attack (Diagram 2). Through the use of qualitative methods, the researchers captured loss of health, control, confidence, certainty and autonomy. Strategies were identified that the participants used to manage change and restore control.

Similar issues emerged as important as those raised in studies exploring the impact and experience of illness, for example control, confidence and constructing meaning. This again supports an argument that a conceptual link exists between recovery and illness experience and impact, adaptation, adjustment, and now loss. However, no research has been conducted to establish or explore this relationship.

**Diagram 2. Living with the change of a myocardial infarction** Adapted from Sutherland & Jensen (2000)



Marris (1993) presents a theory of “conservatism” in order to explain key aspects of the processes associated with loss and change. He proposes that “conservatism” is central to the struggle to deal with loss and epitomised the need to maintain predictability and continuity of life. In order to do this, the loss has to be assimilated in some way, that is, the unfamiliar is integrated with the familiar. As with the sense of coherence theory, Marris (1993) claims that survival depends on being able to predict events, and crisis. A sudden illness can challenge ability to do this. Loss and change of what was previously considered predictable is an inevitable consequence.

Antonovsky (1979) argues that people mobilize their resistance resources to deal with this adversity. On the other hand, Marris (1993) asserts that resistance to change is a fundamental part of learning to deal with loss. The loss associated with sudden illness disrupts our ability to find meaning in experience. This might help to explain why much of the qualitative research discussed so far has emphasised the importance of generating meaning after a heart attack. Marris (1993) explains that a context of meaning is required that allows past and present to be preserved and the loss explained. This raises a question about the role of constructing meaning in recovery from a heart attack. Further research is required to answer this and explore how it contributes to the recovery process.

### **3.5. Justification for the study**

The research in this thesis explores the experience and meaning of recovery after a heart attack. A qualitative methodology, constructivist grounded theory, is adopted similar to that used by Charmaz (2003). From the review of the literature presented here, it is possible to justify this study first, on conceptual and theoretical grounds and second, for methodological reasons.

Conceptually, various links and associations have been established between adaptation, adjustment, coping and recovery. In many studies the same issues emerge, for example control, confidence, loss, mastery and meaning. However, these links are theoretically derived rather than demonstrated from empirical research. Further research is required explicitly to examine recovery experience from the perspective of those who have had a heart attack. A better theoretical explanation of the meaning that recovery has for a person is essential if understanding of the concept is to improve.

In addition, a theoretical position adopted by much of the research presented here, is to depict recovery as either a linear process or as dichotomous (for example, Johnson & Morse, 1990). The linear model presents recovery as starting at the point of the heart attack and moving along a pathway to a point identified as recovery. Where the point of recovery is, and how it is characterized, is unclear. Whilst it is admitted that people may move up and

down the pathway as they encounter stimuli or obstacles, for example, new symptoms, the underlying assumption is that the process of recovery is essentially linear.

With a dichotomous model people are represented, and evaluated, as recovered or not-recovered, for example Reigel & Dracup (1992). In this research the emphasis is on measuring outcomes to demonstrate using objective criteria, such as those for cardiac invalidism, whether people have recovered or not. Research of this nature can indicate the presence or not of a state of being, but does little to give conceptual understanding of the nature of recovery from an individuals' perspective or to reveal the meaning of recovery and related processes. Viewing recovery as linear, staged or dichotomous does have value and purpose. However, there is an underlying question that remains unanswered. Is there an alternative way of conceptualising heart attack recovery that better encapsulates the meaning of recovery from the perspective of the person who has had one?

Some of the models and theories acknowledge social and cultural influences on adaptation, coping, and adjustment. The affects of these influences are, however, complex and our understanding of them limited. We do not know how social factors impact upon recovery after a heart attack. In addition, little research has been conducted in deprived communities in the UK, where people

are at high risk of heart disease. The potential influence of cultural and social norms in these communities needs to be acknowledged.

Methodologically, survey based studies used to measure coping and adjustment are limited in explaining variations in experience and the range of influences open to individuals. Quantitative, cross sectional evaluations establish correlations between certain characteristics and coping or adjustment. From these studies, it is often not possible to detect or understand what influences these correlations and which way the relationships occur. This predominance of cross sectional, correlation design therefore adds to the limitations of our understanding of recovery as a process.

These studies also assume that recovery progression is linear and that options are dichotomous, that is people have recovered or not recovered. However, if there is an argument that recovery is socially contextualized the recovery process may be more complex. Research that uses a qualitative and constructivist approach is required to provide the depth and breadth of understanding to address these points and answer the questions they raise.

The study outlined in this thesis contributes to the gap in existing knowledge by exploring the experience and meaning of recovery from the perspective of people who have had a heart attack. A theory is developed to help explain

recovery from this viewpoint. The research paradigm and methodology adopted to undertake the research is described in Chapter 4.

## CHAPTER 4: Establishing the research paradigm

*“Nothing really was aimed at me sort of thing, specifically at my personal case”.* (Individual interview 9)

*“We want this little bit of individuality, don’t we”?* (Individual interview 2)

### 4.1. Introduction

This chapter describes and explains the paradigm adopted for the research study, the aim of which was theory development regarding heart attack recovery experience and meaning. A paradigm has been described as a *“basic set of beliefs that guide action”* (Denzin & Lincoln, 2003a, p245; Guba, 1990, p17). Research paradigms are concerned with the fundamental principles underpinning the research and reflect the worldview of the researcher (Guba & Lincoln, 1994). The research paradigm is the “lens” through which the researcher views the research world.

The chapter establishes the context of the study from a philosophical and methodological perspective. It is essential that the ontological and epistemological stance of the study have the capacity to direct the design and conduct of the research in such a way that it achieves the core purpose of the study. The chapter therefore begins with a review of key aspects of the research purpose that dictated choices regarding the paradigm. This is followed by an overview of the traditional paradigm approaches within health



services and social science research. This has been described as the “two paradigms approach”, the two paradigms being directed by either positivist or by interpretive, naturalistic beliefs (Hammersley, 1992a; Hammersley, 1992b). The two paradigms are discussed in relation to their ability to develop understanding of heart attack recovery. The polarising effect of placing the research paradigms into opposing positivist and interpretive camps is considered. A third way is adopted in this study, based on critical realist ontology. The nature and methodological consequences of this are explained further in the second half of the chapter.

Denzin & Lincoln (2003a) identify four components of a research paradigm: ontology (beliefs about the nature of reality, the social world and the place of people within that world), epistemology (beliefs regarding the nature of knowledge and how knowledge is acquired), methodology (the best mechanism and approach to gain knowledge) and ethics (how to be a moral person in the world and within the paradigm). The second half of this chapter adopts these four concepts as sub-headings. They are used to describe the research paradigm and philosophical structure that provide the foundation for this study.

#### **4.2. Research dimensions**

As previously stated the purpose of the study presented here was to generate a theory to explain the experience and meaning of heart attack recovery. There are four dimensions to this research purpose that fundamentally influenced

decisions regarding the appropriate paradigm. These are described here as a backdrop to the critical discussion of factors influencing the paradigm decisions that were made.

#### ***4.2.1. Social and cultural influences***

The first dimension relates to the requirement to incorporate a consideration of the social and cultural influences on experiences of and meanings ascribed to illness and health, in this case related to heart attack recovery. It has already been established that the effects of these influences are complex and our understanding of them limited. We do not know how social factors impact upon recovery after a heart attack. Decisions regarding the research paradigm will therefore need to acknowledge a social rather than biomedical or mechanical model of health.

#### ***4.2.2. Variation and similarities in experience***

The second dimension relates to the desire to depict differences and variation in individual subjective experience. This is in addition to generating a theoretical understanding that captures the experience of all. In essence, this requirement relates to a belief that individuals will all differ in the way they experience, represent and recreate an event, such as recovery from a heart attack. The unique nature of individual experience needs to be captured by the study. This need is reflected in the participant quotes that introduce the chapter. They highlight the necessity to understand variation in experience and

what makes individual patients' experience unique. An additional requirement of this study was to generate theoretical propositions that encompass this individuality and difference but also explain how the experience is similar. It was essential to identify the research paradigm that provides the capacity to do both of these.

#### **4.2.3. *Recovery as process***

The third dimension was the necessity to explore recovery as a process. Previous research presented recovery as a linear process but, as argued in the previous chapters, this was often based on assumption rather than empirical evidence. The research paradigm had to be able to explore the existence and nature of recovery as a process in order to challenge and critique previous assumptions.

#### **4.2.4. *Second level truth***

The fourth and final dimension relates to the order or level at which the study was conducted. Gerhardt (1990) discusses this in terms of the historical development of qualitative inquiry. She observes that a risk exists for qualitative research merely to describe or reconstruct biography, which she describes as "first-order" truth. She argues that qualitative researchers should now have evolved to encompass "second order" truth or "verstehen". This "second order" truth addresses and incorporates the above needs. That is, to ascertain how social and contextual influences contribute to individual variation

of experience and meaning of phenomenon. By virtue of the purpose of this study the paradigm therefore needs to encompass the ability to generate second order constructions of reality and experience from the perspective of those who have had a heart attack.

### **4.3. Research paradigms**

#### **4.3.1. *Positivism***

Research incorporating patient experience of illness and health care falls into what has been described as the two-paradigms approach (Murphy *et al* 1998. p61).

On the one side of the divide is a range of quantitative studies. These include biomedical observational, correlation and experimental studies that evaluate patient experience of illness in relation to the presence of physical or psychological symptoms or response to interventions such as drugs or procedures. In addition, there is a wealth of survey-based research that seeks to integrate a subjective element into objective outcome measurement.

Examples of such an approach include Health Related Quality of Life (HRQoL) and patient satisfaction studies.

This research is placed within a positivist paradigm. It is rooted in the traditions of natural science that stress the importance of objectivity. Positivism purports a belief in objective, measurable truth and reality. Such research generates

hypotheses from theoretical propositions, uses evidence to test hypotheses, measures observable phenomena and seeks to demonstrate a truth about reality. There is an implicit assumption in this positivist approach to evaluating illness that achieving certain scores using experimental or survey tools in some way reflects patient experience of, for example, illness or recovery.

#### **4.3.2. Interpretive inquiry**

On the opposite side of the paradigmatic coin, are the various attempts to explore issues related to patient experiences that adopt an interpretive and naturalist paradigm. These studies embrace qualitative methodologies and methods as a vehicle to inquiry. Such an approach seeks to understand subjective human meaning and interpretations of phenomenon. Interpretive researchers claim that positivist research is driven by a belief that *“a stable, unchanging reality that can be studied using the empirical methods of objective social science”* (Denzin & Lincoln, 2003b, p12). Interpretive, idealist paradigms reject this ontology of an objective, measurable reality or truth. In its place interpretive researchers make a distinction between social and physical reality (Paley, 2005). From this perspective is derived a belief in multiple truths and realities. There is also a recognition of the importance of social context and processes on experience and on perceptions of truth and reality. Interpretive approaches seek to explore how individual belief and experience interact with social and cultural environment. Range and variability of reality and experience is acknowledged and explored.

The contribution of both positivist and interpretive paradigmatic approaches is considered below. Their relevance and role in relation to understanding the experience and meaning of heart attack recovery is reviewed. The limitations of these contributions to understanding are then summarized and a third way proposed for this current study. This third way adopts a critical realist approach.

#### **4.4. The limitations of positivist research**

Biomedical and health related quality of life (HRQOL) studies are selected from a positivist paradigm for examination and critique. This will draw on some of the points that emerged from the literature review.

##### **4.4.1. Biomedical research**

###### **4.4.1.1. Mechanism and reductionism**

Biomedical research evaluating patient experience has conventionally focused on appraising the impact of heart attack in relation to physical and psychological function and symptoms. As stated, this research falls within the positivist research tradition that *“reduce human experience to measurable phenomena”* (Wellard, 1998 p53).

Incorporated into this approach are certain core beliefs. These have been critiqued in many ways over the years (Nettleton, 1995; Mechanic, 1962).

Nettleton summarizes the criticisms as follows:

- *Mind-body dualism* which proposes that the mind and body can be treated separately,
- *Mechanical metaphor* which implies that doctors approach the body as an engineer would a machine, mending those parts that don't work,
- *Technological imperative* which suggests that technological interventions take precedence in health care and
- *Reductionism* where the biological aspects of health and ill health take precedence over social and psychological factors (Nettleton, 1995; p3).

Medical research into heart disease and the sequelae of a heart attack has, therefore, been dominated by evaluations of the mechanical and biological impact of the illness and associated treatments and interventions. This activity has, in part, focused on the development and evaluation of devices, interventional cardiology and pharmacology.

Other research has aimed to evaluate the psychological impact of a heart attack by the measurement of hard, measurable outcomes such as anxiety, depression and fatigue (Chapter 2). High levels of distress were revealed (Mayou, Foster & Williamson, 1978a). Emotional distress was demonstrated to be higher in women (Wiklund *et al*, 1993) and those with lower educational and income levels (Frasure-Smith, Lespérance & Talajic, 1995; Hoffman *et al*. 1995;

Frasure-Smith, Lespérance & Talajic, 1993; Ruberman *et al*, 1984; Philip *et al*. 1981). Other studies have demonstrated psychological symptoms are commonly encountered in coronary heart disease but may go undiagnosed and untreated (Musselman, Evans & Nemeroff, 1998).

These findings are of great value in helping to understand the clinical consequences of a heart attack and response to interventions and treatments. However, this body of knowledge has limitations in relation to understanding patient experience and meaning of recovery for the following reasons outlined below.

#### *4.4.1.2. Limitations of biomedical research*

1. This focus on the investigation and treatment of disease has been accused of limiting understanding of the broader perspective of illness and health (Nettleton (1995). Research that has a biomedical emphasis conceptualises illness in professional terms and uses theoretical frameworks and measurement tools that are designed from a professional not patient perspective (Clark, 2005). The way social and cultural factors mediate health, illness and recovery experience are neglected. This neglect is exaggerated by the use of techniques of randomisation and controlling of samples in interventional trails. The result is that the clinical application of trial results can be limited (Gurwitz, Col & Avorn, 1992). In addition there is concern that this research activity does little to explain inconsistencies in the people's



experiences of illness such as CHD (Weatherall, 1995). Positivist research does not have the capacity to explore and account for such variation.

2. The evaluation of psychological and social outcomes is valuable and informative. However, the psychometric properties of the tools used to measure outcomes are not always clear or tested from reported studies. This is particularly true of the earlier studies conducted before the routine use of accepted and validated tools such as the SF 36 (Ware & Sherbourne (1992), Beck Depression Inventory (Beck *et al*, 1961) and Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983).

3. There is little or no justification for the selection of the outcomes that are chosen in biomedical research. The outcomes included are indeed of interest and may be appropriate, but are limited in informing us of patient experience. As the orientation of biomedical research has a “curative intent”, outcomes used have a clinical orientation and reflect professional concerns. This leaves questions unanswered about the perceptions of patients, their experiences and what is important to them. For example, is return to work an appropriate indicator of psychosocial recovery? What other factors, apart from the heart attack might influence return to work?

4. The final issue highlighting the limitations of the biomedical, positivist research tradition in relation to patient experience relates to a general point on

quantitative research. Earlier studies sought to provide descriptive statistics related to psychosocial outcomes after a heart attack (Mayou, Foster & Williamson, 1978a; Mayou, Foster & Williamson, 1978b). Later studies have been more complex and tested associations and links between the presence of outcomes such as anxiety and depression and long-term morbidity and mortality (Mayou *et al*, 2000; Frasure-Smith & Lesperance, 2003; Frasure-Smith *et al*, 1997). Again, this is a worthy endeavour but one that leaves unexplained the correlations and causative effects. Any increase in understanding of the patients' subjective experience of illness is not possible using a positivism paradigm.

The field of biomedical research is, therefore, limited in its contribution to develop understanding of the patient subjective experience in general and more specifically, recovery experience of people after a heart attack.

#### **4.4.2. Quality of life research**

##### ***4.4.2.1. Measurement of quality of life***

In recent research and health policy there has been a growing commitment to involving patients and users into health care and illness evaluation. A sizable body of literature that has tried to facilitate this has used survey methods to capture patient experience. One of the most commonly used and increasingly popular approaches is to measure Health Related Quality of Life (HRQOL).

There is a growing body of HRQOL studies in the field of CHD (Chan *et al*, 2005; Dunderdale *et al*, 2005; Roebuck A, Furze G, Thompson, DR. 2001). This work does look beyond traditional biomedical outcomes. In addition to physical and functional components, HRQOL research endeavours to incorporate a subjective element into evaluation. It acknowledges psychosocial and emotional dimensions influencing illness experience and does recognize diversity and variations of experience (Cheater, 1998). However, the HRQOL studies are fundamentally positivist in nature. Their capacity to understanding patient experience has been widely debated and their conceptual and methodological limitations acknowledged (Rapley, 2003). Comprehensive coverage of the body of criticism is available elsewhere (Rapley,2003; Fayers & Machin, 2000). Four key criticisms are raised here in relation to the contribution of HRQOL in illuminating the experience of people after a heart attack.

#### *4.4.2.2. Inconsistent definition and application*

The first criticism relates to inconsistency and imprecision regarding definition regarding HRQOL (Rapley, 2003; Wellard, 1998). The tendency to use the term as a “catch-all” has contributed to this confusion (Cheater, 1998). The term is generally used to refer to physical, emotional and social well being, thus supporting the claim that it incorporates a subjective element (Thompson & Yu, 2003). However, different theorists approach the concept from different perspectives; these are population, societal and individual. There are also differences on the relative importance given to objective indicators of HRQOL

(for example, income, employment status, working hours) and subjective indicators (for example, sense of community, well-being, satisfaction with family relationships). The incorporation of subjective aspects of evaluation has led to claims that HRQOL can be used as a benchmark against which to evaluate the impact of illness and interventions and to capture patients' experience of health, illness and health care, for example in relation to CHD (Thompson & Yu, 2003). However, variation in the claims of what HRQOL actually means makes it difficult to be clear about what is actually being measured and what its relevance is in relation to a specific line of inquiry, for example, recovery from a heart attack.

#### *4.4.2.3. Conceptual integrity*

Allegations regarding the conceptual integrity of HRQOL and its adequacy as a scientific construct form the second area of criticism (Rapley, 2003). Rapley (2003) suggests HRQOL is flawed as a construct due to the aim to measure objective and subjective outcomes concurrently. As he points out that objective and subjective outcomes are conceptually contradictory.

Nicolson & Anderson (2001, 2000) expand on this concern when they question the qualitative inquiry that has been conducted to identify the subjective components of quality of life scales. Many HRQOL scales are based upon qualitative data with a "broad base". Researchers narrow data down to identify measurable dimensions of HRQOL tools, rather than explore the depth and

meaning of this data. In other words, it could be argued that qualitative work is undertaken for epistemologically and methodologically contradictory reasons. The risk then, is that the qualitative inquiry is inadequate to capture the depth as well as breadth of issues impacting upon HRQOL. This is reflected in the fact that the detail regarding the qualitative methods used and related decisions are not always justified. An example of this relates to sampling decisions. To illustrate, Roebuck *et al* (2001) claim a sample size of 25 to 35 is adequate to collect qualitative data upon which to identify the effects of a heart attack on HRQOL, and to achieve theoretical saturation (when no new issues emerge from the data). This is not, however, well defended. It is possible to speculate that saturation is achieved because the analysis of data remains superficial. Concepts related to HRQOL are complex. Once these concepts are exploded and explored in more depth, saturation is more challenging to achieve.

#### *4.4.2.4. Complexity and capacity*

At the core of these conceptual and epistemological criticisms is an acknowledgement of the complexity of the concept of quality of life and a related inbuilt contradiction. This is that, quality of life measurement is built on an assumption that by adopting a positivist paradigm it is possible to “*reduce complex subjective and experiential data into “valid, reliable and measurable factors and dimensions”* (Nicolson & Anderson, 2001, 553).

When applying this to assessment of recovery from illness, there is an assumption that achieving certain scores using these factors and dimensions represents an improvement. However, due to the complexity of what it is claiming to measure, and a lack of in depth inquiry regarding what recovery actually means to people after a heart attack, a HRQOL score can never really reflect a person's experience of quality of life or recovery. All it will remain is a score and does not have the capacity to explain that score. Claims that such a score represents a subjective assessment must be limited. The one aspect that is important to any individual patients' HRQOL may be lost within the dimensions of a measurement tool. The adequacy of the qualitative work upon which dimensions are based has been questioned. There is additional concern that the dimensions are orientated to the priorities of health professionals rather than patients. (Cheater 1998; Wellard, 1998).

#### *4.4.2.5. Sensitivity of measurement tools*

A final issue related to the value of HRQOL in providing insight into patient experience is the lack of sensitivity of the measures. HRQOL measures tend to be generic or disease specific tools. Generic measures can be used to capture aspects of quality of life across populations and disease groups. Disease specific measures focus on features and dimensions specific to a particular disease. There is a proliferation of HRQOL tools used with people with heart disease but their ability to measure accurately is challenged (Chan *et al*, 2005;

Dunderdale *et al*, 2005). They are alleged to be cumbersome, time-consuming and lacking in sensitivity (Thompson & Yu, 2003).

#### **4.4.3. Summary**

In summary, biomedical and HRQOL research all claim to inform on patient experience but their ability to do this is limited. The two-paradigm approach suggests a major reason for this is the dominance of the positivist paradigm that presupposes that experience can be reduced to measurement. Examples of this include measurement of function, impact of illness or treatment, or a concept such as HRQOL. Using this approach of objective measurement assumes that the attainment of certain scores indicates recovery from an illness or its impact. The fundamental problem here is that if one accepts that experience is essentially an emotional or subjective occurrence or state, using objective outcome measurement, as a proxy of experience will only tell you a limited amount. Generating a score cannot capture the participants' conceptualisation of recovery experience or develop understanding of what recovery means. Neither can the results from such surveys reveal the complexity of experience and the range and diversity of influences upon it e.g. social, familial and emotional aspects. Survey data is sensitive to the subtlety and variation in nature of illness experience. It will demonstrate change in a score if repeated measures are taken over time. This is also limited information as it doesn't tell us the way in which the illness may have disrupted or even enhanced their lives and the factors influencing this. A response to this

criticism is to adopt a more interpretive approach to capture the subjective nature of experience. The potential contribution of interpretive research is now briefly considered in relation to exploring patient experience.

#### **4.5. The interpretive paradigm and qualitative research**

As described above, positivist research adopts a realist ontological stance.

This assumes that an objective reality exists that can be described, analysed and measured in order to generate a truth about the world (Denzin & Lincoln, 2003b; Charmaz, 2003). In response to a growing awareness of the limitations of the positivist perspective, illustrated by the studies considered above, a body of qualitative research has emerged to explore issues related to patient illness experience in more depth. Such work adopts a more relativist ontology, rooted in post-modern and constructivist epistemology. The advantages of such an approach when seeking to understand patient experience of heart attack recovery are discussed here. Three concepts central to interpretive research paradigms form the subheadings for the discussion: interpretivism, idealism and naturalism. Following this, the limitations of the two-paradigm approach are considered before explaining the modified constructivist paradigm that was finally used.

##### ***4.5.1. Interpretivism versus positivism.***

The two paradigm approaches of interpretivism and positivism provide the philosophical context within which much health care research is conducted. As



noted above, positivists focus on the importance of objectivity and the use of evidence to demonstrate truth. In contrast, qualitative research based in interpretivism tends:

*“to place emphasis and value on the human, interpretative aspects of knowing about the social world and the significance of the investigator’s own interpretations and understanding of the phenomenon being studied”* (Snape & Spencer, 2003 p7).

Reality and experience are, therefore, seen to be individually constructed and socially mediated. Individual and group realities are therefore possible. These will continually change and vary across time and between individuals (Denzin & Lincoln, 2003b). Research of this nature would aim to explore and understand the patient experience using the views, values and perspectives of the participant and the understanding and interpretation of the researcher (Charmaz, 2003; Snape & Spencer, 2003).

Conrad (1990) argues if one is to really understand chronic illness it is important to explore social and psychological aspects. A more qualitative methodology is required for this, with the capacity to harness information gleaned from the participants’ perspective of:

*“the meaning of illness, the social organisation of the sufferers world, and the strategies used in adaptation”* (Conrad, 1990, p1260).

It could be argued that the importance of exploring variation of experience and meaning is particularly pertinent where social disadvantage and health inequalities are experienced, as is the case with heart disease. Psychological and social environments, such as socio-economic circumstances are influential determinants of health and ill health (Blaxter, 1990). Amongst the gaps in the existing literature is an absence of UK based research exploring the experiences of socio-economically deprived populations at high risk of heart disease. In order to address this gap in knowledge it appeared advisable for the research paradigm of this study to incorporate a social, rather than biomedical, epistemology. This approach recognises the interrelationship between illness, daily living, social relationships and identity. As Nettleton (1995) states, what emerges from this school of inquiry is an understanding that:

*“responses to illness are not simply determined by either the nature of biophysical symptoms or individual motivations, but rather are shaped and imbued by the social, cultural and ideological context of a persons biography”* (Nettleton, 1995, p69).

#### **4.5.2. Idealism versus realism**

The root of realism lies in the work of Comte, Mill and Durkheim. Realism asserts that:

*“reality exists independent of us. Independent means that it exists whether or not we are aware of it or take any interest in it”* (Smith, 1983 p8).

Positivist, realist research aims to prove or disprove these theories in order to establish one truth. In contrast, idealism rejects the notion of an independent reality. It suggests reality only exists through knowing via socially constructed experience and meaning. The idea of one truth is replaced by the belief that multiple realities can exist, that is there are *“as many realities as there are persons”* (Smith 1984 p381).

Guba & Lincoln explain that idealism holds that:

*“There exist multiple, socially constructed realities ungoverned by laws, natural or otherwise ... these constructions are devised by individuals as they attempt to make sense of their experiences”* (Guba & Lincoln, 1989 p86).

For the idealist, the purpose of research is not, therefore, to prove a theory to be true or “the ultimate truth”, but to reveal different perspectives regarding a phenomenon. The goal is to reveal realities not truths (Charmaz, 2003).

Perspectives may be derived from individual experience or socially constructed. Truth is seen as context-bound and the notion of multiple truths that exist side by side is accepted.

Murphy *et al* (1998) discuss two fundamental problems with this idealist stance relating to health and social science research. First, if there are as many realities or truths as there are people, and the purpose of qualitative research is to uncover and describe these, then what applicable use can be made of these

findings in health services research? In addition, the researcher's account becomes just one more version of reality, no more or less reliable or relevant than any other. A third position of "subtle realism" or "critical realism" has been suggested as a way of resolving this controversy (Snape & Spencer, 2003; Murphy *et al*, 1998; Hammersley, 1992a; Hammersley, 1992b). This suggests that opting for one polarity over another is not necessary. Critical realism is described as the approach where:

*"social phenomena are believed to exist independently of peoples representations of them but are only accessible through those representations (Snape & Spencer, 2003. p13).*

Therefore, the notion of an independent reality and phenomena are accepted. However, how these are experienced, represented, accessed and reproduced will depend on individual experience, cultural context and subjective interpretation. There are not multiple realities, but there are multiple representations. These representations are socially constructed and socially mediated. According to a critical realist approach, reality regarding a phenomenon can only be accessed through the variable individual representations of it. In a research context this means that the representations of both the researcher and the researched are recognised and impact upon one another.

