

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

***Volume 2***

**By**

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## **Chapter 9. Discussion**

*"I think you look at life different" (Group participant P3.1).  
"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".  
(Individual interview 1).*

### **9.1. Introduction**

The grounded theory of Watchful Insecurity has been developed from the results of this study. Watchful Insecurity provides a new theoretical perspective on the phenomenon of heart attack recovery experience. In the literature review it was identified that the meaning of recovery after a heart attack was relatively unexplored. This research makes a contribution towards filling that gap.

The purpose of this chapter is to discuss the contribution of the theory of Watchful Insecurity to existing knowledge. With regard to the theoretical contribution of the research, this will be discussed first by considering conceptual links between the results of this study and what is already known about heart attack and illness recovery. Following this, the ways in which Watchful Insecurity makes an innovative theoretical contribution to the understanding of heart attack recovery is then considered.

The methodological considerations regarding the study are deliberated with reference to the researcher's reflections upon the research process, the adequacy of the methodology, and potential limitations of the theory. The

chapter concludes by proposing and justifying a number of recommendations for future research and for health care and its delivery.

In the following discussion, reference is made to additional literature, not referenced in Chapters 2 and 3. Examples include that of Radley (1998) and Frank (1995, 2002). For the most part this literature was identified towards the end of the study as the emerging concepts and theoretical propositions were directing theory development. This is in line with the recommendation regarding the role of the literature review within grounded theory. Glaser (1978a) advocated not consulting the literature prior to a study. The more pragmatic and constructive stance, adopted here, is 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). The literature identified at this later stage is integrated into the discussion.

## **9.2. Watchful Insecurity: theoretical contribution**

### **9.2.1. *Conceptual links***

As discussed in earlier chapters, previous qualitative research addressed general illness experience or the impact of a heart attack. It did not overtly address the concept of recovery. By undertaking a study that focuses explicitly on recovery, it has been possible to challenge previous assumptions regarding

the concept. One example is, the assumption that recovery is linear or staged, or that it is conceptually similar to adjustment and adaptation.

This study did reveal some conceptual overlap between heart attack recovery and illness experience. Many of the same concepts emerged from participants' representations of recovery that have been reported in research on illness experience. The theory of Watchful Insecurity provides a framework to explain this overlap in relation to concepts, examples of which include control (Johnson & Morse, 1990), making sense (Kerr & Fothergill-Bourbonnais, 1990), living with loss and change (Sutherland & Jensen, 2000; Helpard & Meagher-Stewart, 1998; Marris, 1993), confidence (Jackson *et al*, 2000) and adjustment (Tobin, 2000; Ben-Sira & Eliezer, 2000; Radley & Green, 1985).

The theory of Watchful Insecurity makes it possible to establish links between such concepts in relation to recovery rather than, as previous studies have done, general illness experience or living with chronic illness.

To some degree the findings of this study complement and reinforce knowledge of these concepts derived from earlier research. What this study offers is the consideration of these concepts within a new theoretical structure that explicitly addresses recovery. How the results echo and expand upon those of previous illness experience research is now briefly examined. Reference is made to how these concepts fit into the theoretical framework of Watchful Insecurity. This is

followed by a discussion of ways Watchful Insecurity makes a novel contribution to theoretical knowledge.

#### *9.2.1.1. The nature and impact of the heart attack experience*

The experiences of participants of this study resonate strongly with the results of previous studies on heart attack impact in terms of the degree of threat and disruption experienced during and after illness like a heart attack. Feelings such as fear and vulnerability were universally experienced. The extreme nature of the heart attack, and its impact, reflect the findings in the studies detailed in Table 2 (page 77). In this study, the extreme nature of the heart attack provides a backdrop to recovery. This helps to explain and understand the difference that is experienced as a result of the heart attack. It is this concept of difference that is fundamental to Watchful Insecurity.

#### *9.2.1.2. Threat and Disruption*

The feelings of disruption and chaos that are experienced following illness have previously been described and theorized (Asbring & Narvanen, 2004; Corbin, 2003; Asbring, 2001; Bury, 1982; Bury, 1991; Cowie, 1981). Previous theories recognise how illness can impact upon people psychologically and upon an individual's predicted biography. Radley (1999) discusses how narrative research on illness experience displays disruption as displacement and disintegration. Illness displaces work and social capacity, but also "*the person's*

*dreams, wishes and fancies*” (Radley, 1999. p781). Disintegration emerges from the,

*“altered significance of everything in life where every fragment is drained of the totality of meaning that is the ‘taken-for-grantedness’”* (Radley, 1999. p781).

Disruption of this kind is integral to the theory of Watchful Insecurity. The concept of difference, central to Watchful Insecurity, encompasses disruption, displacement and disintegration. The result of experiencing such difference, and the associated loss and change, is depicted as aggravated Watchful Insecurity.

As part of the theory of Watchful Insecurity a number of tools are identified to help people manage Watchful Insecurity. The tools used to generate meaning and reprioritise Watchful Insecurity reflect the reconstruction of narrative that Cowie (1981) and Bury (1982, 1991) identify as necessary to move forward in life after illness. Narrative reconstruction helps to make sense of the heart attack and its associated disruption. By reconstructing narrative, the difference is incorporated into future life.

#### *9.2.1.3. Threat to coherence*

An extension of the concepts of disruption and difference is the threat this has on the perceived coherence of life. Antonovsky (1979, 1993a, 1993b) suggested that someone’s ability to cope with a stressor such as illness was

related to his or her sense of coherence. This was depicted as a person's ability to see life as comprehensible, manageable and meaningful.

Antonovsky's theory is not disease specific. It relates to people's ability to cope with stressors and stimuli in general.

In this study, the various levels and trajectories of Watchful Insecurity reflected a range of ability in terms of integrating the heart attack into future life; that is seeing life as coherent. It is possible to speculate that the extent to which participants were able to learn to live with and manage Watchful Insecurity may well have a relationship to their sense of coherence. This would, however, have to be tested in future research. The theoretical proposition that this is so, is supported by the conceptual overlap between the components of sense of coherence (how comprehensible, manageable and meaningful life is perceived) and the tools that are identified to manage Watchful Insecurity. To generate meaning makes life after a heart attack comprehensible. By redefining, life can become more meaningful and by taking control, life can be experienced as more manageable.

#### *9.2.1.4. Control*

Control, and the loss of control, is a concept that is ever present in research into the impact of life after illness (Corbin, 2003; Johnson & Morse, 1990). In this study, loss of control contributes to the difference that is experienced and reported as a result of the heart attack. Watchful Insecurity theory provides a

framework to consider the issue of control in relation to heart attack recovery.

To take control, becomes key to learning to manage the Watchful Insecurity that dominates recovery.

The lack of confidence that is a consequence of loss of control was an enduring theme in participants' stories and again emphasises the importance of regaining control. Loss of control can have extremely negative connotations. The implication is that control is irretrievable. By locating control into a theory on recovery, and incorporating "taking control" as a tool to manage Watchful Insecurity, a way forward is conceptualised.

#### *9.2.1.5. Loss*

A concern related to control is that of loss. The earlier literature review demonstrated that it is not just loss in relation to control that is experienced.

After illness, loss of physical and social function is also reported, as well as loss of psychological well being (Corbin, 2003; Corbin & Strauss, 1987; Levy, 1981).

Some descriptions of loss after illness are fundamental. For example Charmaz (1983) talks of "loss of self" following illness and Radley (1999) of the loss of certainty and the mundane and ability to "take things for granted".

Prior to an event that induces loss, such as illness, Marris (1993) refers to an assumptive world. In the same way as Bury (1982) proposes in his theory of



biographical disruption, the suggestion here is that illness brings about a loss of that assumptive world.

The experiences of participants of this current study reflect and verify aspects of the above theories and research findings. They demonstrate how a heart attack can “bring you up short” in such a way that your assumptive world is challenged. Once again, the theory of Watchful Insecurity provides a theoretical framework to explain this in relation to heart attack recovery.

Watchful Insecurity explains the difference that people experience as a result of a heart attack and the state (Watchful Insecurity) that is induced by that difference. That is, they see themselves as a different person because of the heart attack and the loss that results.

In a number of ways, therefore, the theory of Watchful Insecurity resonates with other theories and findings related to the illness experience. As demonstrated, the theory of Watchful Insecurity provides an alternative framework to locate these concepts and enable them to be regarded and applied explicitly in relation to recovery rather than illness in general.

### ***9.2.2. Theoretical contribution of Watchful Insecurity***

The aim of this section of the discussion is to consider the ways in which the theory of Watchful Insecurity adds to, rather than reflects, existing knowledge.

The theory explains the experience of the recovery as a process that is dominated by the state of Watchful Insecurity. This theory provides a different way to view heart attack recovery, and potentially recovery from other sudden, frightening events. The innovative elements of the theory are considered under the following sub-headings, difference, recovery as an enduring state, the undulating nature of the recovery pathway and the tools to manage Watchful Insecurity.

#### *9.2.2.1. Difference and Watchful Insecurity*

Watchful Insecurity as a concept and a theory provides new insight into heart attack recovery. As a core concept, Watchful Insecurity emerges from an acknowledgment of the *difference* that is felt as a result of a heart attack. As previously stated, research into illness experience has referred to the issue of difference, but either obliquely or in reference to illness experience (especially chronic illness). Difference has not previously been considered as key to understanding the meaning of *recovery*. Acknowledging difference, resulting from loss and change after a heart attack, is essential to understanding Watchful Insecurity and the meaning of heart attack recovery.

For example, Frank (2002, 1995) writes with great beauty, honesty and generosity of his experiences after a cancer diagnosis and a heart attack. He makes reference, in his narrative studies to difference, loss and change experienced after illness.