### **4.5.3. Naturalism versus artificiality.**

Naturalism relates to the importance placed on studying phenomena in their natural, as opposed to an artificial context, for example the artificiality of an experimental trial.

*“Central to naturalism is the desire to represent the world as it is, in all its complexity and changeability, and to avoid imposing artificial structures” (Hammersley, 1989. p157).*

In their seminal text, Lincoln & Guba (1985) develop an understanding of the epistemology and methods in naturalistic inquiry. Their description is based on a number of “axioms” that reflect the interpretivist / positivist distinction discussed earlier and demonstrate the contribution of naturalism to interpretive inquiry (Box 4).

### Box 4. Positivist and naturalist axioms

Axioms	Positivist Paradigm	Naturalist Paradigm
The nature of reality	Reality is single, tangible and fragmentable	Realities are multiple, constructed, and holistic
The relationship of the researcher and participant	Researcher and participant are independent, a dualism	Researcher and participant are interactive, inseparable
The possibility of generalization	Time and context free generalizations are possible	Time and context bound hypothesis are possible
The possibility of causal linkages	There are real causes, temporally precedent to or simultaneous with their effects	All entities are in a state of simultaneous shaping, so it is impossible to distinguish cause from effect
The role of values	Inquiry is value free	Inquiry is value-bound

*(Adapted from Lincoln & Guba, 1985. p37)*

Naturalistic inquiry aims to limit artificiality and external influence during the research encounter. Despite this aim it is still important to acknowledge the potential the researcher has for influence in naturalistic research. First, by their presence the researcher might alter the natural setting. Second, as mentioned earlier, the researcher can only represent the participant's reality through the filter of their interpretation. Both of these influences have been seen as criticisms of naturalistic, qualitative research. Others have reversed the argument and claimed this influence should be recognised as a benefit of the

interactive nature of naturalist research and should be considered a resource rather than a threat.

#### **4.5.4. Summary**

From the above discussion an interpretive, constructivist research approach would appear to lend itself to in-depth analysis of people's heart attack recovery experience. However, a key limitation of the two-paradigm approach needs to be considered before describing the paradigm that was finally adopted for this study.

#### **4.6. The limitation of the two-paradigm approach**

The contribution and limitations of positivist and interpretive research paradigms in relation to this study have been discussed above. The aim of this study is to answer an in-depth question about the meaning of heart attack recovery. From the above review, it is clear that this question cannot be answered quantitatively (although the results of the study may generate hypotheses that might be tested quantitatively). The implication is that an interpretive approach and qualitative methods are required. It is at this point that a fundamental limitation of the two-paradigm approach is exposed. The limitation is that the paradigms come as a "package deal" (Paley, 2005).

This research requires in-depth analysis of people's experiences of heart attack recovery. Qualitative methods are required for this, as is an acceptance of the

variations in people's subjective experience. However, according to the two-paradigm approach, to adopt interpretive methods requires a rejection of the notion of an objective reality that is viewed as fundamentally positivist. One is required to accept the whole interpretive or constructivist package. This "all or nothing" approach has been soundly criticised as self-limiting and based on a misinterpretation of positivism (Paley, 2005). Whilst seeking a paradigm that encompasses many aspects of interpretivism, the researcher of this study remained affiliated to a belief in an external, independent, objective reality. The proposition that multiple realities actually exist did not seem convincing or helpful. The notion of multiple representations of experience was adopted as more constructive. In such a situation, the two-paradigm approach suggests that belief in an independent reality dictates an obligation to remain in a positivist "box" (Paley, 2005). This would require the use of quantitative methods and the other trappings of positivism. A third paradigmatic approach was therefore required. The critical realist approach was adopted in order to escape this dilemma.

This third paradigm combines recognition of the variation in individual subjective experience, an epistemology based on a social model of health and naturalistic inquiry, and critical realist ontology. This approach has the potential to generate in depth knowledge related to the experience of illness and health. This "third way" recognises that a reality exists external to people's experiences of it. However, it also recognises that experience and representation of reality



is individually constructed and socially mediated. Individual representations of realities are captured, as well as those held by certain social and cultural groups and sub groups. It is acknowledged that these realities and representations will continually change and vary across time and between individuals.

What follows is a more detailed description of the paradigm approach adopted for this research, using the four conceptual components of ontology, epistemology, methodology and ethics (Denzin & Lincoln, 2003a).

## **4.7. Ontology**

### **4.7.1. *Adopting an ontology***

The ontology underpinning a research project relates to the underlying belief and assumptions of the nature of reality and what can be known about it. The ontology is the “lens” through which the research phenomenon is examined. It is essential that the ontology will fit with the research purpose.

This study aims to develop a theory to explain the experience and meaning of recovery after a heart attack. Implicit in this aim is a belief that exploring individual experience can illuminate understanding and meaning of concepts such as recovery. In order to do this, and to incorporate the varied, individual but also shared experiences and representations, the study adopts a critical realist approach.

#### **4.7.2. Critical realism**

This is the third way that lies between realism and idealism. That is, an external reality regarding a heart attack and recovery is recognised. This view is referred to as subtle, or critical, realism. According to a critical or subtle realist perspective:

*“Social phenomenon are believed to exist independently of people’s representations of them but are only accessible through those representations” (Snape & Spencer, 2003 p13).*

Whilst acknowledging that a world exists independent of our knowledge of it, critical realism recognises that people will have different representations of that world (Schwandt, 1997). Variations in people’s representations are acknowledged. Whilst an objective reality exists, we can only access it via people’s accounts of their experiences of reality and the social and historical contexts. An individual’s beliefs, meanings and subjective experience of heart attack recovery are, therefore, acknowledged from a critical realist perspective. The approach incorporates an element of constructivism in that it accepts that representations are socially mediated (or constructed). The fact that representations can only be accessed via participants’ representations of their experience and views mean they will be influenced by the nature of the researcher and participant interaction.

An examination of social and cultural contextual influences on shared representations in South Yorkshire Coalfields communities is incorporated in the study. There is, therefore, an acceptance underlying this research that there may be some shared or collective representations of heart attacks, recovery and service access that are influenced by cultural context. The intention is, therefore, to explore representations that may be diverse and different, but also to identify those that are shared. A critical realist ontology incorporates and supports this endeavour.

In order to make claims about both multifaceted and collective representations it is necessary to be aware and explicit about any potential influence on the researcher's ability to be objective and neutral. In order to do this reflexivity and rigour are important notions related to the ethics of the research (discussed below). By adopting critical realist ontology, what is captured in this thesis is a theory generated from the interrelation between the representations of the researched and the researcher.

## **4.8. Epistemology**

### ***4.8.1. Selecting an epistemology***

The epistemology of a study is concerned with beliefs about the nature of knowledge and what can be known about the subject. The study epistemology drives the theoretical framework of a research project. The epistemology of the research states how one knows the world in general and the subject under.

study. Affiliation to two theoretical perspectives forms the epistemology of this research. These are symbolic interactionism and a social model of health. A brief explanation of each of these and a justification of fit to the research purpose is provided here.

#### **4.8.2. *Symbolic interactionism***

The symbolic interactionist tradition evolved from the work of social psychologist George Herbert Mead (Strauss & Corbin, 1990; Chenitz & Swanson, 1986; Mead, 1934). Mead acknowledged the contribution of social interaction and situation on the individual in developing a sense of self. Blumer (1969) developed this initial thinking on symbolic interaction into three premises. These are:

- People act towards things according to the meanings they ascribe to them.
- These meanings are derived from social interaction.
- Meanings constantly change according to the interpretive process between a person and the things he encounters (Blumer, 1969).

On the basis of these premises, the purpose of research embracing symbolic interactionism aims to explore people in their social context. This includes the way they behave, the roles they adopt, how they interpret and react to what happens to and around them, and what meanings they generate for phenomena as a result. The concept of change in terms of perceptions,

interpretation and meaning is central as symbolic interactionism recognises the importance of the continually evolving nature of experience; the role people have in constructing their own reality and the complexity and ever-changing nature of life (Strauss & Corbin, 1990).

Symbolic interactionism was one of the early theories that influenced the conduct of qualitative, interpretivist research. Early symbolic interactionist research has been accused of being too descriptive in nature. It was alleged to have made assumptions about social reality that were too unproblematic. In these studies:

*“subjects’ accounts were credited with the dignity of social reality as such” (Gerhardt, 1990, p1152).*

In other words some early ethnographic research that embraced symbolic interactionist theory was accused of being too descriptive and light in terms of the level of interpretation and construction of meaning (Gerhardt, 1990). The development of grounded theory went some way to address these criticisms. It did this by developing qualitative research methods that espoused symbolic interactionism but also provided systematic, inductive and rigorous guidelines to develop theoretical interpretations of research data (Charmaz, 2003; Glaser & Strauss, 1967). Therefore, adopting a grounded theory methodological approach in the study presented in this thesis protected against the symbolic interactionist research being merely descriptive. The study aimed at “second-

order” interpretation and to remain self-conscious or reflexive in the conduct of research (see section on Ethics below).

Symbolic interactionism provides an appropriate theoretical backdrop to this research endeavour. That is to generate a theory to explain the meaning of heart attack experience recovery. There are four main points of justification. First, it focuses on the meanings phenomena have for people. Second, it acknowledges the influence of social context, peoples’ interaction with their social and cultural world and how this influences meaning. Third, symbolic interactionist theory recognizes that an event such as a heart attack can have a fundamental effect on individual meaning and change how a person views the world and their place in it. Finally, the previous points lead to a concept of the self as process as opposed to object (Charmaz, 1999; Gecas, 1982). This recognises the fact that people continually unfold, develop and change according to experience and environment. This conceptualisation of the self as *“always in process and never a static final product”* (Charmaz, 1999, p367) provided an epistemological framework to explore recovery as a process. Bolstered by the grounded theory methodology and rigorous methods of interpretation, symbolic interactionism offered a sound epistemological base for the research.

#### **4.8.3. Social model of health**

The earlier review of the literature (Chapter 2) highlighted the influence of social and cultural context on the reality and perceptions of health. The importance of

considering these influences form the core of a social model of health, as opposed to a more mechanistic bio-medical model.

A considered understanding of how social and cultural factors impact upon recovery experience after a heart attack is lacking. This is despite the fact that high rates of heart attacks in some areas of England are associated with social and cultural influences and health inequalities experienced in high-risk communities. Socio-economic circumstances and social environments are influential determinants of health and ill health (Blaxter, 1990). Amongst the gaps in the existing literature is an absence of UK based research involving socio-economically deprived populations at high risk of heart disease. In order to address this gap in knowledge it is necessary for the research paradigm to be able to incorporate a social, rather than biomedical model of health. This approach recognises the interrelationship between illness, daily living, social relationships and identity. As Nettleton (1995) states, what emerges from this school of inquiry is an understanding that:

*“responses to illness are not simply determined by either the nature of biophysical symptoms or individual motivations, but rather are shaped and imbued by the social, cultural and ideological context of a person’s biography” (Nettleton, 1995, p69).*

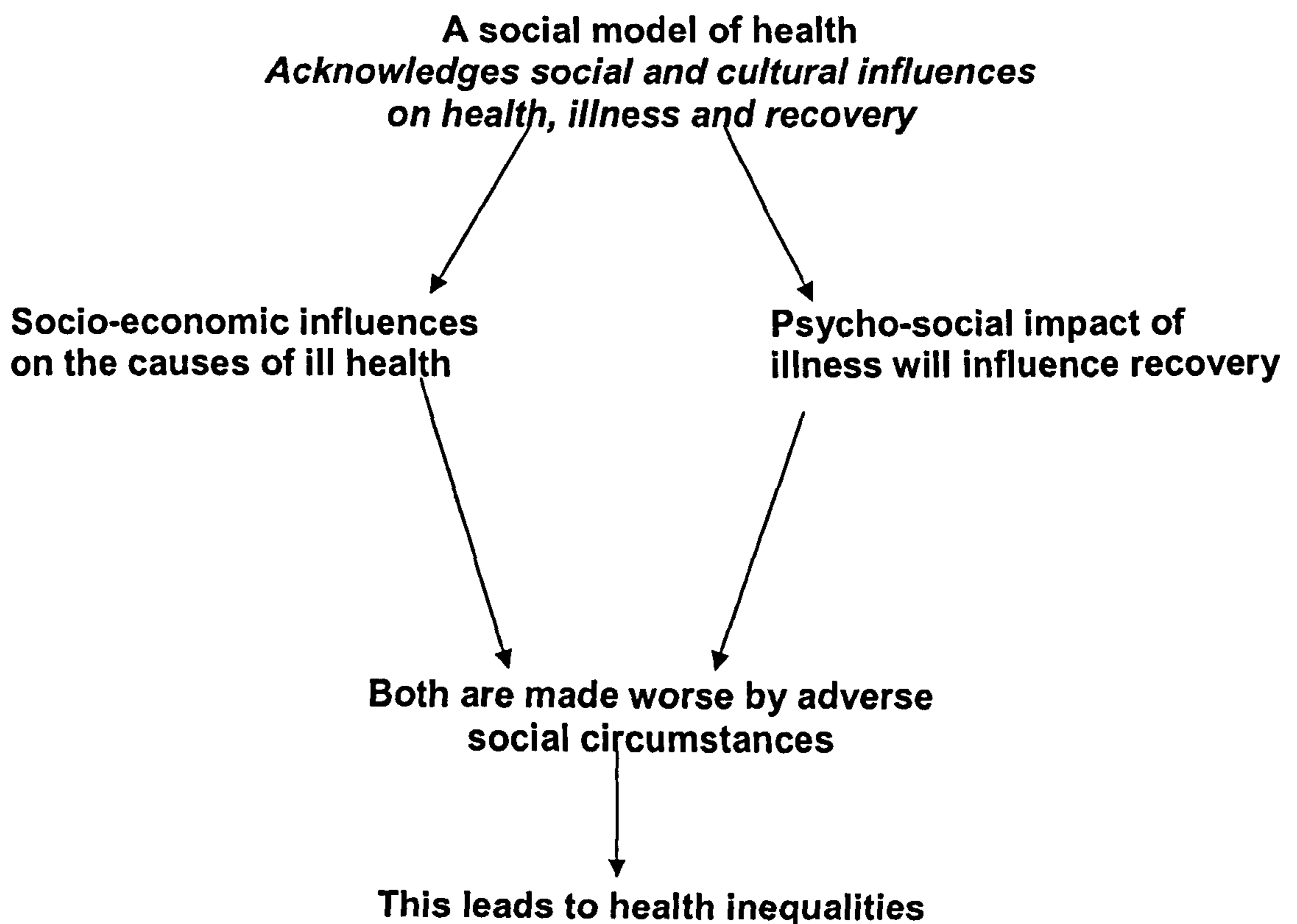
How the social health model is understood and applied to this study is explained diagrammatically (Diagram 3). Social and cultural factors are seen to exert their influence on both the causes of illness and the psychosocial impact

of illness. For those with adverse social circumstances, this influence is unfavourable and potentially harmful. Health inequalities exist where those in more need may be less able to access help, in this case to support heart attack recovery (Tod *et al*, 2002). So, social and cultural influences that contributed to ill health may also obstruct their ability to recover.

Thus, in order to understand better the experience and meaning of recovery after a heart attack it is essential to maintain an awareness of social context, interactions and meanings in relation to health, illness and recovery. The symbolic interactionist and social health theory provided an appropriate epistemological lens to do this.



### **Diagram 3. The social model of health**



#### **4.9. Methodology**

##### **4.9.1. Selecting a methodology**

Methodology has been described as the link between theories of social reality and the method and techniques to collect and analyse data (Gerhardt, 1990). A methodology provides the bridge between the ontological and epistemological underpinning of the study (described above) and the methods adopted to conduct it (described in Chapter 5). For this study a qualitative methodology was required in order to achieve this function (Field & Morse, 1985). Selecting

the appropriate methodology from the range available to the interpretivist, qualitative researcher is a challenging task. Again, it is important to be directed by the research purpose and philosophical approach of the study.

#### **4.9.2. *Grounded theory***

A grounded theory methodology was deemed most appropriate for the study. A more constructivist interpretation of grounded theory methodology was adopted as recommended by Charmaz (2003). The justification for this selection is given here by describing first, the decisions involved in selecting grounded theory over other methodologies, and second, what grounded theory is. This latter section incorporates a brief review of the critical debate regarding grounded theory approaches and the position of this researcher in relation to these discussions. The grounded theory methods and techniques used are given in Chapter 5.

#### **4.9.3. *Grounded theory versus other qualitative methodologies***

Before adopting grounded theory approach, other methodologies were considered. Examples included discourse analysis, narrative analysis and phenomenology. Whilst wanting to capture individual experience and meaning, the importance of social context and exploring recovery as a process were crucial to the research. For these reason, phenomenology and narrative analysis were rejected. These methodologies focus on individual lived experience and life histories of participants (Spencer, Ritchie & O'Connor,

2003; Bowling, 1997). They acknowledge the influence of the social world but they are not as rooted as grounded theory in the social context or focused on exploring social processes. However, discourse analysis was initially more promising. The reasons for this and the reflection related to its rejection are now considered.

#### **4.9.4. Discourse analysis**

Discourse analysis is concerned with knowledge and power (Parker, 1997; Potter & Weatherall, 1995). The backdrop of social influences and health inequalities meant this methodology was initially an attractive proposition. Discourse analysis emerged in the 1950s. It explored the use and social significance of language, for example, in constructing versions of social reality. It affiliated to interpretive notions that no single objective truth is possible. Underpinning discourse analysis is a belief that multiple realities exist accessed by individual interpretations and that research findings are contextually influenced and socially situated (Taylor, 2001).

“Discourse analysis” as a term has been used to describe a wide range of research activities but a broad definition is that it is *“the close study of language in use”* (Taylor, 2001 p5). Foucauldian discourse analysis, the methodology under consideration, explores the ways language is used socially and psychologically to establish social positions and “ways-of-being” (Willig, 2001). The methodology offered the possibility of exploring how after a heart attack,

people use and act through language to socially position themselves. In addition, the potential of examining how the illness impacts upon perceptions of knowledge and power was seductive.

The reasons for finally deciding against discourse analysis in favour of grounded theory are as follows. First, there is a question regarding the extent to which participant's subjective experience and how their perception of reality and social position can be theorized using discourse alone (Willig, 2001).

Second, the conceptual leap between the discourse analysis and the resulting themes and theoretical propositions is based on the assumption that certain discourse is produced by certain material and social conditions. This is a complex assumption, made more complicated by considering the impact of power on discourse and discourse on power. The focus on power, whilst interesting, ultimately would have taken the study away from its main aim; that was to develop a theory to explain the social process of recovery. Finally, discourse analysis focuses on analysis of the use of language rather than analysis of the content of what people were saying (Weatherall, 1995). This meant a key goal of the study would not be realised, that is, to develop a better understanding of patient experience and meaning.

#### ***4.9.5. Selecting grounded theory***

Grounded theory therefore emerged as the most appropriate methodology.

Grounded theory is a general method that can be used with either qualitative or

quantitative data (Charmaz, 2003; Thulesius, 2002; Glaser, 1978b). However, it is more typically associated with and considered appropriate to qualitative research as its orientation is to text not statistics or numbers (Charmaz, 2003; Thulesius, 2002). Grounded theory is a research method that provides a systematic set of procedures to generate theory about a phenomenon that is grounded in the research data (Chamberlain, 1999; Strauss & Corbin, 1990). In grounded theory the unit of analysis is the incident not the person, in this case heart attack recovery (Thulesius, 2002; Glaser & Strauss, 1967). The goals of grounded theory are to explore what is the participant's main concern regarding the incident or phenomenon, how they try to resolve this and what meaning this has for them. The focus is on exploring social processes related to the study phenomenon. In this study the process under examination was heart attack recovery. In addition, grounded theory is not a descriptive method but one that:

*“consists of systematic inductive guidelines for collecting and analysing data to build middle-range theoretical frameworks that explain the collected data”.* (Charmaz, 2003, p249-50).

In summary, grounded theory met the four requirements of a methodology in terms of the study purpose outlined at the beginning of this chapter. That is, grounded theory has a social focus, it has the capacity to generate theory that accounts for similarities and variance in individual experience and meaning, it has the capacity to examine recovery as a process and finally can generate “second-order” interpretations rather than descriptive results. However, controversies regarding different approaches and uses of grounded theory

abound. For this reason, more methodological detail regarding grounded theory is discussed below with clarification of the exact approach adopted for this study.

#### **4.9.6. Grounded theory**

##### **4.9.6.1. The development of grounded theory**

Grounded theory emerged from the discipline of sociology. The originators, Glaser & Strauss (1967) were prompted by concerns regarding the focus of sociological research and theory. They questioned the nature and emphasis given to quantitative methods by sociologists. They were also disturbed by a tendency amongst sociological theorists and qualitative researchers to concentrate on description and stop short of theory generation (McCann & Clark, 2003a; McCann & Clark, 2003b; Murphy *et al*, 1999; Chamberlain, 1999). The intention was for grounded theory to provide sociologists with a rigorous structure and strategy to support theory development. The purpose was to explore a phenomenon, identify related concepts, categorize these using more abstract thinking, and generate a theory relating to the interrelationships between concepts and categories.

The genesis of grounded theory lies in the synthesis of the combined epistemological experiences of its founders, Glaser and Strauss. Glaser's background lay in empirical quantitative research. He brought an allegiance to critical realist ontology, incorporating a belief in an objective reality. He also

emphasised that the researcher is independent from the researched. His scientific background led Glaser to place emphasis on

*“the need for a well thought out, explicitly formulating, and systematic set of procedures for both coding and testing hypotheses generated during the research process” (Strauss & Corbin, 1990, p25).*

In contrast, Strauss’s academic background was in qualitative research and was inspired by the symbolic interactionist tradition. Strauss recognized the importance of the evolving nature of experience and the role people have in constructing their own reality (Strauss & Corbin, 1990).

#### *4.9.6.2. Grounded theory techniques*

Inductive and deductive reasoning are used within grounded theory. That is theoretical propositions are generated from the data and then tested out in subsequent data collection and analysis. This is conducted in two stages. The first stage is described as theoretical sampling and coding. This involves the selection of subjects or contexts on the basis of hypothetical arguments emerging from the ongoing analysis. Data is then categorized via hypothesis-based critique using constant comparison methods (Gerhardt, 1990). The second stage is conducted when saturation is reached, that is no new insights are emerging (Staruss & Corbin, 1990). This involves, by selective coding, the identification of a core category and theory of how this and other categories link

together to explain a social process (Gerhardt, 1990; Glaser & Strauss, 1967). The methods used to do this are described in Chapter 5.

#### 4.9.6.3. *Criticisms of grounded theory*

There has been a tendency to see grounded theory as a prescriptive and restrictive set procedures and techniques to analyse data. In more recent years a more flexible approach has emerged. This is due in part to an acknowledgement that grounded theory like any other method, is evolving and should resist being "*completely codified and structured*" (Chamberlain, 1999. p194).

Another criticism of grounded theory relates to the well-publicised methodological schism that developed between Glaser and Strauss. This schism emerged as each became more influenced by their respective epistemological traditions. The schism has potential to cause confusion but also act as a catalyst to varied, and possibly inappropriate application.

In his later academic career, Glaser maintained his objectivist stance and kept a focus on theory generation. Strauss drew increasingly on symbolic interactionist thought, and developed a greater focus on theory verification. According to Strauss, views that challenge established beliefs and truths are encouraged. He also recognised knowledge and reality as created and influenced by context, and finally, that reality can only be experienced as an



interpretive process between researcher and participant (McCann & Clarke, 2003a; Charmaz, 2003).

Glaser continued to advocate collecting data without any preconceived ideas. He was concerned that Strauss & Corbins' methods would result in data being forced to fit preconceptions (Charmaz, 2003). The core differences between the two approaches are summarized in Box 5.

**Box 5. Methodological and epistemological differences between Glaser and Strauss & Corbin.**

	Glaser	Strauss & Corbin
Epistemology	Critical realist ontology and post-positivist paradigm	Social constructivist and post-structural or post-modern paradigm. Less positivist
Researcher's role	Independent	Dialectic and active
Theory	Emphasis on theory generation	Emphasis on verification and validation of theory and hypothesis
Focus in the field	Main emphasis on symbols, interactions and context. Emphasis on socially constructed world of participants (micro)	Emphasis on structural, contextual, symbolic and interactional influences. Emphasis on describing the cultural scene (macro) and socially constructed world of participants (micro)
Literature review	Main review to support emerging theory	Preliminary review to enhance theoretical sensitivity. Main review to support emerging theory
Research problem	Emerges in study	Personal experience. Suggestion by others. Emerges in study
Data collection and analysis	Principles and practices of qualitative research. Guided by participants and socially constructed reality	Rules and procedures. Paradigm Model to provide structure
Evaluation	Fit, work, relevance and modifiability	Deference to canons of qualitative research outlined by other qualitative researchers

*From: McCann & Clark 2003a, p23*

The methodological differences of Glaser and Strauss and their inflexibility in techniques can create a minefield for a researcher seeking the most acceptable methodology in “real world” research. A more flexible approach is recommended by Chamberlain (1999) and Charmaz (2003) and was therefore adopted for this study.

Despite the move towards giving participants a voice, Strauss shared with Glaser the realist belief in an external, objective reality. This created an additional dilemma in choosing grounded theory for this research. Grounded theory appeared to provide the required techniques. It also had the appropriate epistemological basis of symbolic interaction and an orientation to social processes. However, an ontological dilemma existed. Grounded theory seemed steeped in objectivist beliefs as opposed to this study, which was based on critical realist ontology. This dilemma supported the integration of a constructivist interpretation of grounded theory into the research paradigm (Charmaz, 2003).

#### *4.9.6.4. Constructivist grounded theory*

Following the work of Glaser (1992) and Strauss & Corbin (1990), a third paradigm position regarding grounded theory is the constructivist approach propounded by Charmaz (2003, 1990). This provided the most appropriate methodological home for this research. The choice is supported by the fact

Charmaz (1990, 1983) has successfully used constructivist grounded theory in exploring illness experience. Core paradigm positions of constructivist grounded theory are as follows:

- It seeks to further knowledge of subjective experience.
- It studies experience from the perspective of those who live it.
- It assumes people create and maintain meaningful worlds, confer meaning on their perceived reality and act accordingly.
- It provides an emphasis on meaning without assuming an uni-dimensional external reality.
- It takes a systematic analytical approach and tells a story of people, social processes and situations.

Charmaz (2003) talks of grounded theory being on a paradigm continuum from objectivist to constructivist and suggests the future lies with both. Glaser and Strauss remained affiliated to the objectivist end of the spectrum. Charmaz (2003) explored the possibilities of the constructivist perspective. Flexibility was seen to be the key.

In this research study the original goals and methods of grounded theory provided a sound methodological platform. The goals are to generate theory on heart attack recovery from data exploring basic social processes and using inductive and deductive reasoning. The methods and techniques

recommended by Strauss and Corbin (1990) provided a rigorous and systematic structure for the data collection and analysis. Incorporating constructivist grounded theory methodology into a critical realist perspective contributed to the paradigmatic basis for the study.

It should be emphasised however that, adopting a constructivist interpretation of grounded theory did not mean abandoning the critical realist ontology. The research is not based in the more extreme stance of social constructionism that rejects the existence of an external reality in favour of multiple socially constructed realities (Snape & Spencer, 2003; Bury 1986). What is proposed here is an affiliation to the core tenets of constructivist grounded theory (listed above) integrated with a critical realist belief that an external reality exists. Critical realism *“attests to a reality beyond discourse”* (Williams, 1999 p814) and the possibility of a non-social reality. According to critical realism this reality can only be known through the human mind and experience and through socially constructed meanings and representations.

Constructivist grounded theory makes a distinction between the real and the true (Charmaz, 2003). The constructivist approach seeks to capture multiple viewpoints and realities rather than one single truth. Charmaz (1990) recommends that grounded theory should identify cross cutting themes that incorporate the variation and complexity of experience in illness. This approach therefore provided a methodological fit with one goal of the study, which was to

uncover variations as well as similarities in experiences. Using this more flexible “lens”, it was possible to seek to explore multiple representations and individual experience as well as generating theoretical propositions that applied to all.

An additional reason for incorporating a constructivist methodology was the recognition this gives to the “*active stance*” (Charmaz, 1990, p1162) of the researcher. Glaser and Strauss (1967) advocate the objectivity of the researcher in the collection and analysis. In keeping with an interpretive ontology this research was conducted in the belief that the research results are a product, in part, of the interaction between researcher and the researched. In addition, interpretivism suggests that the results can only be the researchers' representation of those of the participants. To adopt an objective stance would therefore be both inappropriate and undesirable for this study. So, whilst the work of Glaser (1992) and Strauss & Corbin (1990) were valuable in providing methods and techniques for the study, the methodological basis was constructivist. This provided the best match with the interpretive ontological lens through which the research was viewed.

#### **4.9.7. Summary**

By combining elements of the three positions (Glaser, Strauss and Corbin, and Charmaz) and by maintaining flexibility, grounded theory provided an appropriate methodology to develop a theory to explain the experience and

meaning of recovery after a heart attack. Before describing the methods used to conduct the study (Chapter 5), the ethical criteria and considerations related to the research paradigm are now considered. Techniques adopted to demonstrate the ethical conduct of the study will be reported in the next chapter.

## **4.10. Ethics**

### **4.10.1. Rigour**

In order for a study to be ethical it is required to be rigorous and scientifically sound. A core ethical doubt regarding the adoption of grounded theory relates to the potential risk of inadvertently manipulating the data collection and analysis processes. Examples of this include inadequate or biased theoretical sampling or forcing the data to fit pre-existing knowledge.

Concepts such as validity and reliability in their traditional sense are considered inappropriate for qualitative studies, including those using grounded theory. Two sets of criteria were used in this study to facilitate reflection upon the quality and rigor of the study. These are the criteria of “trustworthiness” (Lincoln & Guba, 1985), which relate to the conduct of methods and the criteria of “fit”, which relates to the theory generated (Charmaz, 2003; Glaser, 1999; Glaser, 1978).

## **4.10.2. Trustworthiness**

### **4.10.2.1. Trustworthiness criteria**

The criteria of “trustworthiness” were used for verification of the accuracy and appropriateness of the data interpretation (Lincoln & Guba, 1999; Lincoln & Guba, 1985). These criteria of credibility, transferability, dependability and confirmability were used as tools of reflection by the researcher in order to check for inappropriate interpretation and bias during the research process. Definitions of the criteria and techniques used are outlined in Box 6.

Emerging issues were checked and clarified with the participant during the interviews using feedback techniques. Initial analysis and interpretation was tested in subsequent interviews. The triangulation of group and individual interviews added to the verification of the analytical process. Ongoing reflection and reflexivity helped to ensure “trustworthiness”.

### **4.10.2.2. Reflexivity**

Finlay (2002) stresses the difference between reflection and reflexivity, suggesting they operate at opposite ends of a spectrum. Reflection is described as distanced consideration of an object or event that takes place after it has been experienced or occurred. In contrast, reflexivity is a more immediate, continual, dynamic self-awareness (Finlay, 2002). It involves self-critique and appraisal of the influence and impact of researchers' own presence in the research process (Barry *et al*, 1999; Koch & Harrington, 1998). Both reflexivity and reflection were used in this study to promote “trustworthiness”. It



has already been stressed that this study did not assume the researcher is objective. The researcher's previous professional experience and views would potentially influence the research process and interaction with participants. There is an argument that this experience adds to the theoretical sensitivity of the researcher and perceptiveness in interviewing.

## Box 6. Establishing “Trustworthiness”

CRITERIA	EXPLANATION	TECHNIQUES USED TO MEET CRITERIA
Credibility	The “truth value” or the level of credibility of the results for the participants.	<ul style="list-style-type: none"> <li>• Member checking within and at the end of interviews.</li> <li>• Member checking using comments sheets and group interviews</li> </ul>
Transferability	The extent to which the results can be transferred and applied to other populations and contexts.	<ul style="list-style-type: none"> <li>• Peer debriefing with supervisor, interview observer, and analysis check.</li> <li>• Ongoing discussions regarding interpretation of data.</li> <li>• Testing emerging interpretations in subsequent group, individual and informal interviews.</li> </ul>
Dependability	The extent to which the results would be repeated if the study was to be replicated.	<ul style="list-style-type: none"> <li>• Negative case, between and within case comparison within the analysis.</li> <li>• Reflection and feedback within the interview.</li> </ul>
Confirmability	The extent to which the results are derived from the participants and not due to bias or misinterpretation by the researcher.	<ul style="list-style-type: none"> <li>• Maintaining a study journal and field notes.</li> <li>• Self-reflection by the researcher to maintain awareness of risk of bias.</li> <li>• Comparing and integrating results of previous studies in the later stages of analysis.</li> </ul>

Compiled with reference to Lincoln and Guba (1985)

However, it is important to remain vigilant to ensure that the end results reflect the participants' representation of reality. It is extremely difficult to explain the action of reflexivity or to demonstrate that reflection has occurred. The criteria of "trustworthiness" help to make this more explicit as demonstrated in Box 5.

#### ***4.10.3. Glaser's criteria of "fit"***

As validity is not deemed an appropriate concept in grounded theory, Glaser proposed alternative quality criteria (Charmaz, 2003; Thulesius, 2002; Glaser, 1978). He suggested the quality of a grounded theory study and the theory it generated should be judged by fit, relevance, workability and modifiability.

Fit relates to how accurately the theoretical concepts match the phenomenon and incidents of interest. This is achieved through constant comparison of incidents to concepts. The concepts must reflect the data, not preconceived ideas. Relevance refers to the ability of analytical concepts to address the real concerns of participants, not just the interests of the researcher or academic world. If a theory works, the concepts within it must explain the phenomenon under study and the variation within it. Finally, modifiability relates to the capacity of a theory to be altered or expanded to accommodate new relevant data, when compared to original data.

Reflection, constant comparison and theoretical sampling all add to the ability to generate a theory that meets Glaser's criteria. As Thulesius (2002) states there

is no right or wrong grounded theory, just one that has more or less fit, relevance, workability and modifiability. The extent to which this study achieved fit will be considered in the final chapter in reference to the methods used to undertake the study.

#### **4.11. Conclusion**

By reflecting on the issues above it has been possible to clarify the philosophical framework for the study (incorporating ontology and epistemology). Chamberlain (1999) states that as ontology, epistemology and methodology are inextricably linked it is essential that researchers are clear about the philosophical assumptions underlying a study. In this way belief about what can be known and how reality is viewed in the research is made explicit.

The research described here was conducted within the paradigms of interpretive inquiry. The underlying ontology is one of critical or subtle realism. Symbolic interactionism and a social model of health underpinned the epistemology. A qualitative grounded theory methodology was used that allowed both inductive and deductive reasoning. A constructivist approach was adopted. The constructivist attitude was modified by critical realist ontology in order to account for the belief in multiple representations of reality rather than an objective truth. This modified constructivist grounded theory methodology (Charmaz, 2003) also explores how participants construct their illness

experience in the light of their social and cultural context. Reflection and reflexivity regarding criteria of “trustworthiness” and “fit” were used to ensure the quality and rigor of the study and contribute to its ethical standing.

## Chapter 5. Methods

*“A lot of it really is them not listening, not hearing what you’re putting across”. (Group participant P2.1).*

*“I’ve had no support. I’ve been left in ignorance really”. (Individual interview 4.)*

*“Sometimes I’ve been in bed and I sob into my pillow. You know? There’s just nobody. There’s just nothing. And sometimes I think, “who the hell is going to help me?” (Individual interview 1. Participant’s wife)*

### 5.1. Introduction

The aim of this chapter is to outline the methods used for the study. The purpose is first, to provide a clear description of the participants, components and techniques employed in the study. As indicated by the quotes of the patients and carers above, people report that it is often difficult to find someone to listen to them about their or their partner’s heart attack and its impact on them. This is despite the fact it can be a frightening and distressing event. It was considered important to ensure that the study methods provided adequate means for people to tell their experiences and to be listened to. Therefore, this chapter also provides a reflection on the adequacy of the methods used. This reflective account also helps to demonstrate the reliability of the methods used to develop the theory of Watchful Insecurity.

This research developed a theory to explain the experience and meaning of heart attack recovery, the theory of Watchful Insecurity. In order to do this in

keeping with the critical realist ontology, it was necessary to adopt a method that had the capacity to capture the patient experience, develop conceptual understanding and generate theory from the data. Grounded theory was the methodology selected and provided the techniques appropriate to the study aims.

At this point, it is prudent to remember that the study presented here emerged as an extension from a programme of qualitative work exploring barriers to accessing heart health services. The initial study explored barriers to accessing cardiac rehabilitation and provided the platform for the research presented here. Some of the interview data from the “barriers” study was integrated into this study on recovery. Where and why this was done is described below.

The aims, objectives and setting of the study are restated. The practicalities of sampling, data collection and analysis in this grounded theory study are then briefly described, justifications for decisions are provided and reference is made to some ethical considerations. The chapter concludes with a reflexive account of the methods selected. Glaser (1999) provides a number of points of advice to the grounded theory researcher. These are used as sub-headings to frame the reflexive account.

## **5.2. Aim**

To develop a theory explaining the experience and meaning of recovery from the perspective of those who have encountered a heart attack.

## **5.3. Research questions**

- How do people experience recovery after a heart attack?
- What do people mean by recovery after a heart attack?

## **5.4. Objectives**

- To explore experiences of heart attack patients and their partners at various stages of recovery and times after the event.
- To explore the meaning recovery has for participants.
- To gain an understanding of how recovery is conceptualised by the participants i.e. what are they trying to achieve, where are they trying to get to and how do they know when they have got there?
- To identify what people have to do and what behaviours they employ in order to support and achieve recovery after a heart attack.
- To generate a theory, grounded in the perspectives and experiences of the participants. The theory will account for and explain their experience of recovery from a heart attack.
- To reflect on the implications of this theory for health professionals and health services.



### **5.5. Methodology**

A modified constructivist grounded theory methodology was used.

### **5.6. Design**

The study adopted qualitative methods including semi-structured group and individual interviews, and grounded theory analysis techniques.

### **5.7. Ethical Approval**

Local Research Ethics Committee approval was obtained for this study alongside the Health Action Zone initial “barriers” study on cardiac rehabilitation (Appendix 3). This process was far from straightforward due to restructuring of Health Authorities into Primary Care Trusts and the introduction of new governance regulations regarding the conduct of Research Ethics Committees (Department of Health, 2001).

Details of the frustrations and reflections of this process are found in a peer review publication (Tod, Nicolson, & Allmark, 2002 see Appendix 1 and 2).

A summary of the ethical issues addressed in the Research Ethics Committee proposal is summarised in Appendix 3.

## **5.8. Setting**

The study was conducted in hospital and community settings in the South Yorkshire Coalfields areas of Barnsley, Rotherham and Doncaster. This area has a higher than national incidence of CHD and demonstrable health inequalities linked to socio-economic deprivation and chronic ill-health (Tod, Lacey & McNeill, 2002, Tod *et al*, 2001).

## **5.9. Sampling and recruitment**

A combination of convenience and theoretical sampling was used to obtain the sample. The sample comprised three strata. These were group, individual and informal interviews. The total sample consisted of 44 participants. Twenty-four patients and carers took part in the group interviews. Ten patients participated in individual interviews, plus 10 key informants in the informal interviews. The sample provided a range of patient and carer participants in terms of age, gender, occupation, work status, postcode, time from their heart attack and perceptions regarding stage of recovery. This is indicated in Tables 3 & 4.

### **5.9.1. Group interviews**

The subjects for the group interviews were recruited using convenience sampling, that is subjects are recruited because they are easy to enrol and interested in taking part (Bowling, 1997). A sample of 24 people participated in one of four group interviews. Those attending included people who had had a heart attack or were partners of people with a heart attack (Table 5). The

intention was to include people who were at various points of recovery in terms of both the time since their heart attack and stage of readjustment. Members of cardiac support groups had the capacity to provide a sample of this nature.

The secretary, chair or lead health professional of the support / cardiac rehabilitation groups were gatekeepers for recruitment. They facilitated contact with group members. During initial conversations with them and group members it was important to emphasise the extent of the remit of the research in order not to raise expectations. That is, the study was being conducted for the researcher's doctoral study. It was supported by local NHS organisations and the results were to be fed back to them. However, there was no guarantee that change would follow as a result of the participant's views being shared with these institutions.

The gatekeepers obtained agreement from group members that the researcher could attend and talk to them about the study. Names and contact details of those interested in participating were collected and a discussion held to identify a suitable venue for the group interview to take place. Following this meeting, individuals were contacted by letter or telephone to further explain the study and, if they consented, to arrange the time and location of the interview.

**Table 5: Group interview participants**

Group member	Gender (M/F)	Age	Date of heart attack	Date of CABG	Cardiac rehab access	Other cardiac problem
<b>Group 1.</b>						
P1.1.	Male	75	2001	2001	Yes	None
P1.2.	Female	70	2001	n/a	No	None
P1.3.	Male	61	1993	1993/1997	No	None
P1.4.	Male	69	1997	n/a	Yes	LVF
P1.5.	Female	64	1997	2000	Yes	Angina
C1.1.	Female	69	n/a	n/a	Yes	None
C1.2.	Male	76	n/a	n/a	No	None
C1.3.	Female	54	n/a	n/a	No	None
C1.4.	Female	59	n/a	n/a	No	None
<b>Group 2.</b>						
P2.1.	Female	67	1993/2000	n/a	Yes	Stent
P2.2.	Female	61	1999	n/a	Yes	None
P2.3.	Female	70	1999	n/a	Yes	None
C2.1.	Female	59	n/a	n/a	No	Angina
C2.2.	Female	66	n/a	n/a	No	Angina
<b>Group 3.</b>						
P3.1.	Male	74	1991	n/a	Yes	None
P3.2.	Male	69	1995	n/a	Yes	PTCA
P3.3.	Male	72	2000	2000	Yes	None
P3.4.	Male	61	n/a	2001	No	None
C3.1.	Female	73	n/a	n/a	No	None
C3.2.	Female	60	n/a	n/a	Yes	None
C3.3.	Female	68	n/a	n/a	No	None
<b>Group 4.</b>						
P4.1.	Male	70	1999	n/a	Yes	None
P4.2.	Male	60	2001	n/a	Yes	None
P4.3.	Male	64	1992	n/a	Yes	None

*P = patient, C = carer, PTCA = percutaneous transluminal coronary angioplasty, CABG = coronary artery bypass graft*

Inclusion criteria for the group interviews were people who i) had experienced a heart attack and / or their partners or carers, ii) were able to give informed consent and iii) were able to speak English.

The communities the groups served, and the support groups themselves, were quite insular and close. There was awareness that people may not want their neighbours to know of their participation in the research. By following this recruitment process, agreement to take part was obtained on an individual basis. In this way people did not have to make known to the larger support group that they were participating.

Despite explaining at the support group and in the written information that a criterion for participating was to have had a heart attack, one man (P3.4.) who volunteered, had experienced heart surgery not a heart attack. It was not made clear until he arrived for the interview that he had not had a heart attack. He was very keen and interested to take part. In addition, the other group members immediately welcomed him and included him in pre-interview conversation. It was, therefore, impossible to ask him to leave because he did not meet the inclusion criteria. Upon reflection, his presence was useful as it helped to highlight some of the similarities and differences experienced between the heart attack and heart surgery recovery contexts and experience.

In addition to the group participants, data from ten interviews from the previous study was also selected for use.

### **5.9.2. *Individual interviews***

As the data from the group interviews was analysed, conceptual categories and theoretical propositions were generated. These were then tested using the data from ten interviews from the initial Health Action Zone study on barriers to accessing cardiac rehabilitation (for details see Chapter 1 and Tod, Lacey & McNeill, 2002). These interviews were deemed appropriate to this purpose because they focused on patient experience after a heart attack, rehabilitation needs and access. More crucially, it was this data that had supported the need to investigate the meaning of recovery in more depth and raised the issue that the illness had prompted people to see themselves differently.

All the participants were patients who had experienced a heart attack six to eight months prior to the interview. Patients were invited to participate if they were under 85 and if admitted to a hospital with a heart attack, whether they have had a previous heart attack or not. Patients were excluded if they were unable to participate in an interview due to any significant co-morbidity e.g. severe mental illness, if they did not consent to participate or if participation may cause distress.

The initial study had involved 20 patient interviews. The 10 interviews used in this study were selected using theoretical sampling. The particular interviews and data from them were chosen because of their capacity to challenge or expand the propositions made (Bowling, 1997; Glaser & Strauss, 1967).

**Table 6: Individual interviews participants**

	Age	Gender	Employment	Cardiac Rehabilitation Health Visitor Home Visit	Access to Phase 3 Hospital Cardiac Rehabilitation
1	63	Male	Retired lorry driver	None	Excluded due to angina. Waiting for angiography.
2	51	Male	Lorry driver Still on sick leave	Visited twice	Started 14 weeks post M.I. Stopped 2 weeks later because of chest pain. Trying to get angiography privately.
3	76	Male	Retired bus driver	None	Not interested in attending hospital
4	50	Female	Retired club steward	Yes – but 5 months post discharge	Still waiting to hear
5	43	Male	Unemployed security guard	None	Still waiting
6	68	Male	Retired factory controller	None	Start week after interview
7	52	Male	Company director Retired on ill health	None	Still waiting. Trying to access cardiac rehabilitation through private health care
8	50	Male	Police officer Still on sick leave	None	Still waiting
9	57	Male	Retired sales representative	None	Still waiting
10	71	Female	Retired home carer	None	Excluded. +ve ETT

*ETT = Exercise Tolerance Test.*

Informed consent was obtained at the outset for both the “barriers” study and this doctoral research exploring heart attack recovery.

Table four demonstrates the range of individual interview participants selected using theoretical sampling. At points, theoretical sampling meant selecting people with certain characteristics or experiences, for example younger participants, people who claimed to be able to enjoy life again or people who were stuck in the system and felt their lives were in limbo. At other points theoretical sampling meant the selection of data. Slices of text were selected that reflected the mental impact and implications of the heart attack or that said something about certain concepts. For example, when the core category of Watchful Insecurity began to emerge as the core category, theoretical properties related to it were identified. Text had been coded to these properties, such as those related to what people needed to do and have in order to live with Watchful Insecurity (Box7). This proposition was theoretically sampled and analysed to verify the core category

**Box 7. Example of codes used for theoretical sampling of text**

Need to do	Need to have
Resume activity	Confidence
Seek advice	Understanding
Personalized knowledge	Meaning
Accept <i>change and loss</i> where necessary	Acceptance
Set goals	Control



### **5.9.3. Informal Interviews**

In order to contribute towards the credibility of the results, the theory that was developed, "Watchful Insecurity", was tested out in a series of informal interviews. Informal interviews were not a part of the initial design of the study. However, as the analysis developed and the theory started to emerge, a natural response was to test this out in informal discussions with people who had "expert" knowledge or experience on an issue emerging from the analysis. For example, theoretical propositions related to triggers of Watchful Insecurity were tested in discussion with those who had experienced other sudden, frightening, life threatening events. They were also discussed with staff experienced in the care of other patient groups, such as people with cancer. No formal written consent was obtained, as these were essentially informal conversations. Agreement for the outcome of these discussions to be used as an additional component of the analysis, and in the thesis, was obtained.

No verbatim records were kept, but notes and memos were made in response to the discussions. The decision to include and recognise these informal interviews as part of the sample and data was made on the basis of recommendations in the literature. The first was a recommendation that experienced or expert colleagues can assist in the verification of data categorization (Cutcliffe & McKenna, 1999; Appleton, 1995). In addition, following the tenet of Glaser (1978) that "all is data" the informal discussions were included as part of the inductive and deductive process. It was decided

that they should be acknowledged in the methods. Theoretical sampling was used to identify the “expert” sample. Characteristics of the informal interview participants and reasons for their inclusion are given in Table 7.

**Table 7: Informal interview participants**

	<b>Gender</b>	<b>Expert status</b>	<b>Reason for inclusion</b>
1	Female	Cardiac rehabilitation nurse	Professional expertise and experience caring for patients after a heart attack. Manager of a cardiac rehabilitation service. Currently undertaking PhD study.
2	Female	Cardiac rehabilitation nurse	Professional expertise and experience caring for patients after a heart attack. Works in a different service to informal interview participant 1.
3	Female	Senior sister of a coronary care unit	Professional expertise and experience caring for patients after a heart attack. A close friend who was recently bereaved and prepared to consider potential differences in Watchful Insecurity for people after a heart attack and bereavement.
4	Female	Practice development Sister in oncology	Professional expertise and experience caring for patients with cancer. Able to discuss potential differences in Watchful Insecurity for people after a heart attack and bereavement.
5	Female	Climber and survivor of a car accident	Friend and companion on a climbing holiday. Discussed the theory of "Watchful insecurity" and how it related to feelings and experiences when climbing and after the jeep accident.
6	Male	Nursing lecturer	Professional expertise and experience caring for patients after heart attack. Knowledge of some theoretical and research literature related to recovery from a heart attack. Recently conducted interviews of people after a heart attack to include in Internet distance learning course in cardiac care.
7	Female	Climber and nursing lecturer	Professional expertise and experience caring for patients. Friend and companion on a climbing holiday. Able to discuss the theory of "Watchful insecurity" in relation to professional and personal experience.
8	Male	Climber	Friend with many years experience of rock climbing and mountaineering, with close friends who have been injured or died climbing. Able to discuss "Watchful insecurity" in relation to personal experience of climbing and bereavement.
9	Female	Psychologist	Colleague with extensive experience as a psychologist working with cardiac patients and people with other chronic and acute illness. Able to discuss the theory of "Watchful insecurity" in relation to professional experience and theoretical knowledge.
10	Male	Climber and survivor of a horse riding accident	Friend and companion on a climbing holiday. Discussed the theory of "Watchful insecurity" and how it related to feelings and experiences when climbing and after the riding accident.

## **5.10. Data collection**

Grounded theory data collection and analysis decisions and techniques are interwoven (Strauss & Corbin, 1990; Glaser & Strauss, 1967). Decisions are made as the researcher moves between inductively generating theoretical propositions and looking for data to deductively test them. The techniques used to guide these decisions are described below in the data analysis section.

What follows here is a brief description of the practical and contextual details of data collection.

### **5.10.1. Group interviews**

Data was collected between February and August 2002. Spreading the group interviews over six months supported the inter-relation between data collection and analysis. As analysis took place between group interviews, the focus of the questioning of people and data was able to change. Probing altered in a responsive and flexible way as new theoretical propositions emerged.

The interviews lasted approximately 30 to 60 minutes. A script was prepared for the researcher to use to introduce the interview. This outlined what the participants could expect. The participants were given the opportunity to ask questions about the research and interview before being asked to sign a consent form (Appendix 4). They were then asked to complete a form detailing their cardiac history. This helped to establish the range in terms of heart attack experiences.

An interview schedule was used to guide the discussions (Appendix4). Glaser & Strauss (1967) stress that grounded theory studies should never start with a theory to prove, thus supporting the use of unstructured interviews. However, there were key *a priori* issues underpinning this study that supported the use of an interview schedule and a semi-structured interview approach. These issues emerged from the aims, from the previous “barriers” research and from the underlying epistemology. First, the aims and objectives required that recovery was explored as a concept and required the examination of the influence of social and cultural factors on the heart attack experience. Also, the indication from the initial “barriers” study that people saw themselves as a different person after the heart attack, needed to be explored. An interview schedule was developed to incorporate these issues (Appendix 4). However, a flexible approach was taken in the process of the interview so that the direction of the discussion and data captures reflected the participants’ concerns not those of the researcher.

The group conversation was directed by an interview schedule but also by the interaction generated by the group. The importance of interaction in gaining a better understanding of participants' experience is a key characteristic of group interviews (Espisito & Powell-Cope, 1997; Kitzinger, 1995; Kitzinger, 1994). Notes taken included a record of who dominated the conversations, whether

members were influenced, stimulated, differed or connected with the experience of other group members.

With permission of the participants, data was recorded by audio tape and field notes taken. At the end of the interview brief summaries were written of the interview (Appendix 5). Unfortunately it was not possible for the groups to be co-facilitated. The researcher was obliged to act as facilitator and scribe. It is challenging to adopt both roles concurrently and it is possible that it may have impeded the ability to facilitate the interview. The tapes did ensure an accurate record of the interview. The researcher transcribed these as soon as possible after completion of the interview.

#### **5.10.2. Individual interviews**

Data for the individual interviews had been collected as part of the Health Action Zone cardiac rehabilitation “barriers” study between September 2000 and July 2001. The individual interviews took place in the patient’s home. Interviews lasted between 20 and 40 minutes. A schedule was used to guide the interview. The schedule focused on their experience of a heart attack, how life had been after their heart attack and their access to cardiac rehabilitation services. Attention was paid to developing trust and rapport with the participant through the use of sensitive questioning, being attentive and listening (Legard, Keegan & Ward, 2003; Robson, 2002; Field & Morse, 1985).