*“Serious illness is a loss of the “destination and map” that had previously guided the ill person’s life: ill people have to learn “to think differently”. (Frank, 1995. p1)*

But Frank (1995) does not theoretically expand on the concept of difference in relation to his narrative theories on chronic illness. In comparison, Watchful Insecurity does provide a new theoretical framework to consider the illness experience described in narrative research. This framework makes it possible to consider what this experience means for recovery.

The researcher discovered the following quote from Frank (2002) after the theory of Watchful Insecurity had been developed. It perfectly illustrates Watchful Insecurity and how people describe and talk of themselves as fundamentally different after a sudden, frightening event such as a heart attack. The extent of its resonance with the data and findings of this grounded theory study add validity to the theory of Watchful Insecurity. The theory of Watchful Insecurity also adds another dimension and meaning to the words of Frank (2002) as these can now be applied to theory related to recovery as well as illness experience.

*“Heart problems teach you how quickly life can go out of the body. My fear was that I would go to sleep and not wake up again. Having a heart attack is falling over the edge of a chasm and then being pulled back. Why I was pulled back made no more sense than why I fell in the first place. Afterward I felt always at risk of one false step, or heart beat, plunging me over the side again. I will never lose that immanence of nothingness, the certainty of*

*mortality. A heart attack is a moment of death. Once the body has known death, it never lives the same again” (Frank, 2002. p16).*

Watchful Insecurity helps to explain the findings of other research and also to apply these findings to heart attack recovery. Other examples of this include the work of Dinos *et al* (2005) who suggest illness creates a new baseline in life. If conceptualised as difference, this new baseline means that people perceive their past and present differently after the onset of symptoms. In relation to heart disease, Angus *et al* (2005) talks about a new vulnerability after illness, again implying difference and Watchful Insecurity. Participants in his study saw heart disease as a “sneaky disease”. Prior to having a heart attack it was invisible and therefore, not a threat. After the heart attack, they are made aware of their heart and how it works. This awareness results in a vulnerability that didn’t exist before and denotes difference.

The experiences of participants of these previous studies echo those of this current study. What the theory of Watchful Insecurity contributes is that difference is revealed to be a fundamental issue in heart attack recovery and a theoretical framework is developed to explain this. Difference, induced by illness, emerges as an instigator from which loss, change, vulnerability, and Watchful Insecurity are triggered. In order to proceed with a successful recovery, and learn to live with Watchful Insecurity, this difference needs to be acknowledged. People need to recognise and accept the person they were before, are now and will be in the future.

Acknowledging the importance of difference also emphasises the inappropriateness of defining recovery as “returning to normal”. This phrase has been ubiquitous in patient education and health professional literature. If someone is different, “returning to normal” (if normal is life prior to the heart attack) is clearly an unachievable goal. Before the heart attack one isn’t aware of the heart or health. Afterwards, one can’t return to that same sense of security. This again emphasises the importance of acknowledging difference, and nurturing acceptance of that difference in order that the level of Watchful Insecurity is diminished.

#### *9.2.2.2. Recovery as an enduring state*

According to the theory created from the study findings, Watchful Insecurity is conceptualised an *enduring* state that dominates heart attack recovery. The enduring nature of Watchful Insecurity is evidenced by the vigilance, uncertainty, and precariousness that are reported. Recovery is therefore understood as an ongoing process. Success in recovery is then interpreted as learning to manage and live with Watchful Insecurity.

This is a novel way of conceptualising recovery. In contrast, the implication from previous research is that recovery is time limited, that is, after a specific time, one is said to have recovered. The tendency to perceive recovery as time-limited is reflected in the structure of cardiac rehabilitation services. The

four phases of cardiac rehabilitation reflect a physical recovery pathway. They do not account for the multidimensional and complex aspects of recovery, for example social, cultural, psychological and environmental aspects.

If recovery is understood as a social process, dominated by an enduring state of Watchful Insecurity, this liberates conceptual and theoretical interpretation. Different types and levels of Watchful Insecurity can then be identified that explain the huge variations in recovery representations and experience. The theory of Watchful Insecurity suggests that the nearest one gets to a state of being “recovered” is stable, affirming Watchful Insecurity. Feelings associated with Watchful Insecurity are enduring but experienced subliminally. This means they can always be aggravated again. The aggravated state of Watchful Insecurity, therefore, describes the state of people struggling with Watchful Insecurity and recovery.

The existence of different types and levels of Watchful Insecurity indicates a wide range of different factors and experiences that can potentially influence them, for example social, environmental and physical. This suggests that different people will experience different types and intensities of Watchful Insecurity at different time points from their heart attack. The variation in experience will depend on the individual’s social context as well as medical condition. This helps to explain contradictions in results of quantitative studies discussed in previous chapters. For example, it explains why different people

reveal different levels of anxiety or coping at different times from their heart attack, despite interventions to address this (Frasure-Smith *et al*, 2002; Frasure-Smith *et al*, 1997).

Even though it is an enduring state Watchful Insecurity is not necessarily negative. It can be managed, controlled and affirming. The affirming component of Watchful Insecurity is an essential component of the theory. It encompass the positive growth that can emerge from an illness experience. It is the very fact that Watchful Insecurity is experienced that prompts affirmation of life. The feelings of vulnerability, fear and loss heighten awareness of what was good about life, what is good now and what benefits have resulted. Whilst the heart attack experience and Watchful Insecurity can be devastating and disrupting, the suffering and lack of control can contribute in some way to a renewed sense of meaning in life. Again, Frank (2002) reinforces this by describing the new insight that he ascribes to his suffering and vulnerability.

*“Illness prepared me to pay attention to the world around me, because neither I nor it is going to last”. (Frank, 2002. 154)*

To theorise that Watchful Insecurity and recovery is an enduring state, therefore, provides new freedom to explore recovery as a concept.

### 9.2.2.3. *The undulating nature of the recovery pathway*

The theory of Watchful Insecurity is also innovative in conceptualising recovery as *undulating* rather than linear. Again, this feature allows the theory to encompass the variations in individual recovery experience. The theory claims that people will have different recovery trajectories that will depend on individual and social circumstances and characteristics. Physical influences on their recovery pathway are mediated by social and cultural factors (Radley, 1997; Blaxter, 1990 & 1979). A linear trajectory would assume that recovery starts with illness and moves in a unidirectional way towards a fixed point where recovery is said to have occurred. With this model, measurement of outcomes used to denote recovery can imply that recovery is dichotomous. A score indicates recovery has occurred or it has not. Alternatively this linear pathway may be broken down into stages or phases and classified as a typology of illness (Rolland, 1987). This classification is then applied to recovery. The problem with such classification is that there is an expectation that people will conform to such predetermined pathways and classifications (Wellard, 1998). If they do not they may be viewed as not conforming or failing medically.

In contrast, the theory of Watchful Insecurity depicts recovery as an ongoing process and an undulating pathway. It is a journey of peaks and troughs. There are as many trajectories as people. Each will depend on the complex network of influences any one individual is exposed to over the period of their life.

Managing the recovery process well means learning to live with and manage



Watchful Insecurity. According to the theory of Watchful Insecurity individual's set their own recovery goals and indicators, they are not derived from a biomedical agenda. Ability to do this will depend on mobilizing the appropriate tools.

#### *9.2.2.4. Tools to manage Watchful Insecurity*

By depicting recovery as enduring and undulating, the theory of Watchful Insecurity is able to highlight the range of triggers of Watchful Insecurity and facilitators of recovery. The facilitators of recovery are conceptualised as tools that people use to manage and learn to live with Watchful Insecurity. The tools identified are "taking control", "generating meaning", and "redefining".

The nature of these tools has conceptual echoes with other theories that relate to adjustment and response to illness threat, such as survivorship theory (Hassey Dow *et al*, 1999; Dow *et al*, 1999), Antonovsky's sense of coherence model (Antonovsky ,1979; Antonovsky, 1987) and the theory of cognitive adaptation following threatening events (Taylor, 1983). Illustrations of the way in which these theories conceptually overlap are indicated in Table 9.

**Table 9. Theories on response to threat**

<b>Watchful Insecurity</b>	<b>Sense of Coherence</b>	<b>Survivorship Theory</b>	<b>Cognitive Adaptation</b>
<i>Tools to learn to manage Watchful Insecurity and facilitate recovery</i>	<i>Components of a sense of coherence with life</i>	<i>Themes denoting quality of life in cancer survivorship</i>	<i>Themes of adjustment and cognitive adaptation to threatening events</i>
<ul style="list-style-type: none"> <li>♥ Taking control”,</li> <li>♥ “Generating meaning”</li> <li>♥ “Redefining</li> </ul>	<ul style="list-style-type: none"> <li>♥ Manageable</li> <li>♥ Comprehensible</li> <li>♥ Meaningful</li> </ul>	<ul style="list-style-type: none"> <li>♥ Having control</li> <li>♥ Meaning of health</li> <li>♥ Reclaiming life</li> </ul>	<ul style="list-style-type: none"> <li>♥ Regaining mastery</li> <li>♥ Searching for meaning</li> <li>♥ Restoring self esteem</li> </ul>

These theories differ in how they explain issues related to response to threat and illness but they do demonstrate some common conceptual characteristics. The conceptual replication across the theories adds validity to the themes identified as tools to manage Watchful Insecurity in heart attack recovery. It also indicates that these tools may well apply in facilitating recovery in other illness or after other threatening events.

The findings of this study indicate that people will differ in their level of intensity of Watchful Insecurity, their trajectory and their ability to mobilize tools. The network of influences on an individual's heart attack recovery can be complex and multi-factorial. One of the great advantages of the theory of Watchful Insecurity is its capacity to encompass and explain variations in experience regarding heart attack recovery. To illustrate this, the theory can be applied in order to help to explain an apparent contradiction in the literature. Bury (1982) and Cowie (1976) both suggest that people have to redefine their life and reframe themselves in order to accommodate an illness experience and to generate meaning. The theories they generated to explain these processes are biographical disruption and narrative reconstruction.