As with the group interviews, they were tape-recorded and transcribed and field notes taken. Informed consent was obtained prior to the interview commencing following the provision of written and verbal information (Appendix 6).

Questions about the study were invited. A consent form was completed (Appendix 6). During and immediately following the interviews field notes were taken (Legard, Keegan & Ward, 2003). If patients requested, their partner was present during the interview.

### ***5.10.3. Informal interviews***

The inclusion of informal interviews, the nature of which were incorporated in this study, is unusual. For that reason, this section briefly describes the nature of the informal interviews, considers why they were included and the limitations of this decision.

Following selective coding of the group and individual interview data, the theory of Watchful Insecurity began to take shape. In the final stages of selective coding, a number of theoretical propositions emerged. It became evident that discussion with informed colleagues and others would be useful to help the researcher reflect on the emerging theory. However, it soon became clear that they were helping to clarify and verify the theory. They were therefore incorporated into the study.

The informal interviews took the form of discussions, guided by a memo written prior to the interview. The memos were records of theoretical propositions and thoughts that emerged during the selective coding. The memos were used to build theoretical propositions that would seek to clarify or challenge the theory of Watchful Insecurity. After the interview further memos were written to record aspects of the theory that had been verified and outstanding issues and questions. These were then used to theoretically sample for further informal interviews. The informal interviews were an essential component of the theory verification.

The informal interviews consisted of both opportunistic and prearranged discussions with colleagues and friends. The discussions took place in a variety of locations including the person's home, at work or the researcher's home. Some discussions took place whilst on a climbing trip. Notes were taken during and after the discussions. The reflection on and conceptual examination of these were then integrated into the results through the use of memos and diagrams.

Appendix 9 illustrates how memos were used to ask questions of the theory of Watchful Insecurity, as it had been developed following initial selective coding from the individual and group interviews. The memos were used to build theoretical propositions that would seek to clarify or challenge the theory of Watchful Insecurity.



The memos from the informal interviews were kept as written notes. They were not entered into the electronic database. However, as data, they did provide another form of triangulation. Triangulation, that is the use of different data to help confirm, clarify and refine research findings, is discussed in more detail in the analysis section of this chapter.

The informal interviews provided an invaluable opportunity to expand, challenge and verify the theory of Watchful Insecurity. If there was a limitation, it was that their value and use was not planned in advance. A number of issues arise from this. These are outlined below.

- The consent process was not planned but rather it evolved. All participants were shown how the interviews were used and were happy to have them included in this way. However, a more transparent and written consent process would have been preferable.
- Due to the lack of written consent, it did not seem advisable to use direct quotes from informal interview participants. To be able to use quotes to illustrate findings would have provided additional evidence of the rigour of the theory.

- Because of the ethical issues, and because the decision to include the discussions was retrospective, data from the informal interviews was recorded as field notes and memos. They did not generate transcripts that could have formed another electronic data set, which could have been used for further constant comparison and triangulation. However, the theory had a sufficient degree of resonance with the informal interview participants, to confirm the interpretation of the conceptual and theoretical data from the memos.

The informal interview sample was based very much on convenience. Friends, peers and professional colleagues were asked to take part. If the full use of the informal interviews had been pre-planned, the sample could have been drawn from outside of the researcher's personal and professional circle. However, from this circle it was possible to recruit people sufficient to the task of clarifying and challenging the theory.

More information about how the informal interviews were conducted and the data that was generated is provided in Appendices 9 and 10.

### **5.11. Data analysis**

To describe the analytical processes of grounded theory is a challenge. This is, in part, due to the fact it is impossible to separate data collection activity from analysis activity. Additionally, grounded theory is a conceptual method, making

some of the mental leaps and interpretations difficult to depict in a tangible way. A final challenge is that, as a doctoral study, the conduct of grounded theory was a voyage of discovery for the researcher. There were moments of confusion and enlightenment regarding the nature of grounded theory and how to execute it. In order to describe both the analysis techniques and the learning process experienced by the researcher, grounded theory is explained here under three headings. First, a summary description of some of the key terms and techniques is given. Second an account of the researchers experience of “doing grounded theory” is provided. This identifies moments of discovery regarding the methods and how the grounded theory methodology was translated into analysis action. Finally, a brief reflection of this experience is given, using a number of challenges and risks in conducting grounded theory that have been identified (Fernandez, 2004; Glaser, 2002; Glaser, 1978b).

### **5.11.1. Grounded theory techniques**

Prior to discussing the conduct of grounded theory in this particular study it is necessary to be clear about the use of core terms and techniques used in the methodology. A brief description of the terms as understood by the researcher is now presented.

#### **5.11.1.1. Theoretical sensitivity**

Theoretical sensitivity refers to the ability of the researcher to “*have insight, understand and give meaning to the data, and to detach the relevant from the*

*irrelevant*" (McCann & Clark, 2003b. p8). Having theoretical sensitivity is required to ensure emerging theory is grounded in the data. It will help identify constructs from the data and inform data collection and analysis decisions. Theoretical sensitivity can be acquired from personal, professional experience and knowledge of the field of inquiry. Activity and experience that added to theoretical sensitivity in this study include the conduct of the preliminary "barriers" research, the provisional literature review and clinical experience. The challenge is in being knowledgeable enough to be sensitive and insightful and yet not use prior knowledge to impose concepts on the data.

#### *5.11.1.2. Theoretical sampling*

In the initial stages of a grounded theory study, sampling is guided by what one wants to know about the participants and setting. People will be sampled "purposively" because of some predetermined criteria, for example, age or gender. Later, theoretical sampling takes over. This requires sampling on the basis of emerging data and constructs identified in analysis. Theoretical sampling can involve the selection of participants, aspects of text and areas of questioning. The underlying premise is that selection is driven by the data and the emerging results from different coding techniques (McCann & Clark, 2003a; McCann & Clark, 2003b; Chamberlain, 1999; Strauss & Corbin, 1990). Sampling will cease once theoretical saturation is reached, that is no new insights are emerging from data relating to the theory and its categories (Strauss & Corbin, 1990). Sampling will cease once theoretical saturation is

reached, that is no new insights are emerging from data relating to the theory and its categories (Strauss & Corbin, 1990).

#### *5.11.1.3. Analytical induction*

A key feature of grounded theory, and other forms of qualitative research, is the necessity to move between inductive and deductive thinking. This is the process where:

*“There is a constant interplay between proposing and checking. This back and forth movement is what makes our theory grounded”! (Strauss & Corbin, 1990. p111)*

Inductive / deductive thinking is the core of analytical induction. It is the method of testing and modifying a theory until it is clear that no disconfirming evidence can be found (Murphy et al. 1998). Inductive analysis of data will generate theoretical propositions. Deductive reasoning will use data to prove or disprove such propositions (Snape & Spencer, 2003). In this way coding and categorical propositions and relationships will be proposed at all points of the study. After this:

*“Concepts and relationships arrived at through deductive thinking must be verified over and over again against actual data. Initially they are held*

*as provisional and if not supported they are discarded". (Strauss & Corbin, 1990. p112)*

At the point at which no new propositions and concepts emerge, theoretical saturation has been achieved (Murphy et al. 1998).

Validation of analytical induction is an essential part of demonstrating the rigour and trustworthiness of the theory. Lewis and Ritchie (2003) identify two aspects of this validation each requiring the use of different tools and techniques.:

Internal validation allows the researcher to demonstrate that the theory is grounded in the data and not the researcher's preconceived ideas. It involves the use of constant comparison and negative case analysis. A description of these is given later in this section (5.11.1.6 and 5.11.1.7).

External validation involves the wider testing of the analysis and emerging theory. Techniques employed here include triangulation and member checking (or respondent validation). Triangulation is essentially the use of different methods and perspectives in order to move away from a reliance on a single method. Triangulation can involve the use of more than one method, dataset, researcher or theoretical model (Murphy et al, 1998). The different data generated by triangulation will confirm or improve the validity of a theory by

providing diverse ways of looking at the central phenomenon (Lewis & Ritchie, 2003).

Member checking requires the researcher to take emerging findings or final results back to the research participants. The purpose is to check and test the resonance of the findings with the respondents' experience. Member checking provides a way of validating the interpretation of the data and the meaning of the emergent theory (Lewis & Ritchie, 2003). Within the time and resource restraints of some research, it is acknowledged that member checking can be impractical (Murphy et al. 1998). Member checking will involve testing the findings, in this case a grounded theory, with a group of people with similar experience or characteristics to the participants (Lewis & Ritchie, 2003).

#### 5.11.1.4. Coding

There are three distinct levels or types of coding procedure in grounded theory, open, axial and selective coding. Each stage requires a different level of abstract thinking as the research moves towards theory generation. These are not, however, sequential or conducted in a linear fashion. Different coding techniques are used in different phases as constructs and theories are generated and verified from the data. However, coding also becomes:

*“A cyclical process; shifting from open to axial and then selective coding and, at times simultaneously coding at several levels”*  
(McCann & Clark, 2003c. p37)

Open coding is the initial strategy and requires breaking down the data into codes and conceptual labels that relate to the phenomenon. Axial coding, or theoretical coding links the codes and concepts into categories and sub-categories using constant comparative analysis (see below). This process requires both inductive and deductive thinking as propositions and questions are made regarding the grouping of concepts (McCann & Clark, 2003a; Carpenter, 1994; Strauss & Corbin, 1990). Strauss & Corbin (1990) advocate the use of the “paradigm model” as a structured way of exploring and testing the links and relationships between subcategories and categories in axial coding. This was used towards the end of the axial coding stage to order concepts and test interrelationships (Appendix 7).

The third phase, selective coding, requires the most abstract level of thinking. In this phase a core category is identified and links between this and other categories are tested. The aim here is to move beyond description towards theory. The use of memos and diagrams and developing a “storyline” are used to support the testing of relationships between categories. These help to visualise relationships, establish consistency and support inductive and deductive thinking (McCann & Clark, 2003a). The core category is required to appear frequently in the data, help explain variation, link with other categories, have theoretical implications and emerge from the data. A summary of codes and categories used during the analysis is provided in Appendix 8. This contains lists of codes identified, some of the conceptual categories used during



analysis and examples of notes, diagrams and storylines used to test relationships between categories.

#### *5.11.1.5. Using the literature*

The role and influence of searching and appraising the literature prior to and during the study is well debated in grounded theory. In relation to devising the research question and entering the field of study, Glaser argued that preconceived notions obtained from the literature should not influence the researcher (Glaser, 1992). The study should be driven by the data. In contrast, Strauss considered a preliminary literature review enhanced theoretical sensitivity. Both agreed that a later, and more substantial literature review is required during and after analysis in association with the theory that is emerging.

#### *5.11.1.6. Constant comparison*

A key feature of grounded theory is the constant comparison of concepts to support the development and testing of emergent theory. Coding and theoretical sampling are techniques that facilitate constant comparison. Comparisons are made using "*Incidents, informants or categories*" (Chamberlain, 1999) in order to look for similarities, differences and relationships. Other analytical tools such as memo writing, negative case analysis, questioning, hypothesising and diagram development also support making comparisons and so facilitate analytical induction. Negative case

analysis involves the selection of data that is deviant in some way according to the emerging theoretical position. Examples include cases where features present in most cases are lacking, or coded data that appears to contradict emerging findings (Murphy *et al*, 1998). Data from these cases will be compared with others across the data sets. Negative case analysis may cause coding or classifications to be modified, expanded or abandoned as the theory becomes clarified and refined.

#### 5.11.1.7. *Memos and sorting*

Memos are core to the theorizing and development of codes and propositions during analysis and conduct of constant comparison (Thulesius, 2003). They consist of any notes, diagrams or written records. They help to keep track of emerging ideas and refine emerging theoretical ideas.

Sorting occurs when the data that has been “fractured” by breaking it down conceptually into codes and memos are pulled together to form categories and theories. Whilst it is done conceptually, often sorting involves “*shuffling the pile of memos into stacks, each stack representing a concept like a category*” (Thulesius, 2003. p30). Writing up the analysis and thinking conducted during sorting prompts new ideas and, in turn, additional memos.

#### **5.11.1.8. Qualitative data software**

In this study “QSR *nvivo*”, the qualitative data analysis software programme was also used to support the analysis in this stage of the study. The hierarchical facility of “tree” of nodes or codes was very useful in the initial open coding stage. As categories were collapsed, merged and condensed, codes could be removed, moved or merged using this feature. The search facility was used to assist with constant comparison and negative case analysis. Specific sections of text could be recalled for analysis using this tool and the coding tree altered accordingly.

#### **5.11.2. Doing grounded theory**

The techniques described above were all used in order to undertake the study presented here. However, there were certain points when key issues were encountered and decisions made by the researcher that influenced how techniques were used and applied. These were sometimes moments of “discovery” for the researcher, as someone new to grounded theory. For this reason they are described below.

##### **5.11.2.1. Undertaking analytical induction**

The process of analytical induction is complex. It involves various stages and forms of coding (open, axial and selective). In the study presented here it also involved three data sets (group, individual and informal interviews). In addition, a number of different techniques were used to undertake inductive and

deductive analysis. These were constant comparison of data by interview and by code, memo writing and negative case analysis.

The analysis process was fairly fluid and organic as propositions were raised, confirmed or disproved. The researcher moved between coding stages towards the more conceptual and abstract selective coding. At this point the core category of Watchful Insecurity was identified. As relationships between categories were explored and their link to the core category confirmed or refuted, the theory started to take shape. Memos provided a mechanism to both support analytical induction, but also to illustrate how it was done.

Appendices 7 to 10 provide examples of how memos and diagrams were used.

Appendix 9 illustrates the process of analytical induction as undertaken in this study. This includes a description and depiction of constant comparison, including examples of how negative or deviant cases were used to clarify and modify the theory.

Analytical induction, and the theoretical sampling it demands, is required to continue until theoretical saturation of categories has been reached (Strauss & Corbin, 1990). Using the guidance of Strauss & Corbin (1990) analysis and sampling was stopped in this study when:

- No new issues were emerging from the analysis regarding the categories and concepts that shaped the components and characteristics of the theory of Watchful Insecurity.
- The categories became clear, coherent and dense. The conceptual analysis and theory was sufficient to explain variation and similarities in participants' experience. Nothing seemed to be gained from further sampling and analysis.
- Through axial and selective coding, relationships between the categories are well established and clear.
- The informal interviews formed the last stage of theoretical sampling. After this the data were again checked using constant comparison and relationships between the core category and others was tested. At this point it was decided that new material would not add to the development of the theory (Strauss & Corbin, 1990).

There was an anxiety experienced by the researcher about when to decide that saturation has been reached. There is much more that can be learnt and explored about Watchful Insecurity. However, such inquiry must be the focus of future research. The aim of this study was to develop the initial theory that could inform further research. It was therefore recognised that, for the purposes of developing a substantive grounded theory, saturation had been reached.

#### 5.11.2.2. *Validating analytical induction*

It is claimed that triangulation and member checking both contribute to the validation of the analytical induction in a study and the grounded theory it produces (Murphy *et al*, 1998). How each of these techniques is employed in this study will now be briefly explained. The use and relative advantages and limitations of each will be considered.

Data triangulation was the method of triangulation used in this study. This involves the inclusion of data from different participants, with different viewpoints and experiences (Tindall, 1994). The group, individual and informal interview data sets provided variation in participants. Variations related to different perspectives (patient, carer, professional), time elapsed since the heart attack and experience of health services and support.

Data triangulation allowed the integration of the diverse data that emerged from the different perspectives. As the theory took shape and the researcher moved through the coding stages, it was possible through constant comparison to challenge, test and expand the theory. For example, Watchful Insecurity emerged as an enduring state. It was possible to propose and support that Watchful Insecurity applied to people at different time points from their heart attack. If the sample had been composed exclusively of people in the early stages after the heart attack, this proposition would have been more uncertain.

Triangulation is said to add rigour, breadth and depth to research (Murphy *et al.* 1998). However, it is important to acknowledge the limitations of triangulation in this study. It does help to confirm and corroborate emerging findings but does not make the results generalizable. The resonance the theory has with other literature and theory (discussed in Chapter 9) suggests that the theory is probably transferable to other populations. The resonance the theory has with the informal interview participants, with their breadth of personal and professional experience, also support claims of transferability of the theory. However, further research adopting more quantitative methods is required before confident claims of generalizability can be made. This suggests that triangulation of methods, not just data, would have provided an opportunity to test the external validity of the theory.

Member checking was also used to validate the theory. Some consider it the most crucial in demonstrating the trustworthiness of the results of a qualitative study (Lincoln & Guba, 1985). In this study, member checking was conducted at the end of the study. However, because of the practical constraints, it was not possible to return to the original participants to discuss the theory formally or in any depth. A pragmatic approach was adopted regarding member checking that took note of the recommendation of Murphy *et al.* (1998). That is, if it is not possible to go back to the exact participants, respondent validation should be pursued with people who have similar experiences and background.

The theory was discussed informally with some people who had had a heart attack from the South Yorkshire Coalfields Health Action Zone area. This was in individual discussions and at workshops. Individual discussions were opportunistic and were held with two of the individual interview participants. The workshops were run by a charity and were held to provide training to members of cardiac support groups. I was able to hold a guided discussion to test the credibility of the theory. Both the discussion and workshop took the form of explaining components of the theory of Watchful Insecurity e.g. the issue of difference, loss, change, as well as triggers, types, trajectories and tools of Watchful Insecurity. People were asked if these made sense and mirrored their experiences. No formal record was kept of the discussions, but the theory clearly resonated with them.

The study results have also been presented at various professional and academic conferences, local, national and international. Audiences have included nurses, cardiac rehabilitation staff, researchers and academics, health service managers, public health specialists and those developing and implementing health policy. At all of these conferences members of the audience have approached the researcher afterwards. They all commented on how well the theory matched their experience as patients or carers after a heart attack or after heart surgery.



The member checking undertaken did have limitations. It was not possible to include a formal member checking stage in the study or return to the original participants. Ideally, this would have involved holding further individual or group interviews. It is recognised that resource constraints often require a trade-off between various methods of validation (Murphy *et al.* 1998). In this study a combination of data triangulation and member checking was less than ideal. However, the above strategies went some way to validating the credibility of the theory.

#### *5.11.2.3. Prior knowledge and rigour*

An ongoing preoccupation for the researcher was the awareness of prior knowledge and experience and the fear that this would lend itself to forcing the data to some preconceived theoretical position. This knowledge was from years of working with people who had a heart attack, from the findings of the initial “barriers” study and finally, from the knowledge of related literature (Chapter 2 and 3). The constant comparison, theoretical sampling and other techniques outlined in Chapter 4 helped to check the rigour of the analysis and ensure the data analysis was not forced because of previous research or clinical experience.

Regarding the literature review, in grounded theory Glaser (1992) advises against examining the literature prior to analysis. This is due to a risk that preconceptions will direct analysis or desensitise the researcher to the data

(Thulesius, 2003). A pragmatic approach was adopted here; that was to undertake a limited preliminary literature review to enhance theoretical sensitivity and at the end of the study conduct a review to verify and test the emerging theory (McCann & Clark 2003a; Strauss & Corbin 1990). As the analysis in this study continued, a concern that the review would inappropriately introduce preconceived ideas diminished. When the theory of Watchful Insecurity evolved, it took the researcher to a place that had not been anticipated. A body of literature not previously known or considered then became relevant, in some cases more relevant than the *a priori* knowledge. Examples of this literature include that related to survivorship theory (Little *et al*, 2002; Hassey Dow *et al*, 1999) and the theory of "Reconceptualized Uncertainty in Illness" (Bailey *et al*, 2004; Mishel *et al*, 1984). This literature was incorporated into the analysis at the sorting and selective coding stages and used to test the theory as it emerged. This discovery reassured the researcher regarding the risk to rigour of prior knowledge.

#### *5.11.2.4. Focusing on the phenomenon not the person*

In previous studies, the researcher had used other qualitative analysis techniques, such as Framework Analysis (Ritchie, Spencer & O'Connor, 2003; Ritchie & Spencer, 1994). There the focus of analysis was the person who was sampled and recruited. In grounded theory the unit of analysis is the incident or phenomenon, in this case, heart attack recovery. Initially, this required a

conscious effort on the part of the researcher to do this. The instinct was to think about the person.

In the process of the study, the researcher realised that, whilst the person was important to consider in data collection, during analysis the orientation of thought differed. Models, memos and diagrams helped in this. An example was the use of the “paradigm model” (Appendix 7). This was used towards the end of axial coding to start to develop links between codes and categories, but before the core category was identified. Codes related to sub-categories, for example “taking control, “attribution” and “redefining” were clustered together. In turn these sub-categories were allocated to the category of “recovery mechanisms”. How these links operated was explored and the theme of “trusting the body” began to emerge as a required consequence of recovery. The results of the axial coding, focusing as it did on the phenomenon not the person, provided an excellent platform to conduct the final stage of the analysis, selective coding.

#### *5.11.2.5. Thinking conceptually*

An additional struggle for the researcher in the early stages of analysis was the requirement from the exponents of grounded theory to think conceptually and to work at increasing levels of abstraction as analysis proceeded (McCann & Clark, 2003a; Charmaz, 2003; Carpenter, 1994; Strauss & Corbin, 1990, Glaser & Strauss, 1967). At the beginning of the study, the directive to work at

different levels of abstraction seemed in itself too abstract to achieve. This confusion was eventually overcome by the experience of actually doing the analysis that resulted in a series of discoveries. The first realization was the importance of thinking conceptually, not descriptively. At one point the category “trusting the body” appeared to be the core category and a story line developed to explore this (Appendix 8). However, through the use of constant comparison, memos and sorting, it became clear that this described people’s experience, but was conceptually superficial. It was at this point that the limitations of following the guidance of Strauss & Corbin (1990) became apparent.

This text has provided excellent instruction in the techniques of grounded theory. However, in order to conduct the conceptual work required for selective coding and theory generation, personal advice and mentoring was required. This situation is a classic illustration of “*minus-mentoring*”, which occurs when learning about and conducting grounded theory is done from books, not with the mentoring of an experienced researcher (Fernandez, 2004; Glaser 1999). Help was sought from an experienced grounded theory researcher (see Acknowledgements). He prompted the conceptual analysis required, and “challenged the robustness of the emerging categories/themes” (Cutcliffe & McKenna, 1999, p377). The researcher was steered away from description and considering the theoretical properties and dimensions of recovery and the core category of Watchful Insecurity.

One criticism of grounded theory is that this process “fractures” (Charmaz, 2003) or “shatters” (Conrad, 1990) the data, prevents the complete participant experience being portrayed. It becomes “disembodied” from the context and individual experience (Conrad, 1990). What the researcher realised through doing this analysis was that in order to generate a sound and grounded theory, it is necessary to work conceptually with themes, codes and categories and not be distracted by the subject’s stories and the volume of the whole data set (Charmaz 2003). What is essential, however, is to return to the data and use of theoretical sampling, constant comparison and negative case analysis to test out the emerging theoretical propositions from the abstracted analysis. An example of this was the emerging proposition that Watchful Insecurity was an enduring state. Data was selected from codes and participants in order to test this proposition, such as data relating to declarations that the heart attack was in some way a positive experience.

The demand upon the grounded theory researcher to conduct abstracted conceptual analysis was by far the most confusing and difficult to master. It was only with reflection, supervision and prompting by a mentor, and actually doing the analysis that this was achieved.

#### 5.11.2.8. *Sorting and talking*

Additional discoveries made by the researcher as a result of actually doing grounded theory were the importance of sorting, talking and the realization that *“all is data”* (Thulesius, 2003; Glaser, 1992).

To demonstrate “trustworthiness” of the analysis and illustrate decisions made during the conceptual analysis journey, an audit trail is recommended (Lincoln & Guba, 1999; Cutcliffe & Mckenna, 1999). However, it is still difficult to show how intuitive leaps and hunches are made, and sometimes difficult for the researcher to remember over the time span of a project. In the final stages of the analysis, sorting helped with this process. This took the form of organising memos into piles relating to categories or to coding stage. Analytical decisions were checked by constant comparison of the memos. For example, at the point that Watchful Insecurity was identified as the core category, the sub-categories and codes related to Watchful Insecurity were checked against the earlier (open) coding lists and memos. Any that were omitted or did not seem to fit were used to theoretically sample sections of data to check the omission was justified and to test the integrity of the core category.

The importance of talking and testing the theory also became apparent to the researcher in the final stages of the study. This was an unanticipated component of the analysis and explains why the informal interviews were included as part of the sample. The informal interviews were particularly useful

in teasing out the aspects of the theory relating to triggers of Watchful Insecurity and the trajectories of Watchful Insecurity. This allowed the exploration of why Watchful Insecurity is core to heart attack recovery and the way it may differ in nature and course to recovery from other sudden illness or trauma.

The informal interviews, in addition to the literature included in the later stages of the analysis illustrated how in grounded theory *“all is data”*. Thulesius (2003) claims that this other data, additional to the primary interview data source, is necessary to help in generating concepts to contribute to the final theory. In addition, issues raised from this data can be used by a researcher to interview themselves, as part of the reflexive process. In this study, the extent of the prior knowledge held by the researcher made this particularly important.

Despite the crucial role played by talking and the informal interviews it also became clear that it is important to know when to stop talking. This is guidance offered by Thulesius (2003). He claims that, if not careful, talking about the theory can drain the researcher of the energy and motivation to complete theory generation. Two strategies were adopted on the basis of this advice. First, a clear justification was identified for selecting people to talk about the theory (Table 8). Second, following consultation with the supervisor and grounded theory mentor the decision was made to stop talking about the theory and write it up.

### **5.11.3. A reflexive account**

The section above describes some of the decisions and moments of revelation experienced by the researcher as part of doing grounded theory. The section that follows discusses key points to emerge from the reflexive thinking regarding the methods, in particular the analysis. As depicted above the researcher learnt and developed in terms of skills and knowledge in grounded theory during the conduct of the study. Therefore, this section also highlights some limitations of the study. Some of the ways the study would have been conducted in another way, if repeated, are considered.

#### *5.11.3.1. Tolerating confusion and regression*

As indicated above there were key points of confusion experienced, this was particularly with regard to the impact of prior knowledge and experience, and thinking conceptually. Confusion is identified as an integral part of grounded theory. Being able to tolerate it is seen to be an essential requirement of the researcher (Fernandez, 2004, Glaser, 1999). However, due to inexperience, the anxiety experienced in relation to these at times halted or obstructed ongoing analysis.

What can be learnt then from the experience in terms of confusion experienced during analysis? First, the level of worry was unwarranted. The important tenet is that the emerging results and theoretical propositions should relate to and be grounded in the data. With the experience of this study, the researcher would



feel more confident of the strength of constant comparison, theoretical sampling, memos and sorting in supporting rigour.

Second, whilst confident that the theory can be substantiated by the data, there are factors that would strengthen the study if repeated. Spreading the interviews out and allowing more time for analysis in-between would certainly have facilitated the movement between inductive and deductive reasoning and theory generation. As it was, the analysis felt “lop-sided” or weighted towards the period at the end of and after the interviewing period.

Glaser (1999) maintains that if you can't tolerate confusion, and the regression that results from it, grounded theory is not suited to you. Whilst confusion and regression are challenging to experience, in the case of this study it is possible to propose that the quality of the study was improved because of these feelings. They prompted the researcher to be more reflexive and conscientious by documenting in memos the conceptual leaps made and concerns experienced.

#### *5.11.3.2. Being able to conceptualise not describe*

The development of skills and experience in conceptual analysis has been a crucial outcome of this study for the researcher. Confidence in deriving theory from data and being creative in handling and interpreting data has grown as a result of the research experience. However, from the experience of this study, in the future a grounded theory mentor would be identified at the beginning of

the research. The researcher now has a better understanding of how to use this expertise to contribute to the quality of the analysis. The value of a mentor in helping with times of isolation and conceptual challenge is now recognised.

In addition, the process of conceptualising data should have begun earlier. Much of the initial open and axial coding was descriptive in nature. It was only after experiencing some regression and accessing a grounded theory mentor that the conceptual and abstracted analysis became substantial and productive. Due to the amount of constant comparison and verification that took place during selective coding, there is confidence in the quality and “grounded” nature of the theory. However, confusion would have been avoided, and the process smoother if conceptualisation had commenced earlier.

#### *5.11.3.3. Data collection*

Critique of the data collection method is sometimes overlooked when assessing grounded theory studies. The focus is usually on analysis. With regard to this study, the researcher identified that not forcing data during collection is just as important as not forcing the analysis of the data. Again, there was a risk that the prior research and clinical experience of the researcher may have led the questioning rather than the research question and purpose. To ensure this did not happen, tapes and transcripts were examined to identify examples of where the interviewer may have led the questioning in an inappropriate direction. On

reflection, having more time between the interviews to consider this and the implications for future interviews would have helped this process.

A vital consideration regarding the ethical and rigorous conduct of interviews is the way the participants view the researcher in terms of role, responsibility, power and expectations (Sinding & Aronson, 2003). In order to prevent role conflict, the researcher made it clear that, whilst a nurse by background, there was no direct therapeutic purpose or benefit to the participant. Some people do find it interesting or even helpful to take part in interviews but this cannot be ensured. It was, therefore important that participants knew that the interviewer was acting as a researcher not a nurse. This was emphasised in the information given during consent. A way of avoiding this conflict would have been not to mention the researchers nursing background. However, this often made people feel at ease. They knew the interviewer knew the terms used and had experience of talking to people who had been through similar experience. Overall the nurse as researcher role was seen to enhance data collection.

Constant vigilance was required however to avoid slipping into a researcher as nurse situation. There was a chance that a clinical issue or complaint would emerge as part of the interview that the participant would be advised to inform their doctor or nurse about. The clinical background of the interviewer made detection of this more likely. The fact this situation may occur was pre-empted and addressed in the information sheets and consent form.

The potential vulnerability of the interviewee also needs to be considered. Following reflection, the risk in this study came from two potential situations; that people would feel obliged to take part or have unrealistic expectations of the study. In order to address the first issue, the voluntary nature of participation and right to withdraw at any time was emphasised in the recruitment and consenting processes.

An example of the latter situation is that people may think, if the results are published and fed back to health services, that services will definitely improve. That this could occur became obvious in the preliminary discussions of the first group interview. One of the participants had been a member of an NHS planning group for cardiac rehabilitation service development. He clearly felt frustrated about the lack of development and hoped the research would help. It became necessary to clarify with him the role of this research and its limitations in influencing service improvement. The purpose of the research was therefore emphasised in the verbal information prior to gaining informed consent. In retrospect, the issue of raising unrealistic expectations should have been pre-empted and dealt with during the informed consent procedure.

## **5.12. Conclusion**

Data collection methods were sufficient to provide the data necessary to generate the grounded theory of Watchful Insecurity. Analysis was conducted

in line with the key characteristics of grounded theory. Constant comparison, theoretical sampling, memos, negative case analysis, and use of literature comprised the essential toolbox of analytical methods. The way and level at which these were used varied subtly according to the stage of coding.

Fundamentally however, the analysis process contained a continuous round of developing propositions, constantly comparing data selected using theoretical sampling, further testing by selecting data that does not seem to fit propositions (negative case analysis), comparing this to evidence from the literature (theoretical sensitivity) and continuing this process, interwoven with data collection, until theoretical saturation has been reached.

Whilst there were limitations in the member checking, the methods used proved rigorous and the practical processes and techniques were adequate tools for the purpose of the study. The results from this study are presented in the following chapters.

## **Chapter 6. The experience of having a heart attack.**

*"I think the worst thing anyone can have is a heart attack....your heart somehow I don't know .... your kidneys can pack in and they can help you. But your heart packs in and you're dead. You see my dad died in front of me with a heart attack" (Individual interview 4)*

### **6.1. Introduction**

The results of this study are presented in three chapters (Diagram 4). The first, Chapter Six, will depict the heart attack experience, as described by the participants. The data presented here relates primarily to the time the heart attack occurred. Some reference and links are made to the period following the attack. This data creates a setting for the recovery experience as represented by the study participants. The purpose of this chapter is to describe the landscape within which recovery takes place. It illustrates how sudden and frightening a heart attack can be. The nature of the heart attack experience therefore creates certain challenges for recovery.

This study was successful in generating a grounded theory to explain the meaning of heart attack recovery from the perspective of those contributing to the study. In the interests of clarity, Chapter Seven briefly describes the essence of this grounded theory, Watchful Insecurity. The purpose of this chapter is to provide a setting for the main body of the results.

## Diagram 4. Presentation of the study results

### 1. Heart attack experience (*Chapter 6*):

*A depiction of the experience and landscape within which recovery occurs.*

- ❖ **The nature of the experience**
  - ◆ **Predictability**
  - ◆ **Physical distress**
  - ◆ **Understanding**
- ❖ **Emotional response**
  - ◆ **Fear**
  - ◆ **Vulnerability**



### 2. The Theory of Watchful Insecurity (*Chapter 7*):

*An overview of the theory to emerge from this study, which explains the meaning of heart attack recovery*



### 3. Elucidating the theory of Watchful Insecurity (*Chapter 8*)

*A presentation of the results what depicts characteristics and components of the theory of Watchful Insecurity*

- ❖ **Difference (being a different person)**
- ❖ **The experience of Watchful Insecurity**
- ❖ **The characteristics of Watchful Insecurity**
- ❖ **The components of Watchful Insecurity**
  - ◆ **Triggers of Watchful Insecurity**
  - ◆ **Types of Watchful Insecurity**
  - ◆ **Trajectories of Watchful Insecurity**
  - ◆ **Tools to manage Watchful Insecurity**

The following chapter (Chapter Eight) forms the substantial component of the presentation of the results. The purpose of Chapter Eight is to expand upon and explicate the theory and the phenomenon in question, heart attack recovery. The components of the results chapters, and the order of presentation, are presented in Diagram four.

## **6.2. The heart attack experience**

From the study data the heart attack experience appears as an overwhelming, disorientating and shocking event. This complex experience, as described by participants, can be classified into two categories, the *nature* of and the *emotional response* to the heart attack (Table 8). Within each category are a number of properties that help to explain the experience. The dimensions of the property depict the variation of experience between those interviewed. The dimensions exist as a continuum. For example, the nature of the heart attack is experienced as sudden and unexpected by most. On the other end of the spectrum others predicted it would happen one day.

### **6.2.1. *The nature of the heart attack***

There were differences in the experience representations of the participants. These variations related to three properties, predictability, physical distress and understanding. The degree to which the heart attack was predictable and how physically distressing it was, were important characteristics of the heart attack



experience. In turn, these two aspects of the event seemed to dictate how understandable the event was.

**Table 8. Heart attack experience**

<b>Categories</b>	<b>Properties (<i>dimensions</i>)</b>
<b>The <i>nature</i> of the experience</b>	<ul style="list-style-type: none"> <li>• Predictability  <i>"Out of the blue" → "knew it was coming"</i></li> <li>• Physical Distress  <i>"I felt terrible" → "no pain"</i></li> <li>• Understanding  <i>"Thought it was something else" → "I'm having a heart attack"</i></li> </ul>
<b><i>Emotional response</i> to the experience</b>	<ul style="list-style-type: none"> <li>• Fear</li> <li>• Vulnerability  <i>High → Low</i></li> </ul>

**6.2.1.1. Predictability**

The prevailing experience was that the heart attack came from "out of the blue".

For most there was no warning in terms of previous symptoms

*"It was sudden. Out of the blue. Totally out of the blue. I mean we'd been on holiday the week before, we'd been in Spain the week before and I'd been playing squash .... and I'd been hill walking .... I had no indication whatsoever". (Individual interview 9)*

*"I was just out shopping and I just went, there were no warning, it just went BANG and that were it". (Group participant P2.2)*

In addition, the unpredictability of the experience was compounded by the fact they had not seen themselves at risk of a heart attack. No aspect of their lifestyle or their medical condition had forewarned them.

*"No, I've never been bad. I've never been in hospital. He's never been a badly bloke at all [Wife]. No". (Individual interview 3).*

*"So I could have understood it if I'd have been overweight and smoked a lot and drank a lot. Then you'd have said yeah, it's expected sort of thing. But, you know, it was totally unexpected". (Individual interview 9)*

In the case of only one man the heart attack was not entirely unpredicted. Due to his family history he did see himself at risk of a heart attack but he had still not been prepared for a heart attack to happen when it did. The actual event had still been unexpected.

*"Definitely out of the blue. Waiting to happen, but out of the blue, if you know what I mean. Both my parents have had like open heart surgery and I had a brother that died at 37 with heart trouble, so it was like a disaster waiting to happen". (Individual interview 2).*

The sudden and unpredictable nature of the heart attack emerged as an integral component of the heart attack experience. It contributed to the emotional response. In addition, it placed people in a testing position as it meant there was no opportunity to prepare oneself for the impact it would have

on various aspects of their life and health. Because people had not been expecting the heart attack it was likely that the challenges of recovery would be amplified.

#### 6.2.1.2. *Physical Distress*

Those interviewed reported a wide variety of physical symptoms during the heart attack. For the majority, symptoms were severe and they were in great pain.

*“I got this pain, which I knew I’d never had in my life before, you know? A very distinctive pain. I’d sort of gone to the back door to get some fresh air. I’d laid on the settee. All this within like two minutes, you know? You couldn’t settle”. (Individual interview 2)*

*“I felt like I’d got a steam roller on me chest, I couldn’t move” (Group participant P4.3)*

Symptoms such as dizziness and nausea often accompanied the pain and added to the discomfort and associated alarm.

*“I bent down to pick up my coat and felt dizzy. I went to sit down and then the whole room started to spin and all I wanted to do was to go to bed... As soon as I got into bed I thought, “oh Lord, I want to be sick”, then I realised that I had the pain spreading”. (Individual interview 10)*

The severity of the symptoms was difficult to handle at the time and seemed to contribute to the emotional response to the heart attack. In addition, the

extreme pain contributed to a legacy of anxiety about having another heart attack.

*“You get a pain in your chest and you just lay there and think, “Is it going to start again?” (Individual interview 1)*

For a couple of participants the symptoms were mild or not as severe as they expected from a heart attack. This mismatch between expectation and heart attack experience had an impact on their ability to understand what happened to them. It also made people preoccupied about the threat of another heart attack. This appeared to be because they were not confident they would recognise the symptoms.

*“I just couldn’t believe that I’d had this heart attack. You know? And you get, you know, that you think, “Well, I didn’t have no pain” and it’s like every ... if you get a pain here or you get a pain in your arm, you start thinking you’re going to have another! Even though you didn’t suffer them things when it happens”. (Individual interview 4)*

The nature or absence of symptoms during the heart attack emerged as a recurrent theme in people’s depiction of the heart attack. It influenced their attitude towards the subsequent recovery by contributing to a feeling of vulnerability and uncertainty.

### 6.2.1.3. *Understanding*

At the hub of the heart attack experience was the perception of what people thought was going on at the time of the event. It was less common for people to interpret the symptoms correctly. Only two participants from the individual interviews recognised the symptoms for what they were.

*“I realised what it was. I thought, you know, it was too much a pain for anything else”* (Individual interview 8).

*“I just knew what it was so I shouted upstairs to my wife, “Get me an ambulance. I’m having a heart attack!”* (Individual interview 2)

All other participants initially interpreted the symptoms they were having incorrectly and explained them away as something other than a heart attack. Participants had adopted all manner of ailments as explanations in order to make sense of what was happening to them.

*“To be honest with you, I didn’t know I’d had an heart attack..... I were beginning to think it were pneumonia ‘cos I’d had pneumonia before when I were ill before. No. It never entered me head”.* (Individual interview 4)

*“I never gave it a thought it was a heart attack. It’s awfully like indigestion. A cramp type of thing.”* (Individual interview 10)

*“I thought it started like feeling like a bit of indigestion, so I started off having two Rennies, but then it just increased in intensity within a very few minutes”.* (Individual interview 8)

Whether or not people recognised and understood the symptoms correctly, the experience had a profound effect. If people recognised they were having a heart attack they reported associated fear. Others reported fear because they didn't know what was happening. Confusion and bewilderment were experienced because they didn't understand what was happening. This confusion was compounded when lay remedies, such as taking "Rennies", did not work. The bewilderment and confusion surrounding the event is epitomised by one participant who said "*I was physically and mentally lost*" (Group participant P1.1)

### **6.2.2. Emotional response to the heart attack**

As indicated by the previous quote the heart attack experience had a strong emotional component. The emotional response to a heart attack at the time of its occurrence was depicted by those interviewed as complex, intense and disorientating. Again, people differed in the range, level and combination of responses, but the key components were fear, associated with vulnerability and confusion. These are not discretely experienced but are interrelated to one another as well as to the properties related to the nature of the heart attack experience.

#### **6.2.2.1. Fear and vulnerability**

Fear was a recurring theme throughout the data. People did talk about the fear they felt at the time of the heart attack but did not always expand upon this.

Instead they often moved on to discuss fear related to recovery. However, fear appeared as a fundamental experience rooted in that felt at the time of the heart attack.

*"Ain't it silly? I were scared.... I were afraid somehow".*  
(Individual interview 4)

*"Frightened is the right word. Frightened".* (Individual interview 6)

This emotion is understandable when one considers the nature of the heart attack experience, that is, it is sudden, painful and often people do not understand what is happening to them at the time.

Associated with the fear was a feeling of vulnerability that characterised the heart attack experience.

*"I felt incredibly vulnerable! Really did! Yeah. Definitely. Without a shadow of a doubt".* (Individual interview 8)

All the participants were profoundly affected by the heart attack. This was clearly due, in part, to the nature of and emotional response to the actual experience itself. Issues of fear and vulnerability echo throughout peoples stories of recovery in different levels of intensity. The suddenness of the event and the degree of symptoms also made an impact. An illustration of how the heart attack experience reverberates through their account of recovery is illustrated by Case study 1 (Box 8).

## **Box 8. Case study 1.**

**Group participant P2.2 (Pseudonym = Madge)**

### **Background**

Madge was a 61 year old woman who had had a heart attack 3 years previously. She had experienced problems with an arrhythmia (an irregular heart beat) following this. She was married. Her husband had had a heart attack 25 years previously.

### **Heart attack experience**

Madge had a silent heart attack, one that occurs without classic symptoms. She was admitted to hospital as a result of the subsequent arrhythmia. The absence of pain was disorientating. The sudden and unpredictable nature of the heart attack was distressing. Although she was told she had had a heart attack, she had difficulty understanding and believing her diagnosis because of the nature of the experience itself.

### **Recovery**

As with the other members of the group, Madge felt that she was not the same person that she had been before the heart attack. She said she was now mentally stronger and calmer, with a better sense of priority.

*"You've got to take each day and enjoy it".*

*"I just feel as if I'm a much stronger person, but I mean I was never weak, but now, I feel better....I feel much stronger in myself".*

However, this was only after years of living with fear and uncertainty after the heart attack.

*"I think it's mild depression, 'cos I just wanted to stop in bed. 'cos I felt safe in there".*

The characteristics of her heart attack experience influenced her recovery. The fact her heart attack was absent of symptoms and occurred without warning meant she was hyper-vigilant afterwards. During this time she had been frightened to do anything physically, even walk to the bus stop to get the bus. Her sleep was also disrupted due to fear.

*"There is a fear factor though, the first time you go away from home, you think, I can't do it".*

Madge had overcome this with determined action for example by seeking information and understanding, setting herself realistic goals and redefining the limits of her physical activity.

*"Before I was ill ....I felt as if I had to be dashing about all day long, digging this and cleaning. I don't now. I do what I have to do, if I enjoy doing it, and I just don't force myself the way I used to".*



Case Study 1 (Box 8) illustrates the picture of the heart attack experience, and its categories and properties, as indicated by the study data. This picture forms a backdrop against which to explore the meaning of recovery.

“Watchful insecurity” is the theory that emerges from the analysis of this study data. The theory of Watchful Insecurity explains the meaning of heart attack recovery. In the following chapter (Chapter 7) the theory of Watchful Insecurity will be briefly described. The results will then be presented in the form of illustrative quotes in order to construct, explain and substantiate the theory (Chapter 8).

## **Chapter 7. Watchful Insecurity: a grounded theory to explain the meaning of recovery after a heart attack**

*“It’s at the back of your mind all the time. When you go out, are you going to come back home again?.... I mean I think if I’m going to lift that up I’m going to like have another heart attack or something like that” (Group interview P3.1)*

### **7.1. Introduction**

This research study generated a grounded theory to explain the experience and meaning of heart attack recovery. The theory that has been developed is that of Watchful Insecurity. The theory provides a unique perspective with which to consider the phenomenon of recovery. The purpose of this chapter is to provide a brief description of the theory of Watchful Insecurity in order to provide the setting for the main body of the results. Having provided a short overview of the theory in this chapter, the following chapter will expand on this and present the substantial component of the results in Chapter eight. The results of the study will be presented in alignment with the categories, concepts and components of the theory of Watchful Insecurity (Diagram 4).

### **7.2. Watchful Insecurity as a core concept**

#### **7.2.1. Watchful Insecurity**

Before going on to describe the key theoretical proposition and the characteristics and components of Watchful Insecurity, the nature of Watchful Insecurity as a concept is considered.

The first obvious conceptual characteristic of Watchful Insecurity is that it is dual in nature. Watchful Insecurity comprises both “watchfulness” and “insecurity”. What these two concepts mean in terms of dictionary definitions and, more importantly, the data from this study will now be briefly explored

### **7.2.2. Watchfulness**

When examining the concept of “watchfulness”, it is seen to embody two concepts apposite to the data. These are the concepts of vigilance and cautiousness. Vigilance is a preoccupied state that would encompass the awareness of being different. Vigilance implies a condition of being watchful, protective, careful and overly attentive of your body to the extent that it would restrict what you do. It implies a state of wakefulness, that is, not being at peace or rest so that you are constantly alert or in readiness for another heart attack. As a result there is constant surveillance of body and self. The metaphor of “looking over your shoulder” again emerges. After a heart attack people describe looking backwards in their life to the reference point that is their heart attack. Their ability to look forwards is impaired by the scrutiny of the body and the related fear of another heart attack.

Cautiousness denotes an experience of being wary and heedful as a result of an event such as a heart attack and of the related change and difference.

When a person feels cautious and precarious, care is taken due to doubt. An

example here is doubt about the safety of an activity and because of its likelihood to induce another heart attack. This links to key questions that were asked by the participants regarding their recovery. The main examples of these are “Ought I to” and “Am I allowed”? People who are cautious are tentative, and avoid taking risks in life, about their health and more generally. Being on guard, knowing when to stop, playing safe, being “once bitten / twice shy” are all statements associated with cautiousness.

### **7.2.3. *Insecurity***

Insecurity is a state where people feel perilous. Insecurity implies a lack of safety, feeling unprotected and defenceless. Vulnerability and susceptibility are components of insecurity. In this case insecurity describes the feeling that, having experienced one heart attack, one is undermined by an awareness of susceptibility to another. Insecurity embodies the concept of precariousness and the lack of control and confidence participants report.

From the data presented below, watchfulness and insecurity are identified as concepts that universally apply to the heart attack experience. It is therefore possible to theorize that at different times of recovery, different people in different circumstances will be more or less watchful, or more or less insecure. In addition, Watchful Insecurity emerges as an enduring state and one that is irrevocable. A heart attack, once experienced, can't be taken away. Similarly, once Watchful Insecurity has been felt, it is impossible to go back to being the

person you were before. The same sense of safety, confidence and control experienced before the heart attack cannot be recaptured. Recovery therefore involves developing a new and different sense of safety, confidence and control that acknowledges the person you once were, are now and will be in the future. Heart attack recovery is therefore exemplified by the notion of learning to manage and live with Watchful Insecurity

This conceptual consideration of watchfulness and insecurity, in combination with the data presented so far, demonstrates that Watchful Insecurity is a useful core concept around which to build a theory to explain the meaning of recovery after a heart attack.

### **7.3. The theory of Watchful Insecurity**

An overview of the theory of Watchful Insecurity is now presented. This synopsis describes the essence of the grounded theory of Watchful Insecurity. In this description it will become clear how the concepts of difference, change and loss apply to recovery after a heart attack.

#### **7.3.1. *Theory description***

The grounded theory developed in this study identifies “Watchful Insecurity” as a core category to describe the state that dominates the process of recovery after a heart attack.

Many grounded theories describe basic social processes built around theoretical codes. The codes are clustered conceptually into categories from which one core category emerges. This core category is the one that all other categories have a theoretical link to.

Grounded theories are mainly developed to explain social processes. In the case of the theory presented here, recovery is the process but the theory and the core category, is Watchful Insecurity. Watchful Insecurity is conceptualised as a state, not a process. As a theory to explain the meaning of recovery after a heart attack, Watchful Insecurity describes a state or way of being that prevails after the cardiac event. It is a concept that is central to the process of recovery. The process of recovery therefore requires someone to learn to live with and manage Watchful Insecurity. According to this theory, recovery is not a process of “getting over” Watchful Insecurity, but rather learning to manage it.

The theoretical description provided in Box 9, comprises the proposition that is central to this thesis.

## **Box 9. The theory of Watchful Insecurity**

*Watchful Insecurity describes a state where people are hyper-aware of a sense that they are different due to loss and change following a sudden, threatening and frightening event.*

*Watchful Insecurity is characterised by a lack of trust in the body. There is awareness of a difference between the person they were before the heart attack and the person they are afterwards. This is associated with a sense of loss for the person they were before.*

*Aspects of life prior to the heart attack are preferred and desired. The extent of the difference is magnified when a persons idealizes life before the illness.*

*As a result people feel preoccupied and watchful of their bodies and behaviour, feel perilous, unsafe and susceptible.*

The results of the study are now delivered in the subsequent chapter (Chapter 8). In presenting the results the essence and components of the theory of Watchful Insecurity are expounded and explained.



## **Chapter 8. Results: Elucidating the theory of Watchful Insecurity**

*“I’m not as sort of robust in the way that I tackle things because I’m very unsure about, you know, over stretching myself”.*  
(Individual interview 7)

### **8.1. Introduction**

The purpose of this chapter is to present the substantial component of the study results. The results are arranged in order to depict the grounded theory that is the core outcome of the study, the theory of Watchful Insecurity.

This research study emerged from a theoretical proposition generated from a previous research study on barriers to accessing cardiac rehabilitation services.

The proposition from the initial study was that people thought of themselves as a different person as a result of the heart attack. As will be seen from the following results, the notion of difference was supported by this study and became central to the grounded theory that was developed.

The research results are presented in alignment with components of the theory of Watchful Insecurity. In this way the theory is built up gradually and takes on form and substance as the chapter proceeds. The concept of difference was crucial to the theory. The results that denote difference are therefore presented first. The concept of difference from the perspective of the participants is explored. How the difference was experienced in terms of its nature and impact is then described.

The subsequent section presents data that describe the characteristics and conceptual nature of Watchful Insecurity. The components of the theory of Watchful Insecurity are then presented in order to further convey the meaning of heart attack recovery experience. This data falls into four sections. First, participants' experiences are discussed to explore the unique features of a heart attack that trigger Watchful Insecurity. Second, the different types and levels of intensity of Watchful Insecurity that have been described by patients and their partners are presented. The impact that the different types and experiences of Watchful Insecurity have on recovery trajectories is then depicted. The chapter concludes with an account of the tools and strategies that people adopt in order to learn to live with and manage Watchful Insecurity. The conceptual, theoretical and methodological implications of the theory of Watchful Insecurity are then discussed in the subsequent Chapter (Chapter Nine).

## **8.2. Being a different person**

### **8.2.1. *The concept of difference***

The concept of difference was a widespread experience that ran through all the participants' accounts of their heart attack recovery. This sudden, frightening event was seen to have changed people in various ways. For example, it altered their emotional condition, their lifestyle or fundamentally changed their personality.

After the heart attack participants described themselves as being different in an essential way, that is, their essence had changed in some way. This view was supported and corroborated by those closest to them, their partners.

*“Your own personality, you seem to lose it don’t you?”* (Group participant C.3.3)

*“I think you look at life different”.* (C.3.2)

*“I don’t think there’s any of them are quite the same as they were”?* (C3.1)

*“I was moody”. “You were never a moody person ever, it was like you were somebody else”* (Group participants P.3.1 and C3.1)

### **8.2.2. The nature of difference**

Difference exhibited itself in a number of ways, but the most commonly reported marker of difference was a lack of confidence. This was related to secondary differences. These are first, a difference in the way they led their life and second difference in mood. However, having less confidence than they had before the heart attack was a recurrent theme.

*“I’m not, I am not as confident”* (Group participant P3.1)

*“I were really, I were afraid somehow. It upset me. Yeah. I had no confidence at all”* (Individual interview 4)

*“I just don’t have confidence”* (Group participant P.4.3)

Change of mood exhibited itself as irritability and anger, being morose or depressed. Mood change was a universally cited experience amongst the participants. They struggled to recognise the person they were as a result of the emotions they were now experiencing after the heart attack.

*"I know it's wrong, but I can get really angry. ... it took me a long time at one time to get angry. Once I got angry, I was angry, but it took me a long time. Now, the silliest things I can get angry with".* (Group participant P1.3)

*"I couldn't cope with it emotionally, I got really emotional, I used to cry! And that's not me"!* (Group participant P4.2)

*"I've found out that I'm a very angry man since I had the operation [cardiac surgery]"* (Group participant P.3.4)

*" My wife says I'm very short tempered. You know, she says something and I jump at her, like. ...she says I have changed a lot in that respect"* (Group participant P4.3)

### **8.2.3. The impact of difference**

The difference in personality, confidence and mood had an impact on the way people lived their lives, for example, if an activity aggravated the sense of difference, the activity would be avoided. One participant had experienced more anxiety since her heart attack. She therefore restricted herself to routine tasks.