Whilst these theories have developed great credence in medical sociology over the years they have been exposed to challenge. Pound *et al* (1998) failed to uncover biographical disruption amongst stroke survivors in an English East end community. Instead, the participants appeared to have normalized the illness and demonstrated stoicism and a sense of coherence. Similarly, Killoran *et al*, (2002) also revealed stoicism and a normalizing of metastatic cancer amongst participants who were long-term survivors. The theory of Watchful Insecurity allows the results of these two research studies to come together with those of Bury (1982) and Cowie (1976). The apparent contradiction is explained by Watchful Insecurity theory. Participants in both the stroke and cancer sample were long-term survivors. They were demonstrating signs of

being in a state of subliminal affirming Watchful Insecurity. The experience of aggravated Watchful Insecurity was behind them, although could potentially be reactivated at any time. The trajectory depicted was one of declining and stable Watchful Insecurity. They had clearly had time and ability to mobilize the necessary tools to move away from the disruption of the acute event and had taken control, redefined and generated meaning regarding the illness and their life.

This example demonstrates the capacity of the theory of Watchful Insecurity to explain the meaning of recovery at various time points after a heart attack but also, potentially, other illness or threat.

### **9.2.3. Theoretical dualities**

Recovery is a complex and multifaceted experience. The theory of Watchful Insecurity acknowledges this by encompassing a number of conceptual dualities that emerge related to heart attack recovery and illness experience. These are highlighted below and help to explain the contribution the theory makes to understanding recovery.

#### **9.2.3.1. *Physical and mental distress***

As Charmaz (1999) notes, when one thinks of suffering in chronic illness, it is often the physical dimension that predominates. Symptoms range from fatigue to pain and discomfort. They can be sudden, incremental or relentless in

nature. For some, the same applies to symptoms experienced in recovery after a heart attack. However, the participants in this study indicated that the emotional and psychological suffering after a heart attack could be just as distressing:

*"I think the mental side of it is worse"* (Individual interview 2).

The theory of Watchful Insecurity addresses the multiple dimensions of the heart attack impact. It encompasses the "mental side", acknowledges how physical symptoms can trigger Watchful Insecurity and how being proactive in resuming physical activity can help overcome Watchful Insecurity.

#### *9.2.3.2. Stable and aggravated Watchful Insecurity*

The theory of Watchful Insecurity acknowledges a range and variation in recovery experience. The extremes are represented as stable and aggravated Watchful Insecurity. Those who are successful in recovery achieve a state of stable Watchful Insecurity whilst those who struggle continue to experience aggravated Watchful Insecurity to a greater or lesser extent. Whilst acknowledging these two extremes of recovery experience, Watchful Insecurity does not linger exclusively at either end of a recovery spectrum. Watchful Insecurity is depicted instead as an enduring state that will be experienced in an undulating way over a lifetime after the heart attack. Recovery takes on a profile of peaks and troughs to reflect periods where Watchful Insecurity is provoked.

#### *9.2.3.3. Acute and chronic*

A key feature of a heart attack that impacts upon recovery experience is that it is both an acute and chronic illness experience. People have to move on from the acute event and learn to live with a chronic condition, coronary heart disease (often newly diagnosed). This is complicated by the fact that, whilst CHD may be symptomatic, physically limiting and emotionally distressing for some, it is not always so. For others, it can be invisible, un-symptomatic, either an unacknowledged or insidious threat, a “sneaky disease”. The theory of Watchful Insecurity incorporates all these variations of experience. It depicts the differences and changes in recovery experience that take place between individuals but also for each individual within their lifetime.

#### *9.2.3.4. Control and coping*

Previous research has suggested that recovery requires adequate coping strategies (Chalfont & Bennett, 1999; Bennet *et al*, 1999; Lazarus, 1991; Lazarus & Folkman, 1984) or regaining control (Johnson & Morse, 1990). The theory of Watchful Insecurity encapsulates both coping and regaining control. It explains the experience of loss of control, the meaning of this to patients' recovery and the necessity to be proactive and mobilize tools to regain control. The tools identified reflect both problem and emotion –focused coping strategies.

#### 9.2.3.5. *Loss and gain*

The extent to which loss is associated with illness recovery is discussed above. Many aspects of loss are possible, including loss of control, physical function, self-esteem, identity and also loss of certainty (Frank, 2002; Charmaz, 1999). The ability to explain this impact of lack of certainty, and the ability to take health and the future for granted is fundamental to the theory of Watchful Insecurity. However, the theory also acknowledges that illness recovery is not dominated by loss. There is also the positive, affirming corollary from illness that can prevail during recovery. Watchful Insecurity therefore encompasses the dual components of loss and gain in relation to heart attack recovery.

#### 9.2.3.6. *Self as subject and object*

As a theory, Watchful Insecurity is able to assimilate the concept of self as both object and subject in relation to recovery. "Self as object" is self-concept viewed as the *"organisation of attributes, values and characteristics through which people see themselves"* (Charmaz, 1999. p367). Self as object is how one sees oneself, acknowledging the boundaries one sets for aspects of the self. In contrast "self as subject" refers to subjective experience and, in keeping with a symbolic interactionist epistemology, acknowledges the self as always in process. The self as process is continually influenced by experience. It is possible to see that experience, such as illness experience, can change more rapidly than self-concept. A heart attack can be sudden and frightening, *"like an explosion in your life"* (Clark, 2003). It can take time to restructure self-concept

in response to such threat and to incorporate and make sense of sudden illness such as a heart attack (Charmaz, 1999; Bury, 1982; Cowie, 1976).

This gap between experience and change in self-concept helps to explain why Watchful Insecurity is triggered by a heart attack. It provides a reason for the disorientation, vulnerability and threat to self-image. Watchful Insecurity as a state incorporates the “self as subject” during the heart attack recovery. The tools identified within the theory as necessary to manage Watchful Insecurity all potentially contribute to the rebuilding of self-concept, therefore incorporating “self as object”.

#### 9.2.3.7. *Patient and partner*

Another duality encompassed by the theory of Watchful Insecurity is the interrelated experience of the person with the heart attack and their partner. Previous research has commented on the distress of partners after a heart attack, and the overprotection that can emerge as a result of the anxiety (Stewart *et al*, 2000; Daly *et al*, 1998; Clarke, Walker & Cudy, 1996; Thompson, Ersser & Webster, 1995; Marsden & Dracup, 1991; Thompson, 1990; Thompson & Cordle, 1988). Participants in this study similarly described the psychological impact for the partner and the implications of overprotection. Watchful Insecurity provides an explanation of both of these experiences. Interviewees described overprotection to be both irritating but also obstructive to recovery. By applying Watchful Insecurity theory it is possible to see how the partners protective



response can prevent rather than help the person adopting tools to manage Watchful Insecurity and to progress with recovery. The concept of Proxy Watchful Insecurity explains the experience from the partners' perspective. It provides a context to understand a partners' distress (O'Farrell, Murray & Hotz, 2000), and why this distress may result in overprotection. The theory can help to highlight what support is required for partners in learning to live with Proxy Watchful Insecurity.

In summary, Watchful Insecurity provides a new theoretical and conceptual context and explanation within which to consider the meaning of heart attack recovery. It encompasses individual variations and differences. It explains recovery as a process and addresses a number of dualities that exist relating to the heart attack recovery experience.

### **9.3. Reflection on the research paradigm and process**

This section of the thesis aims to reflect upon the adequacy of the research paradigm in meeting the aims of the study. The study can be described paradigmatically as a modified constructivist grounded theory study underpinned by critical realist ontology. Epistemologically the study encompasses symbolic interactionism theory and the social model of health.

A reflexive account of conducting a grounded theory study has already been given in Chapter five, where some limitations of the study were considered.

This component of the thesis will comprise a personal reflection on the part of the researcher. It concentrates on considerations regarding the adequacy of the overall paradigm, some of the ongoing dilemmas that confronted the researcher during the process and how these were resolved. This is divided into three parts, reflections on the research process itself, reflections on the ontology and epistemology and, finally, reflection on the methodology and methods.

### **9.3.1. Reflections on the research process**

As a doctoral study the expectation is that the research provides a training experience for the person conducting it. In terms of the research process itself, it provided an opportunity to acquire the practical skills required to conduct a qualitative, interview-based study. These were widespread and varied from research design skills to the identification and recruitment of participants through to the actual conduct of data collection and analysis. Skills also included those necessary to obtain ethical approval for the study. Reflections on this ethical process, in the ever-changing policy world, are found elsewhere (Tod, Nicolson & Allmark, 2002).

The researcher development that occurred during the study was not, however, restricted to acquiring practical skills. Advances were made in relation to two, more nebulous, aspects of the research process. Reflection on both of these dominated the research experience. The first issue is explaining the

serendipitous nature of “real world” research. The second concerns explaining the intangible in qualitative research analysis and theory development. These issues will now be considered in turn

#### *9.3.1.1. The serendipitous nature of “real world” research*

Glaser and Strauss (1967) and Strauss & Corbin (1990) all agree that in a grounded theory study the researcher does not bring preconceived concepts to a study. The justification for this restriction is that it may bias the study. The experience of conducting this study revealed that this is often impossible and even impractical of research to follow this tenet to the letter in “real world” research.

In this case, the research was conducted in the current climate of health services practice and prolific policy. The researcher commenced this study with a clear purpose of exploring the meaning of heart attack recovery. During the preliminary study on cardiac rehabilitation access, a question was raised of whether the concept and experience of “difference” was significant in relation to recovery (Tod, Lacey & McNeill, 2002). The doctoral study therefore commenced with a preconceived concept of difference.

It was always the intention that the initial study would provide the context for the doctoral study in terms of generating a research question and data. Research ethics approval for the doctoral study had been incorporated into that of the

preliminary work. In this regard, the grounded theory requirement not to have preconceived concepts was not followed. The interrelation between the two research studies created an ongoing dilemma for the researcher. The root of the dilemma lay in the following questions. Was it valid to enter the study with a preconceived concept, that is, “difference”? Was it valid to use data from the preliminary study in this research, these are, the individual interviews that were selected using theoretical sampling?

Resolution of this dilemma was supported by reference to Charmaz, (1999, 1990), whose experiences reflect those of the researcher. First, ideas for health services research have to come from somewhere. If they are to be useful and applicable to future practice and service delivery, ideas from research have to be driven to some extent from previous evidence and health care experience. In this case the researcher's previous experience, as a nurse and health service researcher, influenced the construction of this study. To some degree, this is, and has to be, serendipitous. What is important, however, is that methods and techniques are in place to ensure that researcher experience does not unreasonably bias the research in progress.

The concept of difference was not preconceived at the outset of the initial research (Tod, Lacey & McNeill, 2002). Its identification was unanticipated, unexpected but also to some extent opportune.

The concept of difference provided a useful hook, upon which to hang the initial stages of research. To ignore the concept because of a directive not to bring preconceived ideas to a study would have been to miss a potential opportunity to develop a theory that had practical application to a health care setting. It was therefore justified on those grounds. However, the use of standard grounded theory techniques ensured that, if it was not supported by the emerging data and analysis, the concept of difference would be dropped in relation to recovery.

A second question about use of data from the preliminary study in the doctoral study was also a matter of continuous reflection throughout this study. Ethical agreement was obtained to collect individual and group data on patient experiences of recovery after a heart attack. It was always the intention that this data would be sufficient for the study on cardiac rehabilitation access barriers and for this grounded theory study. The initial study was completed within a year, written up and published (Tod, Lacey & McNeill, 2002). It formed a platform for this subsequent study and identified the concept of difference. Group interview data was collected in line with the ethics committee approval. Analysis of this data along with that of informal interviews and the initial individual interview data continued for the next three years in order to generate a grounded theory to explain the meaning of recovery.

The interrelation of the two studies was a concern because of an aspiration that the doctoral study should be seen to be substantial, unique and generating innovative results, independent of the initial study. The previous discussion has clarified a number of ways in which the grounded theory offers new knowledge and a new perspective on heart attack recovery. In addition, upon reflection at the end of the study, the interrelation of the two studies is supported for other reasons. First, the grounding of the doctoral study in a health policy driven piece of research, contributed to its potential to be of relevance to patients, health professionals and those involved in service planning. In addition, the integration of the individual data into both studies ensured maximum use of data, avoided duplication of effort and reduced the risk of collecting further unnecessary data and creating a situation where a specific patient group feel “over-researched”.

Commencing this study with a preconceived concept and using data from the initial study merited ongoing consideration during the study. In the final analysis these issues are resolved as they add to the potential relevance of the study. Awareness of these issues also made the researcher vigilant in the use of grounded theory techniques that helped to ensure the theory development was grounded in the data. Finally, both issues reflect the opportune and serendipitous nature of health service research, where the research focus is inevitably guided by an interaction between researcher experience, current

policy priority, previous research findings and, to a certain extent, the right person, being in the right place at the right time.

### *9.3.1.2. Explaining the intangible in qualitative research analysis*

The second enduring concern throughout the research process revolved around the challenge to explain ongoing interpretation, and the conceptual and theoretical leaps that occur during qualitative analysis. An honest response to this challenge, made at the end of the study, is that you cannot explain the intangible. Resolution of the dilemma therefore lies, in part, in accepting that one can never clearly depict the mental processes that take place during qualitative analysis. Themes emerged, codes and concepts become apparent and theoretical propositions surfaced as if from nowhere. To accept this without any attempt at explanation is clearly insufficient. However, it seems wise to acknowledge that to some extent aspects of qualitative analysis are intangible and elusive.

Qualitative methods, and the systematic processes they offer, exist in order to ensure that results are data driven and not researcher driven. These methods are required, in part, due to the intangible nature of qualitative analysis.

Grounded theory is no different. Techniques such as constant comparison, negative case analysis and memo writing help to illustrate and test emerging inductive results. The adequacy of these is discussed in chapter five.

One final point of reflection at the end of this study is the value of illustrative quotes in making the intangible, tangible. There is no doubt that illustrative quotes have great power and value. In conducting policy related work, the researcher has found them invaluable in displaying the patient experience and suffering behind the policy and service rhetoric, figures and targets. In conducting this study, the researcher has become aware of additional benefits in using patients' words.

It remains impossible to depict clearly those invisible conceptual steps that take place during qualitative analysis. However, illustrative quotes can be used to ensure the theoretical and conceptual claims of the study have a basis and grounding in patient experience and the data collected. It facilitates a human connection with the results but also validates the research process and analysis. In the numerous discussions that have been held between the researcher and colleagues (academic and clinical) the use of quotes have forged a connection between the audience of the research and its participants. They provide, in some limited way, a tool to make the intangible, tangible.

In summary, conducting a grounded theory study proved a challenging experience and a road of discovery. Some aspects of this are considered in earlier chapters (Chapter 4 and 5). What is illustrated here is that it is not always possible to have all the answers to the various dilemmas that emerge during the research experience. What is important is to remain flexible,



reflexive and where possible validate and verify processes and techniques used and decisions that are made. It is also necessary to be honest and accept that to some extent aspects of the research process remain ethereal and elusive.

### ***9.3.2. Reflections on the ontology and epistemology***

The paradigm of the study was established in order to meet the four dimensions of the research purpose (Chapter 4). These were to acknowledge social and cultural influences, encompass variations and similarities in experience, explore recovery as a process and move towards second level truth (that is theory, not just description). Critical realist ontology aligned with an epistemology embedded in symbolic interactionism and a social model of health was adopted. The adequacy of this approach in meeting the research dimensions is now considered in relation to the findings and theory of Watchful Insecurity.

#### ***9.3.2.1. Social influences and Individual variations***

The critical realist “lens” maintains the perspective that there will be as many experiences and representations of heart attack recovery as there are people going through that process. This variety of human experience acknowledges the influence of social and cultural influences on health, illness and recovery. Symbolic interactionism assumes that action and behaviour is guided by the meanings people construct to their situations as they are exposed to different social interactions. This view has been debated (Hammersley, 1989).

Symbolic interactionism has been criticised for considering interaction in a vacuum with little consideration of historical and social context (Haralambos & Holborn, 1991). The micro view is considered in the absence of a macro context. Two aspects of this study reduce the force of this criticism. First, as a grounded theory study, the emphasis is on *social* process. Therefore experiences and behaviour of individual participants are considered within their social context. It is possible to speculate that different levels and trajectories of Watchful Insecurity will be experienced according to social, cultural and other influences. The exact nature of this influence is the subject of future research.

A second factor that helps maintain a macro as well as micro perspective is the adherence to a social model of health. Continual consideration was given to how social and cultural factors exert their influence on the cause and impact of illness and recovery.

The theory of Watchful Insecurity that was derived from the study reflects the epistemological premises. The theory provides a framework that is universal in that it embraces the experience of all. Where individuals are located within the theory will depend on the individual experience and the social experiences they are exposed to.

To consider some examples of this the theory suggests that Watchful Insecurity is a state experienced by everyone after a heart attack. The type and level of

intensity will vary for each individual for the length of the recovery trajectory. The ability of people to mobilize tools to facilitate recovery will also be, in part, socially driven. Consideration of some of the social influences on accessing cardiac rehabilitation illustrates this. Take the example of people from traditional working class communities, where a stoical social expectation “to put a brave face on things” is the norm (Tod, Lacey & McNeill, 2002). People from these communities may be less able to undertake some of the actions necessary to facilitate recovery. For example, their stoicism may encourage denial and impede the ability to “take control” or “generate meaning”.

In addition to stoicism, women report restrictions in their recovery because of expectations to resume traditional household responsibilities and childminding for grandchildren. Again, this may obstruct the ability to acknowledge and reflect upon difference, reconstruct their narrative and generate meaning. It is possible to speculate that Watchful Insecurity may be experienced in a more aggravated way according to certain social situations, adding to existing health inequalities.

The variety of individual heart attack recovery experiences can be accommodated by the theory of Watchful Insecurity. This will not just be explained by social differences and inequalities. Other factors will be at play. These include, psychological profiles, coping strategies and, in keeping with a symbolic interactionist approach, past experiences and interactions. The extent

and nature of these influences on the pattern of Watchful Insecurity will need to be tested in future research.

#### *9.3.2.2. Generating theory about recovery as a process*

The study did have the capacity to generate a theory where recovery was perceived as a process. This is in keeping with all grounded theory studies, which focus on understanding social processes. The goal of the study was to bring new meaning to the heart attack recovery process by capturing the experience of those who had had a heart attack. By focusing on process, rather than bio-medically derived outcome measures, the state of Watchful Insecurity was able to come into focus.

Glaser & Strauss (1967) claim that a grounded theory study should generate theories that explain social processes but also help to predict or explain behaviour and be applicable in some way. The components of the theory of Watchful Insecurity do this. For example the theory explains how certain triggers may prompt people to move between different levels of Watchful Insecurity or have the capacity to adopt tools to manage Watchful Insecurity.

One goal of the study was to capture the subjective element of experience and make this central to the theory that was developed. The epistemology and ontology underlying the study supported the development of a theory that achieved this aim. It distinguishes the objective from the subjective. The ability

of the theory of Watchful Insecurity to distinguish the subjective from the objective can be illustrated by comparing the findings with those of studies using other methodologies, for example, studies involving quality of life measurement.