*"I wake up in the morning and get really panicky, and tight, before I get out of bed, if I've got something out of the ordinary to do".* (Group participant P2.1)

Some changes resulted in differences that had an impact upon the family dynamic. For example, differences in the way couples communicated, as they were keen to avoid arguments as a result of the increased irritability, avoiding the grandchildren because their noise exacerbated anger, or avoiding places or tasks that prompted frustration because of reduced physical strength since the heart attack.

*“I just haven’t got as much patience, have I like, with the grand kids.... I used to play with them a lot, and now I just can’t do it now” (Individual interview 1).*

There were numerous examples of how tasks and activity had to be avoided after the heart attack. Often these tasks were part of how people defined themselves. The inability to undertake the task and resultant irritability was associated with the damage this restriction caused to their sense of self. This highlighted the sense of difference in identity, roles and responsibilities after the heart attack. Examples include men who couldn’t carry shopping or do building work on the house feeling less strong and therefore less of a man. Their irritation was further fuelled by a concern of what others would think.

*“They said “don’t do it” so three carrier bags and there’s [my wife] with bags, and people looking “who’s that idle ...”? It hurt. You could see what people were thinking, you could see they was thinking and it really got to you. (Group participant P1.3)*

*I were building this conservatory when it happened to me and I was so angry that I had to pay someone to finish off and I were*

*watching someone thinking "that's not good enough" (Group participant P4.3)*

*"I got really down about it and me wife's going to work on a morning.... I'd always been the breadwinner, you know. What me wife earned were pin money. Now roles have changed" (Group participant P4.3)*

For some participants, like Madge in Case Study 1, the sense of difference had a positive dimension. In these cases people felt they had a different and better perspective on the world and made different and better choices about their life and their future. They were able to find enjoyment in new roles and activities.

*"You look at life different, I think you "let's do today 'cos you don't know what's going to happen tomorrow". "We live from day to day and if we want to do something and feel like doing it, then we do it"! (Group participant C3.2 and P3.2)*

*"You tend to put things into perspective quite quickly ....any silly little worries and you don't worry too much about them"! (Group participant P4.1)*

*"I can see what I've been missing all these, all these years. You can....., stand and look at the flowers" (Group participant P4.2).*

Despite this positive element, the predominant experience of difference was associated with loss and change. As demonstrated by the quotes above, this change was due to loss of control, confidence, role, position, responsibilities, activities or identity. This difference was epitomised by one participant whose sense of emotional and physical difference was extreme.

*"Physically I'm shot. Mentally I'm shot. I think so. I mean I was a lorry driver before so I used to go all over the country on my own,*

*you know....and now everything's an effort, you know? I can't walk hardly anywhere" (Individual interview 2).*

When one considers the intensity and complexity of this feeling it is possible to see how addressing and acknowledging this difference, and its consequences, is fundamental to recovery. In developing a theory to explain the meaning of heart attack recovery it was necessary to incorporate the concept of difference as a vital component. The theory of Watchful Insecurity is successful in doing this.

### **8.3. Experience of the state of Watchful Insecurity**

As depicted in Chapter seven, Watchful Insecurity describes a state or way of being that prevails after a heart attack. Watchful Insecurity is a state that emerges from an awareness of difference as a result of a sudden, frightening event. It is characterised by a sense of loss and change. There is also a lack of trust that relates to both the tangible, for example the body, and for the intangible, for example what life in the future holds.

One example that epitomises how people experience Watchful Insecurity after a heart attack is fear of another heart attack. This preoccupation of risk is a new element to life as a result of the heart attack. It is therefore another dimension of difference.

*"I think there's always that worry at the back of your mind that you might have another". (Group participant P4.1)*

*"It is an invasive inner fear I think". (Group participant P2.1)*

*"when I first came home from hospital, you know, when I was so frightened. Do I have to go up the stairs one at a time sort of thing? ....I even now I'm frightened to pick the mower up and do my lawns because I'm still unsure with the pain" (Individual interview 2).*

Related to this fear is a heightened awareness of one's mortality and risk of death that was not present before the heart attack.

*"I think the bottom line of it all is that you suddenly become conscious of your mortality" (Group participant P2.2)*

What emerges then, is a perception from the participants that life before the heart attack had a security and peace that is difficult to recapture after. The loss of security is due to the experience and impact of the sudden, frightening and life-threatening event that is a heart attack.

People reflected that, before they had their heart attack, they had just considered the physical impact of the event on someone's life. However, after their own experience they became hyper aware of the psychological component related to recovery that related to the watchfulness and insecurity encountered.

*"You never think of the mental side of it until it happens to you. And although you actually suffer the pain when you have the heart attack, I think the mental side of it is worse" (Individual interview 2).*



After their own heart attack, numerous examples were given of how watchful insecurity dominated their lives.

*“I think I’ll do so and so and then I think, “no, I’ll set it off again” and you don’t know how far to go. It makes you frightened to try things, especially if you’re on your own” (Individual interview 9).*

The theoretical statement given in Box 8 summarizes the theory of Watchful Insecurity. This statement is now dissected to identify key elements that characterize and better explain Watchful Insecurity. These characteristics are described in the following section.

#### **8.4. Characteristics of Watchful Insecurity**

Five characteristics can be extrapolated from the theoretical description of Watchful Insecurity. Each of these characteristics are taken in turn and illustrated using the quotes of participants.

##### **8.4.1. Lack of trust**

A fundamental component of Watchful Insecurity is a lack of trust in the body. The metaphor that best explains this experience is that of “looking over your shoulder” for another heart attack, reoccurring symptoms or death.

*“It’s at the back of your mind all the time. When you go out, are you going to come back home again?.... I mean I think if I’m going to lift that up I’m going to like have another heart attack or something like that” (Individual interview 1).*

#### **8.4.2. Awareness of difference**

As described above the notion of difference between the person before and after the heart attack was a recurrent theme and central to the theoretical description of Watchful Insecurity.

*“I’m not as sort of robust in the way that I tackle things because I’m very unsure about, you know, overstretching myself”*  
(Individual interview 7).

#### **8.4.3. A sense of loss**

The difference that was perceived and experienced by participants was associated with loss for the person they were before the heart attack. This loss was either for some aspect of them self as a person, or an activity or pastime that was valued by them. As a person, people described loss related to their physical, subjective and social identify. To illustrate the point, an example is given here of two men who were advised to give up work after their heart attack. For both, work had been a key feature and love of their life. The loss associated with giving up work impacted upon their emotional well-being and sense of identity.

*“This specialist said there was nothing they could do at all. The best thing to do was just finish work. So I got a letter from the doctor like and sent it in to work and I just finished, didn’t I, like that. But it was the worst thing ever. I just came home and cried, didn’t I”?* (Individual interview 1)

*“I got to the stage where I wasn’t doing my job right, and that frustrated me because I was one of those people who always give 105%”* (Group participant P1.3)

#### **8.4.4. Aspects of life prior to the heart attack are preferred and desired**

When considering the difference and loss encountered after the heart attack there emerged a perception and awareness that life before the heart attack was better in some way. Previous quotes have illustrated how people feel less strong, confident, secure or vigorous. As a result, the roles and activities they remember engaging in before the heart attack were viewed positively.

Examples included work, holidays, social activities or roles and responsibilities within the family. This was experienced from the range of participants whether they were relatively young and of working age (as with individual participants 1 and 2) or older participants. As indicated in the following quote, even older frail participants remembered finding enjoyment and achievement in activities they could no longer do or did not feel confident in doing.

*“I used to go to my sisters as well and put the Hoover round. It used to keep me occupied and give me something to do, but I haven’t dared venture up there” (Individual interview 10).*

The extent of the difference experienced therefore appeared to be magnified when the life before the illness is idealized.

#### **8.4.5. Feeling preoccupied and watchful**

A complex network of responses, emotions and experience begins to emerge. As has been noted, due to the nature of and emotional response to the heart attack, people lose trust in their bodies and consider themselves fundamentally

different after the heart attack. They describe feeling preoccupied and watchful of their bodies and behaviour, feeling perilous, unsafe and susceptible. This difference generates a perception that life before the heart attack was better and, in some way, they are less of a person afterwards. These factors interrelate and conspire against people. The result is a tendency to be preoccupied with their bodies and experience a lack of safety. As indicated from the quotations, people become hyper-vigilant of their bodies and behaviour and a pervading sense of insecurity develops.

*“You just expect that it can happen again at any time”* (Individual interview 9).

Watchful Insecurity is a state that is both a product and promoter of the sense of difference between life before and after the cardiac event. This is exemplified by the experiences of one participant. He took great joy in driving heavy good vehicles for a job and driving cars for leisure. Watchful Insecurity meant he lacked the confidence and control in his body and health to risk driving. This was because he felt unsafe driving but also unsafe being away from home. In addition, he didn't have the confidence to do anything even if he had driven somewhere, for example he was nervous going for a walk by the sea.

*“Driving I love driving. Driving was my life. ... with the car now we don't want to go .. Well, I don't want to go anywhere....You just don't feel like setting off because you don't know what's going to happen”.* (Individual interview 2).

#### **8.4.6. Learning to live with and manage Watchful Insecurity**

Recovery from this traumatic event therefore becomes characterized as learning to live with and manage Watchful Insecurity such as that described above. One individual interview participant demonstrated how people could learn to live with Watchful Insecurity (Individual interview 5). He was separated from his wife and had experienced extreme anxiety after his heart attack. He therefore moved back in with his wife for support. His wife was present at the interview and described the following course of events.

*“We’ve worked it through together because when he first came out he came to stay with us, didn’t you ... because he was so scared with him having another one. But now, I mean, we’ve adjusted pretty well to it, haven’t we? At first it was constantly on your mind, but now it’s not”* (Wife of Individual interview 5).

Watchful Insecurity was still an enduring part of their life after the heart attack. However, between them they had learnt how to deal with and control the intensity of Watchful Insecurity. If people learn to live with Watchful Insecurity they can be watchfully insecure without having the heart attack constantly on their mind. This is described later in the chapter in relation to types and levels of intensity of Watchful Insecurity.

#### **8.5. Theoretical components of Watchful Insecurity**

As a theory to explain heart attack recovery certain questions yet remain unanswered. For example, what is it that is unique about a heart attack

experience that triggers Watchful Insecurity? What are the different types of Watchful Insecurity? What are the trajectories of Watchful Insecurity? Finally, what are the tools that people employ to live with and manage Watchful Insecurity? It is to these questions that attention now turns. By exploring the triggers, types, trajectories and tools associated with Watchful Insecurity they develop into the theoretical components of Watchful Insecurity (Box 10).

### **8.5.1. Triggers**

From this study Watchful Insecurity is used to describe the state experienced by people after a heart attack. Theoretically, however, it is possible to propose that Watchful Insecurity can occur in response to other unpredicted, and frightening events: that is events that

- Are sudden in nature.
- Are such that it has not been possible to assess the extent of risk and danger prior to the event occurring.
- Remind people of how fragile their place is in the world.
- Challenge a person's ability to trust their body and themselves in the same way that they did prior to the event.

## Box 10. The components of Watchful Insecurity

Components	Categories and concepts
<b>Triggers</b>	<ul style="list-style-type: none"> <li>• <i>Meanings ascribed to the heart</i></li> <li>• <i>Range of symptoms</i></li> <li>• <i>Illness trajectory</i></li> <li>• <i>The meaning of activity</i></li> <li>• <i>The balance of internal and external threat</i></li> </ul>
<b>Types</b>	<ul style="list-style-type: none"> <li>• <i>Stable</i> <ul style="list-style-type: none"> <li>➤ <i>Subliminal</i></li> <li>➤ <i>Affirming</i></li> </ul> </li> <li>• <i>Aggravated</i></li> <li>• <i>Routine</i></li> <li>• <i>Proxy</i> <ul style="list-style-type: none"> <li>➤ <i>Transferred</i></li> <li>➤ <i>Vigilant</i></li> </ul> </li> </ul>
<b>Trajectories</b>	<ul style="list-style-type: none"> <li>• <i>Accelerating</i></li> <li>• <i>Declining</i></li> <li>• <i>Stable</i></li> </ul>
<b>Tools</b>	<ul style="list-style-type: none"> <li>• <i>Taking control</i> <ul style="list-style-type: none"> <li>➤ <i>Avoiding / keeping safe</i></li> <li>➤ <i>Getting information</i></li> <li>➤ <i>Getting on with it</i></li> </ul> </li> <li>• <i>Generating meaning</i> <ul style="list-style-type: none"> <li>➤ <i>Attribution</i></li> <li>➤ <i>Seeking explanations</i></li> <li>➤ <i>Comparing</i></li> </ul> </li> <li>• <i>Redefining</i> <ul style="list-style-type: none"> <li>➤ <i>Resetting limits</i></li> <li>➤ <i>Reprioritising</i></li> <li>➤ <i>Setting new targets and goals</i></li> </ul> </li> </ul>

Examples of other events that might prompt Watchful Insecurity include illness, trauma, accident, bereavement, crime and redundancy. However, there are a number of features of a heart attack that render it almost uniquely powerful as a trigger of Watchful Insecurity and make the nature of Watchful Insecurity distinctive. A number of issues emerged from the data that support the theory that heart attacks are unique as a trigger of Watchful Insecurity and make the nature of Watchful Insecurity distinctive. These are: the meanings ascribed to the heart, range of symptoms, illness trajectory, the meaning of activity, and the balance of internal and external threat experienced. Let us examine these in turn.

#### *8.5.1.1. Meanings ascribed to the heart*

The heart is unique in comparison to illness or accident affecting another part of the body. If viewed mechanically, for example as a pump, almost everyone knows what it does and they are aware that it is essential to life. On some occasions, where there is denial or a mismatch between experience and expectation, there is a tendency for people not to recognise or to misinterpret symptoms initially (Caldwell & Miaskowski, 2002; Dracup et al, 1995).

However, once they are aware that they have had a heart attack people experience an immediate awareness that if the heart is damaged, life is threatened. This is unlike sudden damage or illness related to another part of the body for example, the spleen or kidney.



*“your kidneys can pack in and they can help you. But your heart packs in and you’re dead. You see my dad died in front of me with a heart attack”.* (Individual interview 4)

This threat, and the Watchful Insecurity associated with it, is exaggerated if a person knows or has witnessed someone have or die from a heart attack.

In addition to the practical meanings ascribed to the heart, there are also complex social meanings and cultural connotations attributed to the heart.

Reference to Valentine’s Day and films such as “Braveheart” illustrate how the heart is considered to embrace emotional feelings and attributes such as bravery, strength, courage or an ability to be loving or spiritual. As noted by Angus *et al* (2005):

*“Others attach a special significance to the heart because of its metaphorical associations with strength, life and death, as well as profound sensory and linguistic connections with a gamut of human emotions”* (Angus *et al*, 2005. p2118).

These associations provide the heart with spiritual, soul like qualities that influence perceptions of the implications of damage to the heart.

Recurrent quotes from this study sample relate to the heart being associated with strength and bravery. As well as being physically weak after the heart attack, there was another dimension to this weakness that seemed to come from social and cultural connotations of the heart. An example of this is given in Case Study 2 (Box 11). In this example, the fact that it was the heart that was

damaged rather than another part of the body, challenged the participant's self image as the strong provider of the family. This image was promoted by the participant himself and by his family.

## Box 11. Case study 2

### Group participant P1.3 (Pseudonym = Jim)

#### Background

Jim was a 61 year old married man who has a heart attack in 1993. Subsequent to this he had had cardiac surgery. He had worked in sales in a job that had required a lot of travelling. He had reluctantly had to give up work after the heart attack. Prior to the heart attack he described himself as being the provider for the family. He was a father who had always been there to provide strength and stability.

#### Meanings ascribed to the heart

After the heart attack Jim lacked the strength and confidence he had had before. Because his heart had been damaged it had an impact on how he saw himself. When he first attended the cardiac support group he reported feeling frightened.

*"I was terrified I was, I wondered what the hell I was going to do".*

This was partly due to physical damage, but also because the heart is viewed as being the repository of strength in some way.

This was compounded by his adult son's reaction to his heart attack. Jim's view of being the strong cornerstone of the family was supported by his son's view of him. Jim and his wife reported that his son had been initially angry on hearing about his Dad's heart attack and had been rude to the hospital staff.

*"You have got my dad, and my dad's indestructible, why's he in here"?"*

His son feared that, in addition to his life being threatened, his Dad would lose the ability to maintain his previous crucial role as the rock of the family. He couldn't even bear to see him because of this.

*"He looked at his dad and disappeared you know? He said, "you [Jim] are supposed to be my rock", he said, "I can't watch him mam".*

Jim's response to this was

*"You know? But he was no good to me at all he wasn't".*

Jim and his son experienced uncertainty and timidity reflective of Watchful Insecurity. This appeared to be as a result of the perceived impact of the heart attack on his strength and their representation of his role within the family

The threat to his image was further amplified by his son's response. The case provides an illustration of how characteristics are ascribed to the heart because of social and cultural influences.

These characteristics can be perceived as negatively affected by the heart attack and can therefore trigger Watchful Insecurity.

#### *8.5.1.2. Range of symptoms*

There are a limited number of symptoms associated with a heart attack or any other heart problem. People tend to be very aware what these symptoms are (Johnson & King, 1995). The most obvious is chest pain. Other symptoms include breathlessness and fatigue. This is demonstrated by the data illustrating how people are hyper-vigilant of any chest pain after a heart attack and fear that they may have another heart attack.

*"I were frightened of little things you get, pains in your chest, and you think, is it indigestion? Is it another [heart attack]? (Group participant P4.2)*

The limited range of symptoms associated with the heart seems to intensify concern. The focus on a small collection of symptoms in association with the heart is very different to other complaints. For example, in comparison to cancer, the range of symptoms can be very different after a diagnosis. With cancer people can experience a diversity of symptoms and signs. Anxiety may

not, therefore, be as focused on symptom recurrence. With a heart attack, the fact that people concentrate on a limited range of symptoms can strengthen Watchful Insecurity.

### *8.5.1.3. Illness trajectory*

Prior to diagnosis with illness other than a heart attack, for example some cancers, there may have been a period where people experience symptoms and warnings. These may in turn prompt a visit to health services resulting in medical assessment and investigations. In such cases, diagnosis will occur after a period when a number of tests and investigations are performed.

Diagnosis is therefore preceded by a period of warning and insecurity. If this is the case, when it occurs, diagnosis can actually be perceived as a positive thing, even the case with cancer. This is because a diagnosis provides an answer after the bewildering period when there is no explanation for symptoms experienced. Obtaining a diagnosis can then mark the start of treatment in pursuit of a cure.

As demonstrated by the data indicating the suddenness of the heart attack, the experience here is different. The heart attack itself is often the first symptom that is experienced. There are no warning signs and there is no period of adjustment. Rather than being positive, a heart attack is an acute event that marks the beginning of life with a chronic illness, coronary heart disease (CHD). Whilst obviously a diagnosis of cancer is traumatic, after the cancer diagnosis

the emphasis is on cure. In contrast, after a heart attack, the emphasis is on living with a chronic condition and reducing the risk of further acute events. The risk of a further event can predominate.

*“If you get a pain here or you get a pain in your arm, you start thinking you’re going to have another. You see now I’m talking to you I can feel a bit of tightening here, or I can be sat and I might have some pain or a twinge and you just ... you think, “Oh, I wonder if something’s going to happen.” And then I say, “Don’t be stupid! All that’s happened to you and you sit here thinking about a bloody twinge!””! (Individual interview 4)*

This risk, and the preoccupation with it can make the illness trajectory more uncertain with CHD than many conditions, thus increasing Watchful Insecurity.

#### *8.5.1.4. The meaning of activity after a heart attack*

After a heart attack the Watchful Insecurity experienced can be intensified because of the meaning ascribed to resuming or starting new activity. Following illness and accident, resuming activity is often seen as a physical marker of recovery and regaining function. It is a reassuring sign. For example, resuming activity after a spinal cord injury or surgery for cancer.

After a heart attack, people are advised to resume or commence activity because it has a preventative role. Patients are given written and verbal information that explains that by doing physical activity the heart works harder and its exercise capacity and efficiency is increased. This proposition contains an inbuilt conflict for people. They must increase activity to work the heart

harder and yet it is the heart that has been damaged. This can create a dilemma for people that, whilst they know activity is good for them, they are frightened that it will induce another event.

*"I should have been walking down the street and back again and I'm sat here, you know, frightened to move, like a zombie!"*  
(Individual interview 1)

The result is an exaggerated insecurity surrounding activity where one becomes watchful of the body, the heart's response to activity, potential and actual symptoms, and the context within which the activity is conducted.

#### *8.5.1.5. The balance of internal and external threat*

With accident, crime, redundancy and some illness, the threat that provokes Watchful Insecurity is external to the person. With a heart attack it is internal. Harm has arisen from within. This impacts upon the sense of control and confidence people experience after a heart attack in terms of limiting risk of further cardiac events. The heart is an internal organ, the damage is not, therefore, visible. Neither, therefore is any healing that takes place.

Because of the external nature of the threat, people experiencing other sudden threatening events like a car or climbing accident or crime are free to make decisions that will reduce the risk of a future accident. They can decide, for example, not to drive, take up safer hobbies or fit a burglar alarm. All these activities can reduce threat but also help people to manage Watchful Insecurity.

With a heart attack, similar action to regain control is limited. People are given lifestyle advice after a heart attack to reduce the risk of another event. They are encouraged to change their diet, increase exercise or stop smoking. However, people are restricted in what they can do to regain control. They can stop smoking but they cannot change their family history.

The threat experienced due to a heart attack is internal, invisible and difficult to tackle, thus amplifying Watchful Insecurity experienced after a heart attack. Whilst people may feel and look fitter after a heart attack, any direct impact on the heart remains invisible and intangible. There are no visible markers of heart muscle healing. As with the work of Angus *et al* (2005), what emerges is a reliance of *“sensory experience of the body as a marker of health and wellbeing”* (Angus *et al*, 2005. p2126). This feeds preoccupation, uncertainty and Watchful Insecurity.

An example that illuminates the sense of difference that can be experienced in association with other conditions is that of spinal cord injury following trauma or accident. A participant in a study exploring the experience of spinal cord injury (Carpenter, 1994) says:

*“it is an experience that calls a halt to life as previously known and that “demands” attention and a change in the individual’s perspective of reality”.*



This nicely summarises the sense of difference that could prompt Watchful Insecurity related to spinal cord injury. However, in comparison, Watchful Insecurity is likely to be enhanced after a heart attack for two reasons. One, the acute health event was caused by an internal not external threat. Second, in spinal cord injury resuming physical function may signify recovery. With a heart attack there is no outward sign that the heart is growing stronger or external injury that can act as a marker of how much activity to do.

Therefore, with a heart attack, both the threat and the markers of recovery are internal and invisible. This has an impact upon expectations patients have of themselves and others have of them. For example, because the damage is internal, and there are no outward signs of illness or invalidity, people sometimes find it difficult to process medical advice and conceive what impact the heart attack has had on their health and life.

*“Well, medically they always appear to hedge their bets, which is understandable, saying, “Well, there’s no reason why you can’t make a full recovery and do this, that and the other. But on the other hand, we can’t exclude the fact that you could have another one.” Which is fair enough. But it’s ... In my situation work wise it’s a bit of a quandary. It’s just the uncertainty I suppose really. I mean inside I feel okay, but ....” (Individual interview 8)*

In addition, because there are no external signs of damage, sometimes people have unrealistic expectations of what they can do. The risk then is that they attempt to do something overambitious. If they fail, an enhanced sense of Watchful Insecurity can result.

*"I don't think I'm capable of making those decisions. I certainly don't think. Because if I .. If I made those sorts of decisions, I would push myself too far because that's how I'd be". (Individual interview 7)*

Watchful Insecurity can be experienced because of many different sudden, threatening and frightening events. This data illustrates that a number of triggers are unique to the heart attack experience.

### **8.6. Types of Watchful Insecurity**

Watchful Insecurity can be experienced in different ways. This is in terms of types of Watchful Insecurity and different levels of intensity. Four types of Watchful Insecurity are described: stable, aggravated, routine and proxy.

Stable Watchful Insecurity has two possible dimensions, Subliminal Watchful Insecurity and Affirming Watchful Insecurity. Proxy Watchful Insecurity

addresses the experiences of the partners of those who have had a heart attack. The two aspects of Proxy Watchful Insecurity are "Transferred" and "Vigilant". These are illustrated with reference to a number of case studies.

The different types and levels of Watchful Insecurity are not mutually exclusive.

People may move in and out and between them over time.

Depending on the type of Watchful Insecurity and the circumstances and context influencing it, the experience may be predominantly watchful or insecure.

### **8.6.1. *Stable Watchful Insecurity***

According to the theoretical description, Watchful Insecurity is experienced as an enduring state. It is not a state that is “got over” but rather one that is irreversible. This means that once it has been experienced, Watchful Insecurity will always be present to some degree. In this way, people describe themselves as being a different person after the heart attack than they were before.

In the light of the enduring quality of Watchful Insecurity, recovery is characterised as the process of learning to live with and manage Watchful Insecurity. If management is successful, Watchful Insecurity is experienced as *Stable Watchful Insecurity*. Two categories of stable Watchful Insecurity emerge from the data, Subliminal Watchful Insecurity and Affirming Watchful Insecurity.

#### **8.6.1.1. *Subliminal Watchful Insecurity***

Subliminal Watchful Insecurity is conceptualised as the state where, to all intents and purposes, someone has “recovered”. Watchful Insecurity exists, but just beneath the surface. It is not intrusive in terms of people’s day-to-day lives but has influenced decisions about how to live and behave. In this state, Watchful Insecurity is not ever-present, at the forefront of people’s minds. The experience and awareness of Watchful Insecurity will, however, have influenced

lifestyle changes (such as diet), decisions regarding types and level of activity, resumption of roles and interactions with family and friends (Box 12, Case study 3).

A core feature of Subliminal Watchful Insecurity is that it can be aggravated at any time. Although people in Subliminal Watchful Insecurity have achieved relative stability, there was an indication that Watchful Insecurity remains very much present under the surface, illustrated by a persistent awareness of how the heart attack experience impacted upon them. Metaphors such as “knocked off your feet” and “having the rug pulled from under you”, are used. An example of this comes from a group participant who had built up his confidence, had a sense of control and reached a good level of physical fitness. However, amid a description of his achievements is an acknowledgement of the impact of the heart attack. He speaks as someone who was in a state of Subliminal Watchful Insecurity.