A critique of quality of life studies was presented in Chapter Four. In comparison to reducing patient experience to a quality of life score, the theory of Watchful Insecurity reflects the complex nature of a social process such as heart attack recovery and variation in subjective human experience. This is evidenced by comparing the theory of Watchful Insecurity with a quality of life study that identified insecurity as one of seven categories to be integrated into measurement of quality of life after a heart attack (Roebuck, Furze & Thompson, 2001). As commented upon elsewhere, the qualitative work conducted to identify the quality of life domains is broad based, superficial and lacking in conceptual depth (Nicolson & Anderson, 2001). The material is narrowed down so that a reported measure of insecurity should be obtained. Understanding of what insecurity means in the context of heart attack recovery is not deepened by quality of life studies. In contrast, the theory of Watchful Insecurity does help to contribute to a new and deeper understanding of the meaning of recovery and all its complexity and variation.

The capabilities of the ontological and epistemological basis underlying this study is also illustrated by contrasting the theory of Watchful Insecurity with the

findings of work driven by the recent policy initiative to use experiential knowledge of patients as a resource to influence health care delivery (Caron-Flinterman *et al*, 2005; Department of Health, 2003; Boote, Telford & Cooper, 2002). One example of work driven by this policy is that of the Coronary Heart Disease Collaborative, a component of the Modernisation Agency (Coronary Heart Disease Collaborative, 2003). The CHD collaborative undertook “discovery interviews” of patients asking them to retell their experiences. Key experiences and themes were identified with the intention of NHS service providers using these to redesign services. Whilst well intentioned and interesting, this work can only ever be cursory. It lacks the theoretical depth of a study such as the one presented here. The superficiality is in part explained by the lack of epistemological basis for “discovery interviews”. The results say more about health service structure and process than the social process of illness recovery.

*In comparison, the theory of Watchful Insecurity has more substance and is successful in generating additional understanding of the meaning of recovery. That it is able to do this is because of the ontological and epistemological gaze of the research. It enables the researcher, and those reading the research, to put themselves in the shoes of the person who has had a heart attack. One is able to consider what their experience actually was like. In this way the study and the theory that it generated is “people-centred”. It is able to capture and*

recreate *"users' views on what precisely the problem is within their own unique situation"* and their social context (Williams & Grant, 1998).

It is possible to suggest that a more "in-depth" view of the patient experience would have been possible by adopting narrative methods and a pure social constructionist approach. However, as with discourse analysis, the risk here is that emphasis tends to move away from experience of social process and more towards language, its use and meaning. An extreme social constructionist epistemology would have meant rejecting the critical realist ontology in favour of a more relativist approach. Such an ontological view accepts the existence of multiple realities rather than multiple representations and experiences of the same reality. It would not, therefore, have lent itself so well to looking for similarities in experiences, but rather the individual lived experience. This was not appropriate to this study, the purpose of which was to generate a theory to explain the meaning of a social process, heart attack recovery.

In summary the ontological and epistemological underpinning for this study provided the ability to capture individual subjective experience, and the similarities and variations within those experiences. The approach taken was sufficient to examine and generate new understanding of the meaning of recovery as a social process. In addition, the theory that was generated offered greater depth and insight about heart attack recovery experiences than

alternative research approaches, such as quality of life surveys or “discovery interviews”.

### **9.3.3. *Reflections on the methodology and methods.***

The adequacy of the study methodology and methods has been examined previously (Chapter 4). The steps taken to ensure the research met the criteria of “Trustworthiness” (Lincoln & Guba, 1985) and “fit” (Glaser & Strauss, 1967) have been reviewed. The discussion here therefore concentrates on the issue of methodological creativity and ingenuity.

Both Charmaz (1999, 1990) and Chamberlain (1999) recommend methodological flexibility in grounded theory. They argue against accepting the earlier instructions, rules and procedures as being “set in stone” (Glaser & Strauss, 1967; Strauss & Corbin, 1990). Charmaz (1990) and Chamberlain (1990) propose that the researcher should bring their own experience, values, philosophy and methodological proclivities to grounded theory.

The ways in which this study used a more flexible and creative approach to grounded theory are examined here. Some of the more atypical interpretations and actions in terms of grounded theory methods have already been discussed earlier in this chapter. For example, having a pre-determined theoretical concept and proposition that people feel like a different person after a heart



attack. As discussed earlier, this concept was only retained and upheld because new data justified it.

This component of the discussion is, therefore, focused upon the use of group as opposed to individual interviews and semi-structured rather than unstructured interviews. The use of both of these techniques is not standard to grounded theory and so could open the study up to criticism. To conclude, the adequacy of the methodology and the methods used are reflected upon with reference to the theory of Watchful Insecurity and whether it meets the interrelated criteria for a grounded theory (Glaser & Strauss, 1967).

#### *9.3.3.1. Group interviews*

Following on from the original grounded theory research, most studies have used similar data collection methods, that is, individual interviews and observation (Glaser & Strauss, 1967). However, justification for these methods is scant. Detail on the techniques and accuracy of data collection in grounded theory studies is generally lacking (Charmaz, 1990). Therefore, continued use of the same data collection methods may be a reflection of lack of creativity rather than good practice.

In this study, group interviews were conducted, before theoretically sampling ten individual interviews from the “platform” study (Tod, Lacey & McNeill, 2002). The use of group interviews was justified on the following grounds, despite the

fact they are not common practice in grounded theory. First, it was possible to capture a wider variety of complete accounts of the heart attack recovery process. In addition, it was possible to talk to a broader range of people at different times from their heart attack. This gave the opportunity to explore the concept of difference at different time points. Finally, the interaction between the group members meant that variations and similarities in recovery experience were raised by the participants themselves, and not just from the analysis of concepts. On reflection at the end of the study, it was this combination of factors (variety of recovery accounts, time from the heart attack and participant interaction) that helped to raise and test the notion that Watchful Insecurity was an enduring state.

It has been proposed that longitudinal interviews provide data of better quality (Charmaz, 1999). This is because the researcher is able to build trust and rapport with the respondent over time. If time and resources had allowed conducting longitudinal interview may have been a preferable approach. It would have been possible to trace people's experiences over time and develop a better relationship with the interviewees. However, this was not possible. Conducting group interviews seemed the best alternative to get views from people at different time points from their heart attack and at different places in terms of recovery.

Data collected from the group interviews may well have been sufficient to develop the theory of Watchful Insecurity. However, mindful that this is not the most common or accepted grounded theory data collection method, additional data was required. The individual and informal interviews allowed the theory components to be expanded and explored in more depth. They also allowed for additional theory validation. The experience of using group interviews in grounded theory was both positive and productive. The groups did provide the rich, detailed data required and facilitated the theory development. It would be interesting to witness more creative approaches to data collection in grounded theory and test their capacity within the methodological requirements.

#### *9.3.3.2. Semi-structured interviews*

Another expectation amongst grounded theorists is that data should be collected using unstructured interviews. This is because to have an interview schedule implies the existence of prior knowledge and preconceived ideas. As explained earlier, this study did commence with prior knowledge and experience on the part of a researcher. The social process of heart attack recovery was pre-selected and the concept of difference was identified for exploration. To conduct an unstructured interview in this situation would have been unnecessary. Again reflecting the views of Charmaz (1990) and Chamberlain (1999), the previous experience and knowledge was seen to be an advantage and reinforced theoretical sensitivity. Semi-structured interviews were therefore the most appropriate format. What was important was that they

were conducted in such a way that different experiences and new concepts were allowed to emerge, and existing concepts challenged.

Both the individual and group interviews were conducted as “*directed conversations*” (Lofland & Lofland, 1983). It was necessary to guide discussion, but not be overly directive. The interview schedule helped to prevent the researcher from asking leading questions and inadvertently influencing participants in reinforcing emerging conceptual and theoretical propositions. Open questions were asked to allow the interviewees occasion to present their unique experience. The prompts facilitated deeper inquiry into aspects of recovery.

On reflection, therefore, semi-structured interviews provided the most suitable approach to data collection. Achieving the right balance of openness and direction was the ongoing challenge. The nature of the interview schedule, the demeanour of the researcher and the combination of three strands of data collection helped to maintain this balance.

#### *9.3.3.3. Interrelated jobs of theory*

Glaser & Strauss (1967) proclaim that a grounded theory should be able to perform a number of interrelated tasks. It should:

- Predict and explain behaviour
- Advance theory

- Be applicable by helping to understand and control certain situations
- Guide and provide a style of research on that particular process and related behaviour.

The theory of Watchful Insecurity is able to meet these demands. For example, the levels and trajectories of Watchful Insecurity that are experienced by individuals will influence behaviour. An illustration of this is in people's ability or preference in mobilizing the tools to manage Watchful Insecurity. The ways in which the theory of Watchful Insecurity advances theoretical and conceptual understanding of recovery has been described above. Examples include the way the theory i) challenges the concept of recovery as linear, ii) asserts that Watchful Insecurity is an enduring state that dominates recovery and iii) shows that there are as many recovery trajectories as there are individuals with a heart attack. It should be stated, however, that the theory of Watchful Insecurity remains a substantive, not a formal theory. That is the theory is grounded in one substantive area, heart attack recovery.

Further research would be required in order to test and verify the grounded theory of Watchful Insecurity as a formal theory. This would seek to understand how it operates and is experienced in other fields of recovery.

The application of the theory of Watchful Insecurity to clinical and health service settings and its capacity to influence the direction of future research is discussed in more detail in the final component of this chapter.

To summarize, the methodology and methods proved to be adequate to generate a substantive grounded theory. The selection of some of the methods was driven in part by constraints of the study context. However, despite the slightly unconventional use of data collection methods, the study had the capacity to provide a fresh perspective on heart attack recovery. On reflection they proved to be the best methods available to get depth and range of data required and support the call for more methodological creativity in grounded theory studies.

#### **9.4 Recommendations for future research and health care**

The intention in this final section of the discussion is to consider the implications of the results of the study and theory of Watchful Insecurity on future research and health care delivery.

##### ***9.4.1. Implications for future research***

###### ***9.4.1.1. Developing a formative theory***

The purpose of this study was to develop a grounded theory to explain the experience and meaning of heart attack recovery. This has been achieved.

However the limited scope of the theory need to be acknowledged in terms of the sample it is derived from and the theory type.

The sample used for this study was socially discrete. Although the sample contained a range in terms of age, gender and socio-economic status, participants were drawn from areas of social deprivation in the South Yorkshire Coalfields. The communities have a strong British working class history and culture. The population is strongly homogeneous in terms of ethnicity and there is a tendency for people to remain close to their place of birth. It is not a transitory population. These factors add to the socially distinct nature of the communities. Caution therefore needs to be taken in assuming the theory applies to people who have had a heart attack from other populations.

Research that explores the relevance of the theory of Watchful Insecurity in a broader population would be informative. The resonance of the data from this study with those of others, suggests that the theory of Watchful Insecurity may well apply to wider populations. However, this needs to be tested and cannot be assumed.

In addition, the conduct of culturally sensitive research to apply the theory of Watchful Insecurity in black and ethnic minority populations would also be helpful. Research to explore the relevance of Watchful Insecurity to people of South Asian origin would be particularly useful in a UK context. This is because of evidence of high levels of coronary heart disease, poorer outcomes after

cardiac events and low uptake of cardiac rehabilitation services amongst South Asian communities (Tod *et al*, 2001). There are also indications that people from different ethnic backgrounds interpret and respond to symptoms differently. Whether and how Watchful Insecurity is experienced by Asian patients, may also be affected by cultural influences on health beliefs, for example, fatalism and illness causation (Fox, 2004; Chaturvedi, Raj & Ben-Shlomo, 1997; Orwin, 1996).

In keeping with this study's aims, the theory of Watchful Insecurity has so far only been applied to heart attack recovery. In order to develop this theory and establish it as a formative theory it is necessary to explore Watchful Insecurity, its presence and nature, in other recovery situations. Consideration of recovery from other illness, accident, bereavement, crime and redundancy was integrated into the theory generation, especially when reflecting upon the triggers of Watchful Insecurity. Research that explores the relevance of the theory to other recovery situations, compares Watchful Insecurity between such situations, and expands on understanding of the variations in experience would help to establish Watchful Insecurity as a more robust and formative theory. One line of inquiry that has received positive interest amongst the researcher's academic and clinical colleagues is to conduct further qualitative research exploring similarities and differences in Watchful Insecurity experienced in patients with cancer, CHD and patients who fall into a high risk group. Examples of the latter include women with a strong family history of breast



cancer who are candidates for mastectomy as a primary prevention measure, and people with a strong family history of CHD alongside exceptionally raised cholesterol and blood pressure.

Further research exploring the application of Watchful Insecurity to broader populations will help to expand understanding of recovery theoretically.

However, it will also help to generate practical ways in which people can be supported through recovery. If it is possible to establish that certain people experience Watchful Insecurity in a certain way, at certain times and respond to certain strategies to manage Watchful Insecurity, then services can be developed and targeted more effectively and efficiently.

#### *9.4.1.2. Characteristics influencing Watchful Insecurity*

When discussing the theory of Watchful Insecurity or when presenting the theory at conferences, one question is always raised. Do certain people, with certain characteristics experience Watchful Insecurity differently? That is, do men or women, the young or old, experience different patterns of Watchful Insecurity after a heart attack? Exploring such difference and variation was not the purpose of this study. The purpose here was to develop the theory.

However, having derived the theory of Watchful Insecurity from this study, future research could investigate different patterns of Watchful Insecurity experience.

Further research need not be limited to examining the influence of certain characteristics on Watchful Insecurity. Studies can also be conducted to look into potential correlations between Watchful Insecurity and psychological profiles. This work could be approached from any manner of theoretical perspectives. Examples include exploring correlations between Watchful Insecurity in people with different coping styles (Smith & Lazarus, 1993; Carver, Scheier & Weintraub, 1989), those who adopt different modes of adjustment (Radley & Green, 1985) or those who have a different sense of coherence (Antonovsky, 1979; Antonovsky, 2003a). Research of this nature would help to explore the psychological influence on Watchful Insecurity and has the potential to inform psychological strategies to support people in recovery.

#### *9.4.1.3. Quantitative measurement*

The conduct of this study has been embedded in a desire to understand people's experiences from a qualitative perspective. It, therefore, differs in paradigm from the more reductionist research that measures of biomedical and clinical markers in people after a heart attack. This does not mean, however, that in the future the theory of Watchful Insecurity could not be usefully adopted and used within that research domain. There is the possibility that the basic theory of Watchful Insecurity and its components could form the basis of an assessment tool that could measure the nature and level of people's Watchful Insecurity. This has a huge potential benefit and application to health care delivery.

If a psychometrically tested tool can be developed to measure levels of Watchful Insecurity it will be possible to conduct research to examine the prescription of recovery support interventions. An assessment tool could determine the type and level of intensity of Watchful Insecurity a person is currently experiencing and whether the trajectory is accelerating or declining. Support services can therefore be delivered to those who are best placed to receive them. If people are in a state of aggravated Watchful Insecurity they will require intervention of a different nature to those in a more stable state. For example, it may be that people in an aggravated state of Watchful Insecurity need more “talking and listening” therapy, aimed at helping a person understand the difference, loss and change experienced as a result of the heart attack. Someone in a more stable state may require more information and practical help in “taking control”, “resuming activities” and “getting on with it”. This approach has the potential to be more accessible, acceptable and appropriate than current cardiac rehabilitation services that are bio-medically driven. Cardiac rehabilitation is currently organised and allocated on the basis that someone will be ready to attend a service or resume an activity because a predetermined number of weeks passed since the heart attack.

The development of an assessment tool would be essential in conducting research to explore correlations between Watchful Insecurity and other

psychological and social profiles, such as sense of coherence (Schumann *et al*, 2003; Antonovsky, 1979).

There are numerous avenues for future research expanding and developing the theory of Watchful Insecurity. However, as indicated above, the theory has great clinical application and could form the basis of future interventional studies evaluating services allocated according to the level and nature of Watchful Insecurity experienced.

#### **9.4.2. Recommendations for health care**

Cardiac rehabilitation is the main contribution health services make in supporting recovery after a heart attack. In Chapter two, the low levels of access, uptake and adherence to cardiac rehabilitation services after a heart attack were noted (Beswick *et al*, 2005; Beswick *et al*, 2004). Incomplete and inconsistent service provision has been held responsible (Bethell *et al*, 2001; Bethell, 2000). Up to 63% of patients are not referred to or offered cardiac rehabilitation services (Healthcare Commission, 2005).

The quality as well as quantity of services has been criticised (Thompson, 2002; Thompson *et al*, 1997). Research into currently underserved and high risk communities revealed that low uptake may be partly explained by the fact that people do not see services, as currently delivered, appropriate, accessible or acceptable (Beswick *et al*, 2004; Tod, Lacey & McNeill, 2002). This situation has

been identified as a policy and healthcare priority. There has been a call for more places on cardiac rehabilitation programmes that are more acceptable and offer patients more choices (Healthcare Commission, 2005). However, a recent review of the literature has revealed little evidence of interventions to improve uptake and adherence in cardiac rehabilitation (Beswick *et al*, 2005). There is a lack of research, therefore, to inform the expansion and redesign of services necessary to increase acceptability and access.

The theory of Watchful Insecurity can provide some insight and answers to the current problem of poor access to and uptake of recovery support services after a heart attack. It is possible to theorize that, even if offered, cardiac rehabilitation services are not seen to be acceptable because they do not acknowledge Watchful Insecurity and the meaning of recovery from the patients' perspective. As stated above, the phases of cardiac rehabilitation are derived and developed to reflect the physical recovery of the heart muscle, rather than the complex interaction of social and psychological factors that actually influence recovery. The theory of Watchful Insecurity can provide an alternative perspective to the biomedical one. Key issues of note to health service professionals and planners are as follows:

- People feel differently after a heart attack. That difference must be acknowledged and understood in order for people to progress with heart attack recovery. It shouldn't be ignored as is implied by currently

misguided cardiac rehabilitation services that emphasise “returning to normal”. Patient assessment in cardiac rehabilitation needs to acknowledge that difference as it establishes a new baseline for people in their lives. What this means for individuals in terms of their recovery requirements and aspirations can only be identified if difference is acknowledged.

- Recovery is ongoing and Watchful Insecurity as a state is enduring. People need time to learn to live with and manage Watchful Insecurity. People will respond in different ways and at different times after a heart attack. It is possible, therefore, that if people are being referred to cardiac rehabilitation at all, they may be being referred to the wrong service at the wrong time for them.
- Consideration of Watchful Insecurity could enlighten the development of new content and structure for cardiac rehabilitation. Examples could be the integration of cognitive behavioural therapy techniques to prevent aggravated Watchful Insecurity spiralling into a more extreme state, and move to a point where they can start to take action and learn to live with Watchful Insecurity. Motivational interviewing techniques could be used to support people in accepting change, reprioritising and resuming activity. These examples do not necessarily require additional staff and services, but may require retraining of staff and the redesign and better targeting of existing services.

- As stated above, assessment of Watchful Insecurity could provide an additional mechanism to identify the type and level of Watchful Insecurity currently being experienced and the type and nature of service required to promote recovery.
- People move in and out of types and levels of Watchful Insecurity over the years. This requires services to be flexible and have open routes of referral back into support. Watchful Insecurity can be reactivated by exposure to triggers at any time in life after a heart attack. This needs to be recognised in order for access to appropriate care to be provided.
- The content of cardiac rehabilitation could be adapted to incorporate services that facilitate people in adopting the tools and strategies to manage and learn to live with Watchful Insecurity. Again this does not necessarily require additional services but may be a redesign or change in emphasis in existing services. For example, Watchful Insecurity provides a framework to explain and promote the psychological as well as the physical benefits of exercise cardiac rehabilitation services.