*“I go swimming every week, I’ve got a bike and I work in XXXX and I cycle to work and its nine miles to XXXXX, nine miles back and I, .... this month I’ve done it, its early days, I’ve done it twenty odd times. I’m in the printing trade, I stand up all day, but I did get back to work, I was just off for three months and then... but then it does knock you over”. (Group participant P4.2).*

Whether Subliminal Watchful Insecurity is aggravated will depend on a range of individual circumstances and encounters as well as social and cultural contexts

and influences. This is discussed later in relation to Aggravated Watchful Insecurity. Subliminal Watchful Insecurity is predominantly watchful.

#### *8.6.1.2. Affirming Watchful Insecurity*

Affirming Watchful Insecurity refers to that state where there is an awareness of difference. However, the experience of loss and change, vigilance and uncertainty around the heart attack, encompasses a positive aspect. Despite still being watchful and insecure, there is a heightened sense of something affirming emerging from the crisis. Cases that illustrate this are having a better sense of priorities, increased strength of character, and a heightened appreciation of life or one's family.

### **Box 12. Case study 3**

#### ***Individual interview 9. (Pseudonym = Norman)***

##### **Background**

Norman was a 57 year old married man who had had a heart attack nine months prior to the interview. His wife was present at the interview and contributed to the conversation. There was a sense that the heart attack had been a shared experience that they had got through together

Norman had taken early retirement but he had been extremely fit and active before his heart attack. He was committed to returning to an active life after the heart attack. Norman and his wife had also always had a healthy diet.

##### **Heart attack experience**

Norman's experience after his heart attack had been unsettling for both him and his wife. He had been readmitted with further chest pain the night after he had been discharged with his heart attack, thus aggravating his sense of Watchful Insecurity

*"Nervous! Very nervous!" (Norman's wife) More nervous than you, I think.  
(Norman) Because you're just expect that it can happen again at any time.  
(Norman's wife).*

### **Case study 3. Individual interview 9 (Continued).**

He subsequently had further investigations and an angioplasty. He was still taking medication for high blood pressure, high cholesterol and for secondary prevention.

#### **Recovery**

Both Norman and his wife reported that to some extent they had "got through" the experience. They had supported one another and helped one another seek advice, for example on the Internet. The interview took place immediately after Norman had returned from a ten-mile bike ride.

*"Your body will tell you if you're doing too much. Say like I've been for a bike ride, a 10 mile bike ride, this morning. If I'd have been doing too much, my body would have told me, won't it?"*

This renewed confidence and control over monitoring symptoms was reflective of being in a state of stable Watchful Insecurity. His Watchful Insecurity didn't dominate his life on a daily basis but did influence lifestyle and health decisions.

He did remain Watchfully insecure, however. Thus illustrating the enduring nature of the state. He referred to Watchful Insecurity in relation to wanting regular, but not frequent monitoring of his blood pressure, cholesterol and medication.

In addition he still experienced doubts about what was safe and advised activity and what wasn't. His wife's Watchful Insecurity compounded this. Her anxiety highlighted or aggravated his own uncertainty and Watchful Insecurity

*"even now [my wife] will say, "Oh don't pick him up[grandchild]! He's too heavy!" But he's not too heavy to me. I can pick him up. Now am I doing right or am I doing wrong? I don't know".*

It is possible to theorise that Norman's state of subliminal Watchful Insecurity could be aggravated at any time in a more extreme way, for example, a reoccurring symptom or if his wife was to be taken ill.

This was illustrated by Madge in case study 1. It is possible to detect from the participants who experience affirming Watchful Insecurity that this heightened awareness would not have occurred without the vulnerability and insecurity induced by the crisis. The trauma of the heart attack has in some way facilitated psychological or social growth in some way.

### **8.6.2. *Aggravated Watchful Insecurity***

According to the theory of Watchful Insecurity, the recovery process is conceptualised as periods of relative stability whilst experiencing Stable Watchful Insecurity interspersed with periods of Aggravated Watchful Insecurity. Initially after a heart attack people may predominantly live in a heightened state of aggravated Watchful Insecurity. It is at this time that the participants reported feeling the most vulnerable.

After this initial period, people reported moving between different levels of intensity of Watchful Insecurity. In response to different influences, encounters and context people moved from a stable state of Watchful Insecurity to a more aggravated state.

This movement contributes to the conceptualisation of the recovery process as a journey through a series of peaks and troughs as Watchful Insecurity is aggravated and then subsides. Life after a heart attack therefore becomes an undulating pathway where a greater or lesser intensity of Watchful Insecurity is

experienced. This undulating pathway challenges the linear process suggested in the literature.

A number of factors have been identified as prompting aggravated Watchful Insecurity. In the case of Norman (Box 12) his Watchful Insecurity was aggravated by the recurrence of symptoms after discharge. Other factors reported to aggravate Watchful Insecurity include interactions with a stranger, friend, family member or health professional. Any of these people could aggravate Watchful Insecurity by proffering unsolicited advice, poor communication or a consultation that goes wrong.

One man talked about his family doctor who he had completely lost trust in. Any interaction with this doctor led to aggravated Watchful Insecurity.

*"I don't go because it makes me so angry! As soon as I walk through the door I get angry and that don't do me any good at all and I end up with blood pressure anyway!"* (Individual participant 6)

Another example was a participant who had been for a secondary prevention check. As a result, he had a renewed awareness of his CHD risk due to family history. This heightened awareness of risk prompted his aggravated Watchful Insecurity.



*“They said “have you got anyone in your family”? and I says “well, err, (0.2) me dad had angina for 20 year, oh yea, me mum, and her sister had a stroke”. And I went through the family and I thought “bloody hell, it’s a wonder I’m still here”! (Group participant P4.2)*

In addition, where an event heightens or reinforces an existing concern regarding the heart attack, a symptom or an activity, Watchful Insecurity can be aggravated. Examples include having a health care intervention such as being admitted for an angiogram. Resuming a role or activity such as returning to work can aggravate Watchful Insecurity.

Experiencing a new symptom was, however, a frequent reason given for aggravated Watchful Insecurity. Even if the symptom was nothing to do with the heart, its occurrence threw people into aggravated Watchful Insecurity and it was interpreted as a heart related symptom.

*“Like I say, I’m a devout coward and I hate pain and when I came out of hospital obviously I’d still got these chest pains and I was thinking, “Oh God, am I going to have another heart attack?” I didn’t realise whether it was muscular or whether it was heart or what” (Individual interview 2.)*

Aggravated Watchful Insecurity related to resuming a role or activity is a common experience. This is particularly true if the person links the heart attack to the activity in some way, or was engaged in the activity when the heart attack occurred. Some will limit this activity to avoid the aggravated Watchful

Insecurity. The following example was from a man who had his heart attack when walking up a mountain in the Lake District.

*“Well I don’t do as much climbing..... you know I’ve done, erm, ten miles I think is as much as I’ve done, but not, not the climbing...”*  
(Group participant P4.1)

Where Subliminal Watchful Insecurity is predominantly watchful Aggravated Watchful Insecurity is predominantly insecure.

### **8.6.3. Routine Watchful Insecurity**

Participants also provided descriptions of how behaviour can become ritualised after a heart attack. Such behaviour can be a demonstration of a manifestation of Watchful Insecurity and a way of trying to manage Watchful Insecurity. In this way Watchful Insecurity can also become routine.

Routine Watchful Insecurity can occur in response to feeling frightened or uncertain about a particular implication or consequence of having the heart attack. An example of this is provided by Case study 4 (Box 13). Bert was told he needed an urgent investigation on his heart, but was still waiting for the test seven months later. This man adopted a routine behaviour of rushing to the post every morning to see if the hospital appointment had been made and letter sent. He experienced routine Watchful Insecurity as he was doing this, an experience that was predominantly watchful. Once the appointment letter had

arrived it was possible that this would trigger a move into a state of Aggravated Watchful Insecurity.

Alternatively, Routine Watchful Insecurity can emerge as a way of managing Watchful Insecurity. Routine becomes essential in managing the uncertainty and lack of control underlying Watchful Insecurity after the heart attack. For example, doing things at a certain time each day (catching the same bus to do the shopping in the same shop) or doing things in the same way (walking up the same hill at the same time of day for exercise). Routines are constructed to ensure exercise is had, but limits are set.

*"I have a set routine. ... Up at ten past 7. Get the quarter to 9 bus. Back on the 9.25 bus. Dinner. ....I go shopping every day barring Thursday....I catch a bus down and take a bus back"*  
(Individual interview 3).

## **Box 13. Case study 4**

### ***Individual interview 1. (Pseudonym = Bert)***

#### **Background**

Bert was a 63 year old married man. His heart attack had been seven months prior to the interview. He was interviewed with his wife present. She participated in the interview. He was a retired lorry driver, a man who had loved his job and loved driving. To stop both seriously impacted upon his quality of life and self-image.

#### **Heart attack experience**

Bert's heart attack was a sudden unpredicted event. He was in an unstable medical condition afterwards, necessitating an extended stay in hospital (14 days). Whilst in hospital they discussed conducting an emergency angiogram but Bert's condition improved and they sent him home to wait for an urgent appointment for the investigation. However, seven months later he had heard nothing. It appeared that, for some reason, he was lost to the system.

*"Well, if this is urgent, I don't know what it is! I mean it's, what, nearly 7 months now!"*

#### **Recovery**

The uncertainty and lack of control experienced as a result of waiting for this test aggravated Bert's feelings of Watchful Insecurity. He knew he had underlying heart disease that was unstable. He was not experiencing chest pain, which further increased his Watchful Insecurity. He thought without the chest pain he had no indication that he was doing too much.

*"I mean they've really frightened me in the hospital telling me that ... I'm likely to have another one and my heart's in a bad condition and, you know, I can't do this and that and the other and then when I come home I don't get no pain, I get nothing. I'm just like back to normal except for breathlessness. And then it's at the back of your mind all the time... you've always got it in the back of your mind now that it's going to happen again. This heart attack's going to happen again".*

In response to this an aspect of his behaviour became ritualised. His Watchful Insecurity became focused upon waiting for the angiogram appointment letter. A daily routine was enacted, which was recounted by his wife.

*"He gets all het up and every morning when the post comes, he's waiting for a brown envelope coming, you know, from the hospital and of course there's just nothing coming and, you know, he's just getting more and more, if you can call it, agitated about it, you know"?*

***Case study 4. Individual interview 1 (Continued).***

The experience and display of routine Watchful Insecurity was therefore part of Bert's day-to-day existence. It is possible to speculate that, if a letter was to arrive and an appointment made this would be a catalyst out of routine Watchful Insecurity. His aggravated Watchful Insecurity would spiral and intensify.

The routine nature of behaviour calms the feeling of insecurity but at the cost of becoming overly attentive of the body and wary of the activity. In this way routine Watchful Insecurity emerges as a predominantly watchful state.

***8.6.4. Proxy Watchful Insecurity***

Proxy Watchful Insecurity is a concept that encompasses the carer or partner's experience of Watchful Insecurity. The partner of someone with a heart attack will also be hyper-aware of the disparity before and after the heart attack. They will be aware of difference, resulting in change and loss. This awareness of difference will be for the person with the heart attack and for them as the partner. The roles and responsibilities within the relationship will change accordingly, which can provoke Watchful Insecurity.

A prevailing experience was for Watchful Insecurity to emerge from a feeling that the person who has had a heart attack can no longer be relied on in the same way, physically or emotionally. This is a reported response from partners and adult children of people after a heart attack, as is seen in case study 3.

This was often characterized by a lack of trust by the partner.

*“In MY opinion, the only thing I can say to her is, if I saw her “for God’s sake put that down, I’ll do that”. You, you tend to be OVER cautious” (Group participant C1.4)*

The result is that people feel “mollycoddled” and overprotected.

*“We patients we hate being mollycoddled” (Group participant P1.4)*

*“Yea, you molly-coddle them don’t you, Wrap them up in cotton wool”. (C3.2)*

In such cases there is an obvious risk that patients and partners will aggravate one another’s Watchful Insecurity. Many examples were given of where partners avoided this by not responding to irritation or argument.

*“When I would really like to have a go back. I will walk away, purely and simply because he gets upset and it just isn’t worth getting upset about”. (C1.3)*

Two dimensions of Proxy Watchful Insecurity come to light from the interview data: transference and vigilance.

*“Transferred Proxy Watchful Insecurity”* conceptualises the state of Watchful Insecurity that is communicated from the person that has experienced the heart attack to their carer. This state of Watchful Insecurity therefore reflects that of the patient. It centres on an awareness of the disparity felt by the person who

has had the heart attack. That is, the difference between the person before and after the heart attack, the related distrust of the body and fear of subsequent cardiac events. It is predominantly a feeling of insecurity experienced by the partner that is transferred from the person who has had the heart attack. There was a call from the carers that the difficulty of coping with this should be pre-empted and appropriate advice given by health professionals.

*“One of the problems, individuals, from a carer’s point of view, I would have liked to have been told “Look, I don’t know how they are going to react, they might go into themselves and you’ll have difficulty with their character while they adapt to the situation” (Group participant C3.3)*

*“I says “don’t worry love”, I says “It’s not them that need the rehabilitation, it’s the wives” (Group participant C3.1)*

Also transferred is a heightened awareness of risk. After a heart attack people seek out a cause, attribution or meaning for the event. Cardiac rehabilitation services help people review their risk factors. By nature of their proximity, partners are likely to share many risk factors with patients, whether behavioural (smoking, diet, inactivity) or social (deprivation, high demand-low control employment). A facet of the Watchful Insecurity experienced by partners will be accounted for by this more sensitive awareness of their own personal risk of a heart attack.

*“Vigilant Proxy Watchful Insecurity”* is a concept that explains the response of the partner to their new role as carer. Participants describe how they become a

mediator between the person that has had the heart attack and the rest of the world. In the immediate period after the heart attack this often relates to role changes within the family and household.

*“Actually it told more on the wife, more than I did. I mean she took it harder than I did because ... certainly for the first couple of weeks staying at home and she was sort of doing the running about and having a ... doing a lot, although I was doing what I should be doing. It's not like the same because you can't drive and you're sort of house bound and whatever” (Individual interview 6).*

Over time, Vigilant Proxy Watchful Insecurity can occur as a result of longer-term changes. An example, is where a person has lost the social contact they had at work if unable to return. The partner has to then mediate or replace this social contact.

*“But it's like you've just said, it's, it's, they were on their own, and it's when they mix with the men that they were better, because they were with men's company because, they're used to that at work aren't they, and that's all stopped, hadn't it”. (Group participant C3.3)*

Watchful Insecurity is therefore experienced as the carer vigilantly tries to replace or make up for the social loss the patient has experienced as a result of the heart attack.



The carer also becomes an assessor and arbitrator in decision making related to the illness. Examples here include making decisions on the level of activity or interpreting the meaning of symptoms.

*"[my husband] feels as fit as a fiddle most of the time, and he will do things that he's always done heavy lifting, digging, anything and I get very, very frightened and, you know, [he] says, "I'm all right. I'm all right!" And I'm not sure, you see? I don't want to stop him doing anything, but, you know, if he is all right .. but we just don't know". (Wife of individual interview 6).*

The advisability of commencing or increasing activity was also reported to aggravate Vigilant Proxy Watchful Insecurity.

*"I was held back, I think". "You still are, I think". Yeah. I'm held back, you know. I think (wife) worried more than me and was saying, "hang on, you know, don't walk as fast, or no, we're not going up that hill". (Individual interview 9 and his wife).*

There is a risk that this role is interpreted as over protection and policing by the person with the heart attack. Irritability and anger are reported responses to this, prompting a spiral of aggravated Watchful Insecurity in both patient and partner. This experience is characterised by extreme vigilance and so is biased towards the watchful component of Watchful Insecurity, for example not being able to sleep because they are checking their partner is breathing.

*"Yes, but carers have heart attacks as well but they have them differently. They don't have the physical pain, they have the emotional pain". (Group participant P1.4).*

The stress and isolation experienced by some carers as a result of proxy Watchful Insecurity was in some cases extreme. Some people had good support from friends, family or health professionals. Others did not. All the carers reported to some degree, that they felt alone in dealing with their partners and their own Watchful Insecurity. This experience was epitomized by one participant.

*“There’s nobody to talk to. You know, because sometimes when he’s gone to bed, I just sit and cry. I do. I cry. Or sometimes I’ve been in bed and I sob into my pillow. You know? There’s just nobody. There’s just nothing. There’s no back up at all, is there, or there hasn’t been for me anyway. And sometimes I think, “who the hell is going to help me?” (Wife of individual interview 1).*

To summarise, Watchful Insecurity as a state that governs recovery after a heart attack, will manifest itself in different types and levels of intensity.

Watchful Insecurity will range in intensity from a stable, subliminal state to an aggravated state. Related to these states participants reported examples of challenging and constructing routines around Watchful Insecurity. Proxy Watchful Insecurity depicts the experience of carers.

## **8.7. Trajectories of Watchful Insecurity**

### **8.7.1. *The undulating nature of recovery***

As previously proposed, Watchful Insecurity is a permanent and enduring state that is experienced after a heart attack and that dominates recovery. Several types and levels of intensity of Watchful Insecurity have emerged from

participants' accounts. What emerges, therefore, is a picture of recovery after a heart attack as an undulating pathway. This journey will involve moving between different levels of intensity of Watchful Insecurity. This theory therefore conceptualises recovery in a very different way to those suggesting recovery is linear in nature. If recovery followed a linear course it would start after the heart attack and end at some point where an individual achieves those criteria that indicate recovery. Movement may be possible forwards and backwards along the pathway.

The theory of Watchful Insecurity takes a different stance and proposes that such a linear model is inappropriate. According to the theory of Watchful Insecurity recovery experience is more uncertain and periodic. The recovery journey is depicted as an undulating pathway, with peaks and troughs. The extent of the undulation will be reflective of the level of intensity and types of Watchful Insecurity experienced throughout life after a heart attack.

The trajectories of Watchful Insecurity conceptualise and explain the direction and intensity of Watchful Insecurity as people move between the different types and levels of intensity. People will have periods of aggravated Watchful Insecurity interspersed with other types and intensities of Watchful Insecurity; subliminal affirming, challenged and routine. The speed and direction of movement will depend on a variety of triggers, including physical, psychological and social factors and encounters.

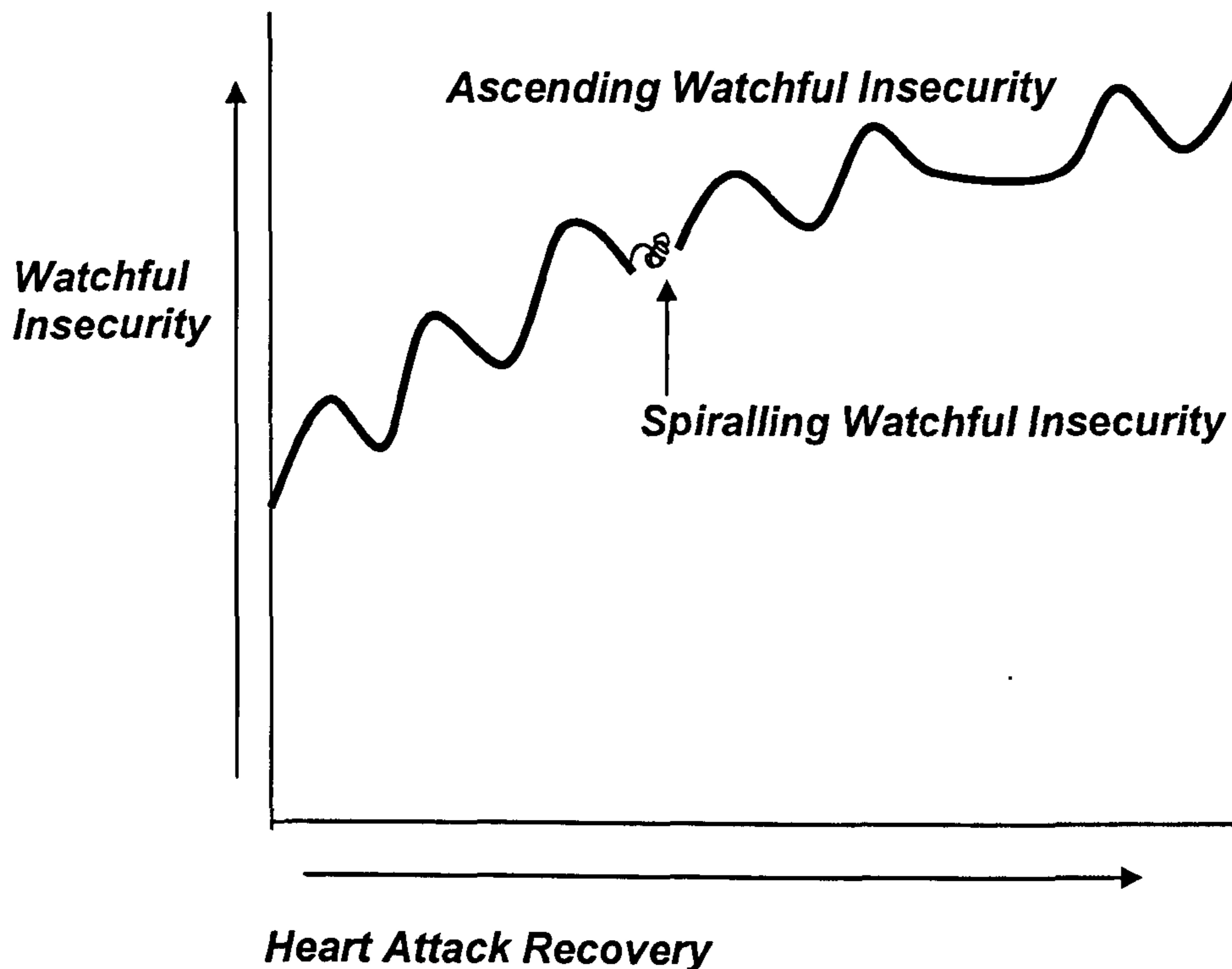
Whilst the overall nature of recovery after a heart attack is characterized by this undulating experience of Watchful Insecurity, within this theory certain overall trajectories emerge as possible. These are described and illustrated with short case studies below. The exact nature of an individual's trajectory will be unique. Different people will experience different triggers and so different recovery pathways will evolve. By adopting Watchful Insecurity as a theory to explain the meaning of recovery after a heart attack, the situation emerges where there are as many recovery pathways as there are people with a heart attack. The theory acknowledges the individual subjective experience and representation of recovery.

### **8.7.2. The trajectories**

#### **8.7.2.1. Ascending Watchful Insecurity**

Ascending watchful insecurity describes a situation where the pattern of Watchful Insecurity is undulating but the underlying trend is one of increased Watchful Insecurity. Over time, the periods of Aggravated Watchful Insecurity are experienced with increasing frequency, intensity and degree. This is due to an inability to successfully challenge Watchful Insecurity or employ tools to manage it. Case study 5 illustrates ascending Watchful Insecurity.

**Diagram 5. Ascending and Spiralling Watchful Insecurity**



**Box 14. Case study 5**

**Wife of individual interview participant 6. (Pseudonym = Mary)**

Mary was present during the interview with her husband. Her husband was a retired factory controller who had been fit, well and active before his heart attack. Mary worked part time as an administrator at a general practice.

Mary and her husband appeared very close. They consulted one another about decisions related to the heart attack. The heart attack had a presence in the household. Mary describes a path of ascending Watchful Insecurity. It worried both her and her husband that they will never know the extent of the damage in terms of damaged heart muscle. This is partly due to its internal and invisible nature.

This worry was exaggerated by the fact they feel unsupported by the

medical staff, in particular their general practice doctor. They interpret the fact they could not be told how much heart damage there was as the doctor deliberately keeping them in the dark. They had lost faith in this doctor. The frustration this caused was increased by Mary's knowledge from her workplace that their care could be better. There was no other general practitioner within travelling distance that had space for new patients. They, therefore, had to remain with their doctor.

This increased their lack of control and further aggravated their Watchful Insecurity. Without information and support, Mary feels frightened all the time. This is aggravated when her husband does something physical. She feels worse if she can't stop him. However, this physical restriction and protection means both the individual participant and his wife are without the reassurance of being able to increase his activity. As they both experience aggravated Watchful Insecurity in response to activity, over time this will gradually ascend.

*"I mean if I've been doing something strenuous and my arms start aching or something like that, you start thinking it's ....".(Individual Interview 5)*

*"We still to this day have no idea of the extent of the damage to the heart or the arteries and that ... So we've been .... totally in the dark about the extent of the damage. And the result is that [her husband] feels as fit as a fiddle most of the time, and I get very, very frightened and.... I'm not sure, you see? I don't want to stop him doing anything, but,.... but we just don't know. I needed .... really needed to know what the extent of the damage ...I think it has frightened me enough to be wary" (Wife of individual interview participant 5).*

#### 8.7.2.2. Spiralling Watchful Insecurity

Spiralling Watchful Insecurity describes a chaotic period of aggravated Watchful Insecurity where it spirals out of control. An example of this relates to the situation described earlier related to resuming or commencing activity as a preventative measure after a heart attack. Despite feeling Watchful Insecurity a person might start going for a daily walk because they have been advised this is good for their heart. However, they know exercise will make their heart work harder and their heart is damaged. This apparent contradiction that an activity

can be both good for them and a danger might aggravate their Watchful Insecurity and make them hyper aware of their body. They become watchful of their body and heart, vigilant for new symptoms. This then triggers a further increase in Watchful Insecurity. They may move into routine Watchful Insecurity in acknowledgement of their insecurity. For example they may conduct their walking exercise according to a schedule and in a “safe place”, for example, near the hospital. Activity that occurs outside of those conditions may then start to further aggravate Watchful Insecurity and spiral.

Some participants described examples of episodes of spiralling Watchful Insecurity as episodes when Watchful Insecurity is aggravated and people experience to chaos and confusion.

*“Well you don’t actually know what you’re doing sometimes” (Group participant P3.4)*

An example of spiralling Watchful Insecurity was provided by a participant in Group 2 (Case study 6). This illustrates why Spiralling Watchful Insecurity is clearly a trajectory to be avoided.

## Box 15. Case study 6.

### Group participant C.2.1. (Pseudonym = Peggy)

Peggy is a 59 year old woman who has had to retire from work because of angina. She was already very worried about her own condition. She was over vigilant, always on the outlook for symptoms to reoccur. Her husband then had a heart attack. This was three years before the interview. Since then she has experienced Watchful Insecurity, stemming from concern about her own health and her husbands.

Peggy comments that the sudden nature of the heart attack aggravates Watchful Insecurity. This is further increased by the fact that neither her nor her husband had access to cardiac rehabilitation. She wanted access to someone to talk to about her worries and stresses. She wanted:

*“Somebody there that you could talk to. Because you worry, you feel that, I feel as if they think you’re a fool or you’re stupid, you worry over little things”.*

Her anxiety and Watchful Insecurity was further amplified by the fact she could not sleep. This was due to worry, partly waiting for her own symptoms to return and also checking her husband was still breathing.