The provision of health care to promote recovery is poorly understood and delivered. Services are structured and driven by biomedical approaches to care. The theory of Watchful Insecurity provides a patient perspective to help redesign services to make them more acceptable as well as more accessible. The theory integrates physical, social, cultural and environmental factors that influence recovery and the complexity and variations of experience. The

provision of menu-based cardiac rehabilitation has been discussed for many years (Coats *et al*, 1995) but to provide such an individualized service has proved to be impossible logistically, financially and professionally. The theory of Watchful Insecurity can play a role in providing a framework within which to understand recovery and redesign services accordingly.

### **9.5. Conclusion**

In this discussion of the study, it has been established that the theory of Watchful Insecurity mirrors findings of other studies related to illness experience. In addition, it makes a unique contribution to theoretical understanding of recovery. The methods adopted proved to be capable of meeting the aims of the study, despite the flexible and creative approach taken to grounded theory. The study provides a sound basis for further research to verify and expand the theory of Watchful Insecurity in other groups and contexts. It also has application to practice and health care delivery.



## **Chapter 10. Conclusion**

*“You’ve only got to get a twinge, it doesn’t matter where it is on your torso sort of thing. You’re straightaway thinking, “God, I’m going to get it”! You know? And I know you’ve got to get over it and carry on with your life, but it takes some getting over that hurdle, you know”?* (Individual Interview 2)

### **10.1. Introduction**

In conclusion, this chapter will pull together the main strands of the research. This is done briefly under the headings of the research findings, the research paradigm and recommendations.

### **10.2. The research findings**

This research commenced with the realisation that empirical understanding of recovery is limited. Little research exists to illustrate what recovery means and how it is experienced, in relation to a heart attack but also other illness. Much research is based upon assumptions that recovery can be explained by exploring illness impact and experience. To an extent this is true. However, this route of inquiry does not illuminate the *meaning* of recovery after a heart attack for those who have experienced one.

The results of this study do demonstrate conceptual links to the results of previous research on illness impact and experience. It adds to their interpretation of heart attack recovery experience and offers additional dimensions to previous studies. Importantly, the theory generated in the

research presented here provides a new theory to explain the meaning and experience of heart attack recovery. Watchful Insecurity, the theory that has been generated, provides a theoretical framework and a new perspective on recovery.

Key innovative aspects of the theory are that recovery is a process that is dominated by the state of Watchful Insecurity. Watchful Insecurity emerges from a sense of difference after a heart attack. The state (and therefore recovery) is enduring in nature. Recovery is not, therefore conceptualised as a linear process. This both liberates, but also adds to the complexity of, understanding of the meaning of recovery. A number of tools and strategies have also been identified that help people to learn to live with and manage Watchful Insecurity.

### **10.3. The research paradigm**

Despite a number of unconventional interpretations of grounded theory methods, the methodology adopted proved to be adequate to generate a theory and meet the aims of the study. The experience supports the claims of others that health services researchers should be more creative and flexible in their use of grounded theory methods and techniques. In this way researchers can rise to the “real world” challenges of conducting health services research.

The underlying epistemology and ontology contributed to the paradigm by allowing the range and variation in individual subjective experience of heart attack recovery to be given recognition. It facilitated the identification of similarities as well as differences in experiences.

#### **10.4. Recommendations**

Whilst the study did succeed in developing a theory, further research will add to the robustness and range of the theory and to develop it from a substantive into a formative theory. Glaser & Strauss (1967) accept that theories developed using grounded theory are set in time, reflecting the symbolic interactionist stance that life and self are process. This does not need to be seen as a limiting factor of grounded theories, rather the opposite. A new, grounded theory can provide a foundation for future research that will expound and develop it as new components are added and its relevance is explored in different populations.

In the case of Watchful Insecurity, there is potential for future evaluative studies exploring the effectiveness of new cardiac rehabilitation interventions that have been developed with reference to Watchful Insecurity.

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## **Appendices**

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## **Appendix 1. Publications associated with the study**

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Tod AM., Allmark P. Nicolson P (2002) Ethical review of health service research in the UK: nursing implications *Journal of Advanced Nursing* 40 (4) 379-386

Tod AM (2001) Overcoming barriers to uptake of services for coronary heart disease: cardiac rehabilitation (South Yorkshire Coalfields Health Action Zone, Rotherham Health Authority)

## Ethical review of health service research in the UK: implications for nursing

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Ethical review of health service research in the UK: implications for nursing

**Background.** This paper examines the current systems and structures for ethical review of health services research in the United Kingdom (UK). Past criticisms and the adequacy of recent governance arrangements for Ethics Committees in addressing these are discussed. The implications for nurses are then considered.

**Rationale.** This examination of the situation is prompted by the demand for more innovative research designs in health care evaluation, new regulations and guidance, and a climate of public anxiety regarding research conduct in the UK.

**Findings.** The evolution of Research Ethics Committees (RECs) has been slow and resulted in a lack in consistency. Criticisms made of RECs can be categorized into four main areas. New governance arrangements for RECs have emerged as potential solutions to these criticisms. This review identifies the limitations of the new governance arrangements in addressing past criticisms because of two factors. The first is insufficient funding. The second is confusion about the confidentiality and consent requirements of clinicians working in areas where research is conducted and on whom recruitment processes often rely. The current situation regarding health research ethical review has implications for nurses, whether they are working as researchers, members of Ethics Committees or clinicians where research is conducted.

**Conclusion.** The new governance arrangements may go some way to addressing past problems. However, investment in RECs is required. It is also important to realize that maintaining ethical probity in health service research is a tripartite concern. It is reliant as it is on the actions of Ethics Committees and clinical research partners as well as those of the researchers themselves.

**Keywords:** research ethics committees, health services, nursing, qualitative, confidentiality, consent, governance

## Introduction

The purpose of this paper is to examine the current systems and structures contributing of ethical review of health services research in the United Kingdom (UK) and consider their implications for nurses. The evolution of ethical committees to review the ethics of health research is described, along with a summary of criticisms made to date. The adequacy of recent governance arrangements for Research Ethics Committees (RECs) in addressing these criticisms is discussed (Department of Health 2001).

In the past, systems to review ethical aspects of health research have been criticized and found wanting by nurses (Dolan 1999). This present examination of the situation has been prompted by three factors. The first is the increasing complexity of health care delivery, which demands equally complex evaluation methodologies and generates associated ethical challenges. The second is a raft of new regulations such as the Data Protection Act (1998), governance regulations for research and development and new governance arrangements for RECs (Department of Health 2001) which create new expectations of researchers and RECs and seek to address previous criticisms. The final factor is public anxiety concerning recent alleged breaches of trust between the health professionals and the public in the name of research. Examples of this include the retention of organs in the case of Alder Hey Hospital (Redfern *et al.* 2001) and unauthorized use of patient information for epidemiological research (Caldicott Committee 1997).

Nurses may act in any of three capacities in the health research environment: as researchers, ethics committee members or clinicians working in areas where research is conducted. This paper considers the implications of the current situation for nurses working in any of these roles.

## Background

In the UK, Local Research Ethics Committees (LRECs) are charged in the National Health Service (NHS) with the ethical review of research using human subjects and NHS premises and facilities (Department of Health 1991). Local Research Ethics Committees aim both to protect research subjects and patients, and to facilitate research which results in new and better treatments and health service delivery (Blunt *et al.* 1998, Alberti 2000).

The LRECs emerged in the UK in 1967, partly in response to the Declaration of Helsinki (World Medical Association [WMA] 2000) and the recommendations of the Royal College of Physicians (1967). Evolution of LRECs was slow. In 1968, the Department of Health made an informal

recommendation that hospitals establish LRECs. However, it was not until 1991 that the Department of Health formally required an LREC in each health district (Alberti 1995). Guidance on how the Committee should operate soon followed in the form of a book commonly referred to as 'The Red Book' (Department of Health 1991); this laid down the requisite functions, membership and working methods of LRECs. Lack of guidance before 1991 has, however, been held responsible for many of the problems experienced by LRECs and for the battery of criticisms levelled at them (Gilbert *et al.* 1989, Forster 1995, Garfield 1995, Dolan 1999).

A number of guidelines (Royal College of Physicians 1996), standards (Bendall 1994) and manuals (Foster 1995) have been developed in an effort to address the causes of the criticisms. It appears, however, that there are still many problems, for example, the current system is seen as obstructive and inconsistent (Alberti 2000, Lux *et al.* 2000, Tully *et al.* 2000).

The establishment of Multi-centre Research Ethics Committees (MRECs) was offered as a solution to some of the problems. Lux *et al.* (2000) suggest this promise has been unrealized. Researchers whose studies are approved by MRECs must also submit to LRECs. This creates an inefficient 'two tier system of ethical review' (Lux *et al.* 2000).

As all health services research must be submitted to LRECs, the following review of criticisms of RECs will focus on the local committees.

## Criticisms of LRECs

In brief, the key problems experienced by and criticisms made of RECs can be categorized into four main areas: different ways of working; differences in opinion regarding the research process; workload and resources; and philosophical stance. These are examined in turn.

### Different ways of working

The location of a research study may necessitate applying for approval from up to four LRECs. Any more than this would require review by an MREC. Negotiating with more than one LREC can illustrate how the 1991 Department of Health guidelines have been interpreted and applied differently at a local level. *Different ways of working* manifest themselves at all points of the application and approval process. These variations have been held responsible for delays and confusion (Alberti 2000, Lux *et al.* 2000). Delays are compounded by differences in the application forms, supplementary

documents required from the researcher, response times and working practices. From initial contact to approval by the numerous committees delays of many months can occur; delays due to the workings of the LREC, not the ethical quality of the study (Lux *et al.* 2000).