*“You’re listening in the night”.*

In the context of this state of Watchful Insecurity Peggy describes an episode of spiralling Watchful Insecurity. This occurred after she had been admitted to hospital after a bad angina attack. As a result of her admission she was already experiencing aggravated Watchful Insecurity but this got worse and started to spiral out of control.

She felt very frightened on return home fro hospital and had gone to her GP for reassurance. Her Watchful Insecurity started to spiral due to two subsequent factors. The first was that her husband came home from work, didn’t know she had gone out and, when he couldn’t get her to answer the door, he thought she had collapsed. His panic then aggravated her Watchful Insecurity. The second factor was that the reassurance she was seeking from her GP did not materialize. His lack of understanding and compassion added to the spiralling Watchful Insecurity. She depicts the panic and chaos that can occur in response to a succession of stressors.

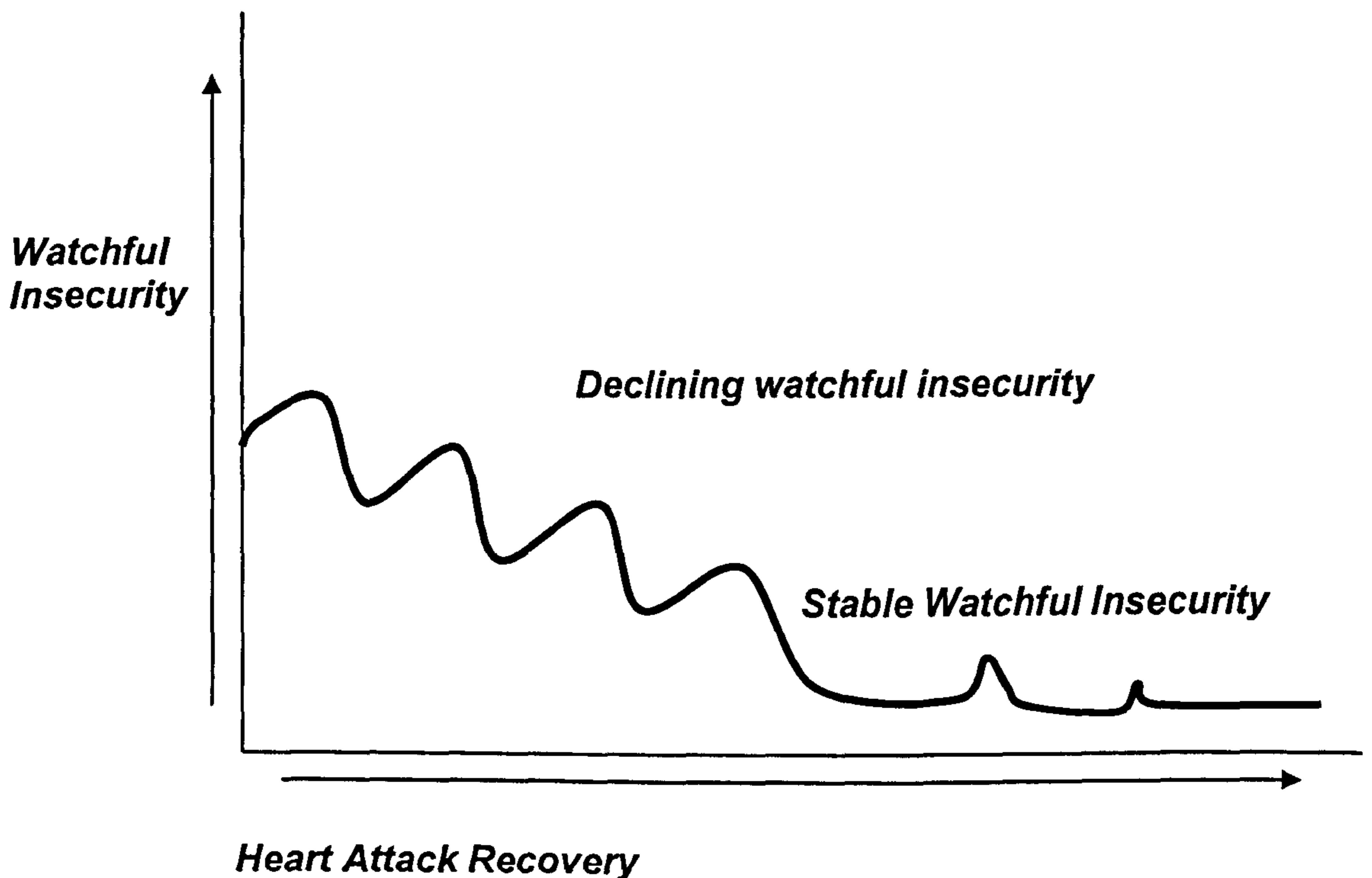


*"The whole thing just turned into a panic, because I'd come home .... went up to see the doctor, and my husband was wondering - the doors were locked, he'd gone to work without his key, they were all running round thinking I was collapsed inside. And what I'd done, I was so frightened? I'd gone up to see my own GP. And he made me feel as if I were a criminal, he didn't listen!"*

### 8.7.2.3. *Declining Watchful Insecurity*

Declining Watchful Insecurity describes the opposite trajectory where periods of Aggravated Watchful Insecurity are experienced with less frequency, intensity and degree. If this trajectory continues people will eventually move into a state of Stable Watchful Insecurity.

**Diagram 6. Declining and Stable Watchful Insecurity**



A common experience was for Watchful Insecurity to decline in response to increased activity and a lack of further symptoms.

An example of this was provided by Jim (Box 11, Case study 2). He described a state of aggravated Watchful Insecurity in the immediate period after his heart attack in 1993. His Watchful Insecurity was aggravated by the impact the heart attack had on him socially and his identity. He had to give up work, which was a severe blow. However, as the years past he described his Watchful Insecurity declining. He started to increase his activity and came to terms with no longer going out to work. At the time of the interview he was running the cardiac support group.

*“I found that the more time that elapsed, the more confident you become. (General agreement with everyone saying yes). You build up gradually. It takes time.... you realise “well, I’ve done that and I’m OK and I’ve done that and I’m OK” and you just build up to it gradually” (Group participant 1.3).*

#### **8.7.2.4. Stable Watchful Insecurity**

The trajectory of recovery may be stable. This describes a state where people are in a long-term position of Subliminal and / or Affirming Watchful Insecurity. Whilst in this state they may experience occasional episodes of Aggravated Watchful Insecurity but generally remain in a state of Subliminal Watchful Insecurity. People in this state talk positively about life after their heart attack, for example, “I’ve never been fitter” or “I have a better sense of priorities now”.

An example of this is found with Individual interview 3 (Case study 7).

## **Box 16. Case study 7**

### **Individual interview 3. (Pseudonym = David)**

David was a 76 year old retired bus driver. He had not experienced any health problems before his heart attack. He had an uncomplicated recovery after the heart attack. The heart attack was sudden and frightening when it had happened. One concern was that he would not be able to look after his disabled wife, who relied very heavily upon him.

After a few weeks of gradually building up his activity, he progressed well. He worked within his limitations and planned his day so that he had the energy to care for his wife. He also made sure he built in social time, for example, going to the club with his friends to play snooker.

His wife comments that:

*"He's not had any problems at all. Ironing - it gives me that bit of exercise as well. Of course I go playing snooker three times a week. He's made a marvellous recovery. ...he [the doctor] says "just carry on as you're doing. Everything seems to be working." He described it as .... More of a slight heart attack. That's all" (Wife of individual participant 3).*

Over the months since his heart attack his wife described how David's Watchful Insecurity gradually declined to a point where he was in stable Watchful Insecurity. He feels back in control, has confidence with activity and his responsibility (especially looking after his disabled wife). They both assume a trajectory where he will continue in stable Watchful Insecurity. They comment that in some ways he is fitter than before his heart attack.

One can theorise that he may experience the occasional episode where his Watchful Insecurity is aggravated in response to life's stressors.

The recovery journey after a heart attack materializes as one where people experience a trajectory that will, at different times of their life, be accelerating, declining, stable or spiralling. The types and intensity of Watchful Insecurity experienced will depend upon life events, encounters and the profile of the individual. Changes in the direction of the recovery trajectory will be similarly

affected. This will add to the undulating and individual nature of the recovery pathway.

Conceptualising trajectories of Watchful Insecurity potentially provides health professionals with a model to monitor people's experience after a heart attack and identify those who are at risk of or experiencing Accelerating or Spiralling Watchful Insecurity.

### **8.8. Tools to manage Watchful Insecurity**

If Watchful Insecurity is a permanent and enduring state, the goal in recovery becomes one where a person tries to manage Watchful Insecurity and live in a stable state of Watchful Insecurity. The best-case scenario that then emerges is one of Subliminal Affirming Watchful Insecurity. This state means that, although people still feel watchful and insecure, they also feel positive. The experience has given them time to reflect and reassess their lives. In this state of Subliminal Affirming Watchful Insecurity people are successfully managing the state of Watchful Insecurity and the process of recovery.

The study participants made reference to a number of tools and strategies that helped them move towards and maintain this state of Subliminal Watchful Insecurity. The tools described by those interviewed fall into three thematic categories: "taking control", "generating meaning" and "reprioritising". These

are taken in turn. In relation to the category of “taking control”, the concept of Challenging Watchful Insecurity is introduced and discussed.

### **8.8.1. Taking control**

The heart attack is experienced as a sudden and frightening event (Chapter 6). Loss of control is, therefore, a fundamental feature of the heart attack experience. Regaining control then becomes an essential component of recovering. A number of tactics were identified in order to do this.

#### **8.8.1.2. Avoiding/keeping safe**

Avoiding activity or situations deemed to be perilous was a common strategy. People instinctively tried to keep safe and be protective.

*“Taking it steady really. Doing what I should do. Taking the medication. Doing the exercise”.* (Individual interview 8)

This was a way of maintaining control. In this way they would not induce a situation where symptoms recurred and they would feel out of control again.

*“Everybody tries a little bit of a challenge but I worked strictly to the book. If you go to the book, you can’t play the devil can you. You don’t try to do too much”.* (Group participant P3.4)

There were examples of people who Challenged Watchful Insecurity where Aggravated Watchful Insecurity was the result. For some in this situation, the way of regaining control and moving towards stable Watchful Insecurity was to

avoid the activity that when challenged, had made their Watchful Insecurity worse.

*“I daren’t get on a bike, because I know when I were in France and I walked to the station and I walked up this hill and I pushed meself too far and I got really bad chest pains and I sprayed meself and I were going dizzy and I thought “ops, I’m coming! Is this it”? You know, really frightened me, so now I don’t push meself that hard”. (Group participant P3.3)*

It is possible to speculate that avoiding and keeping safe may not always be a productive strategy. In the short term it can help people feel in control. In the long term, however, it may be deleterious. For example it may mean people deny themselves activity and pastimes that give them pleasure and contribute to their quality of life. In addition, by avoiding physical activity, people do not build up their fitness and muscle efficiency. This can potentially lead to unnecessary restriction, decline and invalidity.

#### *8.8.1.3. Getting information*

For many, taking control involved being proactive in seeking information.

Sources of information included family and friends, health professionals at the hospital and in primary care, voluntary organisations (e.g. British Heart Foundation), cardiac support groups and the Internet.

*“Well, we actually went on the Internet, didn’t we, to look up stuff on heart attacks and everything”. (Individual participant 9).*

Information from people who had been through a similar experience was particularly valued (see section below on “comparing”).

*“The best source of information really is coming from people, you know who’ve also had heart attacks”* (Individual interview 6).

This tactic of seeking information was identified as particularly important when the information provided by health professionals was insufficient. An example would be where information was general and not personalized. In order to take control and move towards stable Watchful Insecurity, people needed the information to contextualize their heart attack, that is, what did their heart attack mean to their individual health, their life and their recovery pathway?

*“I think that was a general description that they give to everybody. Nothing really was aimed at me sort of thing, specifically at my personal case”.* (Individual interview 9)

#### **8.8.1.4. Getting on with it / resuming activities**

Another aspect of taking control was being proactive in resuming activities. This tactic encompasses challenged Watchful Insecurity. Participants that adopted this approach described being frustrated by inactivity and decided the only way forward was to resume activity and just “get on with it”.

*“You’ve got to decide what you’re going to do and I decided that we would change everything that we could change ourselves”.* (Individual interview 8)

The fact that you are being proactive, resuming activity and moving forward was part of taking control. It was seen to have a positive mental as well as physical impact.

*"I came home from that first session [of an exercise class], Monday, having done all these clever things like.... and you [his wife] said to me, "I don't know what the hell she's done for the muscles in you heart, or what she's done for your head"? And that was the start of getting better". (Group participant P1.1)*

A crucial aspect of resuming activity was to build up gradually. People took great encouragement and regained confidence and control by setting short-term goals and building up. It illustrated the way people used activity to gradually move from aggravated towards Stable Watchful Insecurity.

*"I used to just walk up to the side gate, up to the garden gate, then 100 yards this way, twice a day, 100 yards that way, twice a day. Then on towards the club on here.... then sit on this here form, then walk back on this side of the road, then you set yourself 200 yards, 400 yards until you just, you just ease yourself into it". (Group interview P.1.4)*

However "getting on with it" did not just relate to physical exercise, but to resuming social and relationship activity as well.

*"It's the first time you go down to the club for half a pint, it's the first time you take your wife for a steak, whatever it is, you know, something you used to do that you used to enjoy. It's a very personal thing to you". (Group participant P1.2)*



By getting on with things themselves and working through things together, couples started to build up confidence.

*“We’ve worked it through together because when he first came out he came to stay with us, didn’t you? But now, I mean, we’ve adjusted pretty well to it, haven’t we? At first it was constantly on your mind, but now it’s not. You know? So we’ve adapted pretty well”. (Wife of Individual interview 5)*

Taking control was essential in promoting a successful recovery. It helped people to avoid or move away from aggravated Watchful Insecurity and establish periods of stable, subliminal or even affirming, Watchful Insecurity.

### **8.8.2. Challenging Watchful Insecurity**

Linked to “taking control” is the concept of challenging Watchful Insecurity. The participants’ stories revealed that at certain points after a heart attack people were seen to confront their feeling of Watchful Insecurity as a way of seeking mastery over it. Challenging Watchful Insecurity marks the point when people seek to move away from denial or avoiding and move towards resuming activity and seeking information.

When challenging Watchful Insecurity there is a realisation that although people still feel watchful and insecure, they are aware that they need to deliberately take action in order to move forward and progress with their recovery. As with Aggravated Watchful Insecurity, instances illustrating challenging Watchful Insecurity include resuming an activity, behaviour or role that was important to

them. Another illustration is seeking understanding or help from a health professional in the hope of being able to move forward.

In such situations people are demonstrating a need to “take things into their own hands”. Even though someone may feel watchful and insecure in relation to the activity, they want to confront and challenge it anyway. They are aware that risk is associated with the action but this is coupled with awareness that it is essential to recovery. On some occasions, challenged Watchful Insecurity was linked to a frustration with the status quo.

*“I just said to meself “well, I can’t have this” because I’ve got a long while to live yet so I’ve got to get, get fit again, and that, that became a prime aim, you know, to sort of really sort of, knuckle down and get stuck into it”. (Group participant P4.3)*

Challenging Watchful Insecurity involves risk, that is, the risk of increasing the sense of Watchful Insecurity. Action will be taken if, on reflection, people think the potential benefit accrued from the action is worth the risk. If the action taken is not successful it leads into a state of aggravated Watchful Insecurity.

In the following extract a woman recognised that information and reassurance were required to proceed with recovery. She therefore sought out help from the cardiac health visitor. Unfortunately the consultation was delayed and unsuccessful. In this context challenging Watchful Insecurity resulted in Aggravated Watchful Insecurity.

*“Me husband kept phoning up the health person thing and eventually this health visitor came. She came to me door and came in and she said, “I’ve been asked to visit you. I don’t know why.” So I said, “Well, I’ve had a heart attack.” “Oh right!” .... so she said, “Well, when did you have your heart attack?” So I said, “Well, it could have been any time from so and so to so and so.” “Well, didn’t you have pains in your arms or your chest?” I said, “Well, no.” I said, “I had difficulty in breathing and I were taken in hospital.” So she said, “Well, it don’t sound like you’ve had an heart attack to me.” So then that confuses me more you see”?* (Individual interview 4).

The action may be a sensible strategy but if it goes wrong may aggravate Watchful Insecurity. For others, challenging Watchful Insecurity helped people move towards a stable state of subliminal Watchful Insecurity.

*You realise “well, I’ve done that and I’m OK and I’ve done that and I’m OK” and you just build up to it gradually. (Group participant P3.2)*

In short, challenging Watchful Insecurity is experienced at a point when people feel they have to take action. In doing so they take a risk and “challenge” Watchful Insecurity. For some it is a successful strategy leading to a more stable Watchful Insecurity. For others it is an ineffective and unproductive strategy and results in aggravating Watchful Insecurity.

### **8.8.3. Generating meaning**

From the participant’s stories it became apparent that in order to move forward in the recovery process the heart attack had to have meaning for them in their

lives. Without this they experienced confusion, which compounded the lack of confidence and control underlying aggravated Watchful Insecurity. Three strategies were detected that were adopted in order to generate meaning regarding the heart attack. These were attribution, explanation and comparing.

#### *8.8.3.1. Attribution*

It was apparent from people's accounts that having something to blame for the heart attack was essential to recovery. This helped them make sense of the event and understand why it had happened.

*"I'd decided it was definitely hereditary, I think our family have got dodgy hearts". (Group participant P3.2).*

In addition, being able to attribute the heart attack to something helped people make decisions regarding secondary prevention. It was easier to generate meaning and subsequent action if attribution was focused onto one factor.

*Interviewer: "Diet's the big thing that you concentrate on"?*  
*Interviewee: "Well, it seems to be the only thing that we can sort of latch onto and the wholesome thing about it". (Individual interview 6)*

One of the key features of attribution was it allowed people to mobilize preventative strategies regarding their risk of a future heart attack. This was a way of managing the Watchful Insecurity related to the risk of another event.

*“I mean you look for reasons as to why you’ve had a heart attack and I’m sure everybody does this bit of soul searching, but I kept top side of, you know, looking after my weight and because of that I’ve had a very good diet”. (Individual interview 7)*

#### **8.8.3.2. Seeking explanations**

In addition to having something to blame the heart attack on, it was similarly important to seek explanations for events and occurrences during recovery. If activity was not resumed as swiftly as expected or a symptom was experienced, an explanation was sought in order to give it meaning, understand the event in the context of their lives and move on. The following example involves a man who was breathless after his heart attack. He explained this with reference to his medication rather than damage to the heart. What is apparent is that, in terms of managing his Watchful Insecurity, it does not matter whether he is right or not. The important thing is that he is able to make sense of his situation and progress.

*“I think a lot .... is down to the medication taken!.... I think when I get out of breath it’s partly because the Atenolol is not allowing your heart to work at it’s better higher rate”. (Group participant P3.4)*

The two main explanations given for untoward occurrences were age and tablets.

*“Age comes into this as well, you see you’ve got, you’ve got to put the two together”. (Group participant P3.2)*

### 8.8.3.3. Comparing

Comparing yourself with others was also crucial in facilitating recovery and managing Watchful Insecurity. People sought out others to compare themselves with for different reasons. For some it helped to provide the explanations that were so important to understanding recovery progress.

*“When you talk to people, they’ve all gone through the same sort of thing, you know. So then its “Oh Champion” you know, “it’s not just me” It does help you mentally”. (Group participant P1.3)*

Others took solace from knowing people who have survived a heart attack for a long time and had a good quality of life. It enabled them to start looking to the future. This forward vision was in direct comparison to looking over their shoulder for another heart attack. The latter state was indicative of aggravated Watchful Insecurity.

*“You hear a lot of people, someone who had one 10 years ago and he gave me a lot of confidence”. (Group participant P4.1).*

Comparing themselves with others also helped people maintain a “glass half full” rather than “glass half empty” perspective on life after a heart attack. Through comparison they were able to see themselves in a better position in terms of recovery challenges. They were able to put a positive spin on things but also generate goals that appeared more achievable. This reduced the risk of spiralling into aggravated Watchful Insecurity.

*“We’re fortunate that we’re older and that we don’t have to necessarily get back to work. Now a younger person after a heart attack, somebody with a family to bring up, that must be very difficult”. (Group participant P2.3)*

There were also examples of people using comparing to maintain a state of affirming stable Watchful Insecurity. They did this by comparing themselves to people who had not had a heart attack. They saw the heart attack as a useful warning that enabled them to take action and reduce the risk of another attack.

*“I was saying, he might be fitter than a normal man in the street who’s got heart problems and doesn’t realize it. I mean at least we know what our problems are and we have control over it with either medication or surgery, but I mean there’s millions out there on the street that don’t even know, do they”? (Group participant P3.3)*

#### **8.8.4. Redefining**

The third thematic category of tools to support the management of Watchful Insecurity involved the process of redefining yourself in some way. This overlaps with the previous theme, as redefining will require to some extent, generating meaning. Three approaches were detected in the data, resetting limits, reprioritising and setting new targets and goals.

##### **8.8.4.1. Resetting limits**

Doing different things or doing things differently was often a required strategy after the heart attack. Immediately after the heart attack this may necessitate large changes and a significant reduction in activity, roles and responsibilities. However, as physical recovery took place people were able to build up again.

New limits may, however, need to be accepted. The next quote illustrates this. This man no longer has the speed and strength he had before. He is still able to enjoy his bike riding, but at a slower, steady pace. By accepting this he is able to manage his Watchful Insecurity.

*“You can’t go to extremes, you’ve just got to take it slowly. You can do it! And then I do a lot of bike riding and I used to love sprinting up hills. It was the end to get the legs really going and now, I can still get up there and I don’t get off and walk, but I just have to take it steady”. (Group participant P3.2)*

#### 8.8.4.2. Reprioritising

There were many examples of people generating new priorities in life after the heart attack. For some this seemed a natural response to the threat of the attack as it prompted a heightened sense of being alive. For others they had to work at acquiring this and taking a new quiet enjoyment out of life. The following participants demonstrate how some people develop a renewed sense of living. Things like money start to become less important than making the most out of every day.

*“I also say now, he says “do you fancy going anywhere”? To hell with that, I think, I’m off”. (Group participant P1.3)*

*“I said you look at life different, I think you err, “lets do today ‘cos you don’t know what’s going to happen tomorrow”. (Group Participants C1.2)*

*“We live from day today and if we want to do something and feel like doing it, then we do it! Forget the cost. Forget the other things, if you like doing it, do it”! (Group Participant P1.2)*



The following man had consciously tried, with success, to slow down and take enjoyment out of different things when he was walking. Pleasure came, not from walking harder or further but from what one saw along the way.

*“As a walker, even if you do walk, you can graduate it by doing a bit of bird watching and all this sort of stuff. You can study the flowers on the roadside and it, it sort of spreads it out and slows you down”. (Group participant P.4.2)*

Another group member echoed this attitude.

*“Makes you realise what you’ve missed in life when you’ve worked seven days a week like me, and shift, you’ve either been at work or in bed. (Group participant P.4.3)*

By reprioritising in this way people were able to maintain the affirming nature of their Watchful Insecurity. To do otherwise, to try and work or walk as aggressively or competitively as before would have increased the risk of moving into aggravated Watchful Insecurity.

#### *8.8.4.3. Setting new targets and goals*

Related to the previous tool is the task of setting new targets and goals. These may be long or short-term goals, but importantly they must be realistic.

Theoretically, by setting unrealistic goals, challenging Watchful Insecurity is more likely to move people towards Aggravated Watchful Insecurity. By setting and achieving realistic goals people described how they managed and maintained a state of Stable Watchful Insecurity.

*“You just set yourself a target, and once you’ve reached that target then you look to a bigger plane up to a target than the one you’ve just set yourself”. (Group participant P1.2)*

In some cases this is just a short-term strategy and they resume their previous roles and level of activity. An example of this is Norman (Box 11). For others, setting realistic goals required them to come to terms with the fact they are not as physically capable as they were before the heart attack. This does not mean that they cannot take enjoyment out of the fitness they do have and the activities they can do. This ability to accept and adapt by setting realistic new targets is essential in managing Watchful Insecurity.

For example, the man below is still fit but not as strong, as before the heart attack. He is, however, still able to focus on what he can do. He had taken the additional step of getting a dog. This meant that, whilst he couldn’t do what he used to do, he still had exercise. He also had the additional benefit of the dog’s companionship.

*“You see, I feel physically fitter, I know I’m not as strong.... I mean I can walk, I’m alright, I can walk as long as I’m not pushing meself up stairs and on hills, I get out of breath on stairs and hills, but walking on the flat I’m alright, I walk at me own pace. I know what I tend to do is I walk and if I get tired I got meself a little dog so that I would exercise because when the weather’s foul it’s easy to sit in the house and think “oh, I’ll do it tomorrow”. But I’ve got a dog now so I shall take him out. I, I make meself go like with getting this dog”. (Group participant P4.1)*

One man's experience epitomised the impact of tools such as resetting limits, reprioritising and setting new goals on Watchful Insecurity and how it facilitated the state of Stable Affirming Watchful Insecurity. His wife was still exhibiting Proxy Watchful Insecurity. She was anxious of him doing too much and phoned him up to check on him if he was out for too long. This anxiety could very well have transferred to him and aggravated his own Watchful Insecurity. Instead of this he had applied himself to taking enjoyment from other things, which involved reprioritisation, and setting new goals and targets.

*"My wife phoned me up last summer. I were just starting to get a bit o' confidence and I were going round XXX Dam and me mobile phone rang and she asked "are you alright? I've been ringing, I were worried about you, are you alright"? "Yea, I'm fine"! "What are you doing"? "I'm watching this heron fishing". "You're doing what"!? And I were watching it through binoculars, I'd watched it for 20 minutes, it was stood on this bough in the water, it were staring and it never moved and I thought "this is marvellous. And she says "that can't be bad, it's got to be better than working". (Group participant P4.2)*

## **8.9. Conclusion**

This study developed a grounded theory, Watchful Insecurity, in order to describe heart attack recovery experience. This chapter describes the emergent theory and in doing so has described the concepts and components of the theory of Watchful Insecurity. This theory emerges from the reported awareness of difference that occurs after a heart attack. This difference relates to loss and change resulting from the cardiac event.

The theory suggests there is something unique about a heart attack that acts as a trigger to Watchful Insecurity, which is characterised by a preoccupation and lack of trust in your body and feeling perilous, unsafe and susceptible.

The theory proposes that recovery is a process that is governed by the state of Watchful Insecurity, which is an enduring state. The recovery journey is described as undulating, with peaks and troughs encountered along the way. Different types and trajectories of Watchful Insecurity are identifiable from participant's accounts and there are as many trajectories of Watchful Insecurity as there are people with a heart attack. Within the stories people described tools and strategies that could be employed to manage Watchful Insecurity.

The theory of Watchful Insecurity challenges contemporary perspectives on recovery. This is discussed further in the following chapter (Chapter 9).