Work is underway to develop a standard application REC form (Central Office for Research Ethics Committees [COREC] 2002). Reaching a consensus regarding the standard form is proving to be a challenging and lengthy business. The ease with which the standard form will be adopted, and its impact on delay, has yet to be tested.

The LRECs also differ in terms of open and closed meetings. Some hold meetings *in camera*, where researchers are not invited to attend. This may add to delay and obtaining LREC approval in such circumstances can be a protracted experience. Questions are raised and changes to the proposal and documents are requested but researchers cannot respond immediately as they would do if they were present.

Arguments made in support of closed meetings include the protection of patient and academic confidentiality, protection of the researcher from harsh treatment by the committee and protection of the independent nature of the LREC review of a study. All three arguments fail to stand up to scrutiny (Ashcroft & Pfeffer 2001).

Delay in obtaining ethical approval due to different ways of working has serious implications for the progress of a research study. Studies are often constrained by tight time deadlines dictated by the lifespan of the research funding. Prolonged interaction with the LREC therefore shortens the time available for data collection and analysis, thus threatening the range and value of the results. In addition, delay in starting a study means potential participants are lost to recruitment, again compromising the study (Tully *et al.* 2000).

The REC governance arrangements acknowledge the responsibility of committees to 'consider applications in a timely manner' (Department of Health 2001). The document stipulates that the LREC's decision should be communicated to the applicant within 60 days of submission. Evidence exists that LRECs have failed to achieve the recommended response time for reviewing studies approved by MRECs (Tully *et al.* 2000). Delays of over 6 months were experienced. In the light of this evidence the ability of LRECs to meet this requirement without additional resources must be questioned.

Committees vary in terms of size, and in the breadth and range of their members' backgrounds and expertise (Foster 1995). Some committees include a lawyer amongst the members. Current legal uncertainties and inconsistencies in interpretation of new statutes, such as the new Data

Protection Act (1998), increase the importance for the LREC of such representation. Whilst it does emphasize the importance of multidisciplinary and diverse methodological expertise, the new REC governance arrangements does not highlight the benefit of legal expertise on the committee, whether as 'experts', lay members or specialist referees (Department of Health 2001).

### Differences in opinion regarding the research process

The second main area of criticism and problems related to LRECs concerns differences in opinion regarding aspects of the process and conduct of research. These appear to fall into two categories: first, variations between different LRECs and second, variations between individual committees and researchers

Differences between committees are usually minor and result in different requests to change patient and participant documentation such as consent and information sheets. Although minor, they can add to the procedural delays in obtaining ethical approval (Tully *et al.* 2000).

Variations between committees and researchers may have more fundamental implications for a research study and may result in questionable changes to the study design. Examples include issues relating to the processes required to identify, contact and recruit patient participants and how these affect informed consent and confidentiality. The obligation to protect confidentiality and autonomy in the recruitment and consent process places responsibility on researchers to be conscientious in ensuring consent is as informed and genuine as possible. Related issues which could emerge and which merit examination and questioning by the LREC include possible bias due to researchers' clinical role and experience, role conflict during qualitative interviews and the possibility of unrealistically raising patients' expectations of service improvement. It is reasonable to anticipate that the LRECs may wish to explore recruitment and consent processes and seek confirmation of the integrity and awareness of the researcher regarding the ethical implications. However, with nursing or qualitative studies there is concern that there is a lack of appropriate methodological experience or a tendency to confuse such studies with audit (Dolan 1999). If this is indeed the case, there is a risk that ethical examination of such studies will be limited and issues relating to consent and confidentiality may not be picked up.

### Workload and resources

Problems relating to the conduct and decision-making of LRECs can often be attributed to workload pressures. The

indication is that workload has been made worse, not better, by the establishment of the MREC system (Lux *et al.* 2000, Tully *et al.* 2000). Lack of resources and inconsistency of provision of financial and administrative support at a Local Health Authority level increases the workload of already pressured committees. Insufficiency of administrative support has resulted in a call for trained administration staff who would work solely for the committee (Blunt *et al.* 1998). It seems reasonable to suggest that the most efficient committees would be those with dedicated administrator time and the most constant membership.

Inconsistent approaches to support at a local level can exacerbate underlying national limitations, for example the lack of recompense to LREC members in terms of time or payment (Alberti 2000). These problems further aggravate difficulties regarding the adequacy of an LREC's membership. An overburdened committee is likely to find it difficult to recruit the range and calibre of members it requires. In addition, a committee struggling to cope with its routine business within the constraints of other employment obligations is unable to release its members for adequate training.

Where the workload of an LREC is unwieldy and membership problematic, the standard of review is bound to suffer and the LREC fail to meet new challenges placed upon them. Challenges identified by Blunt *et al.* (1998) include conducting research synthesis, assessing researchers' ability to carry out a study in terms of ability and involvement in other trials, detection of malpractice and fraud, and ongoing monitoring of publications. A future challenge will be implementation of the new governance regulations for RECs.

### Philosophical stance

The heritage of LRECs lies firmly in that of medical research and practice. Medical members have always made up the majority of Committee membership (Dolan 1999). It is claimed that this cultivated an environment where medical research with a positivist emphasis is most highly valued. In contrast,

...the traditional approach of ethics committees too often leads to the denigration of nonpositivist research approaches (Dolan 1999, p. 1009).

Such approaches have been adopted in nursing research. They are now more widely used. The complexity and changing environment of modern research activity, related legislation and health policy demand an expansive approach to research design (Pope & Mays 1996). Research conducted to support and inform specific health policy initiatives and service

dilemmas often require innovative combinations of methods and techniques; for example, the role and value of qualitative research has been increasingly acknowledged (Pope & Mays 1996, Barbour 1999).

The LRECs have lacked members more conversant with the range of research methods adopted by nurses (Dolan 1999). This creates a situation where methodological inexperience of committee members impairs their ability to review a study. There is a risk of avoidable delay when time is needed to explain, clarify or seek a second opinion on methodology, sample size issues and the difference between qualitative research and audit.

The new governance arrangements for RECs require a Committee to appoint members from a range of clinical and methodological backgrounds. Despite this, a quantitative emphasis may continue to prevail. This is partly due to the historical predominance of medical representation on LRECs. In addition, workload and lack of resources make it difficult to recruit and ensure the appropriate range of expertise, including qualitative research experts. Finally, the climate of evidence-based practice, where the randomised-controlled trial is seen as the gold standard, has a number of implications. These include the inappropriate challenging and rejection of good quality qualitative studies by LRECs and the:

...questionable practice of [qualitative] researchers calling their studies 'audits' in order to circumvent the vagaries and inconsistencies of research ethics committees (Dolan 1999, p. 1010).

In summary, RECs have been accused of thwarting well-designed, beneficial research for many reasons. All these are intensified by the increasing workload.

### Governance arrangements for RECs

Despite the discussion and criticism in the literature cited above the problems with LRECs persist and threaten to compromise the ethical conduct of research (Tully *et al.* 2000). For a number of years there has been a call for a system of greater accountability for RECs which will oblige them to justify their decisions (Gilbert *et al.* 1989, Savulescu *et al.* 1996). The newly published governance arrangements for RECs is the most recent attempt to improve the situation (Department of Health 2001). The new requirements are wide-ranging and tackle issues relating to membership, processes and delay. The potential of the governance arrangements to succeed is limited for at least two reasons; the first relates to REC funding, the second to the way tertiary parties who are not directly subject to REC scrutiny can affect the way that research is conducted. I shall examine these in turn.

## REC funding

The content and intentions of the new Governance arrangement from the Department of Health are laudable. However, the targets are demanding and create huge operational, administrative and workload challenges. These challenges include the introduction of guaranteed response times and systems of appointing and training committee members. Some committees may find themselves in a 'catch 22' situation. Without the necessary funding and support, the lack of resources and onerous workload that already hinders their conduct may well prevent them from implementing the new arrangements. Improving the standard and consistency of the application process and provision of adequate administrative support will require financial support. Recruitment of the necessary range and quality of clinical and methodological expertise will be obstructed without financial remuneration and funded training of members.

## Multi-agency influences on research ethics

The focus of REC attention is on the rigour of the study and researchers' capacity to conduct the research. Committees will assess researchers' awareness of the ethical dimensions of the study design and their ability to deal with these in a satisfactory manner. The ethical probity of health service research is not only dependent on researcher. The ethical conduct of research is also reliant on the health service staff who researchers are obliged to interact as a result of undertaking the research.

This is of particular concern following recent alleged breaches of trust between the medical profession and public in the name of research. Examples of this include the retention of organs as in the case of Alder Hey Hospital (Boseley 2001) and the unauthorized use of patient information for epidemiological research (Guardian 2001).

After LREC approval has been obtained for a study, there are a number of ways in which clinicians, as research partners, might compromise the ethical conduct of a project. This may well be inadvertent behaviour on the part of a well-meaning individual. For example, a large component of the ethical review of a study involves analysing how participant identification and recruitment processes would protect patients' confidentiality and their right of autonomy. During the recruitment process the researcher may interact with and rely on a range of health care professionals. The level of ethical and legal awareness of these clinicians can be as important as that of researchers and LRECs in maintaining ethical rectitude. Illustrations of this are discussed here with a focus on confidentiality and consent.

## Clinicians' legal and ethical awareness

### Confidentiality

In order to identify and recruit participants to a study a researcher will need the co-operation of the health professional responsible for their health care. In most cases this would be the hospital consultant or general practitioner. The doctor is, therefore, obliged to provide the patient participant with written or verbal information regarding the study. It is only if that patient agrees that the researcher can contact them. Participant consent is required for the researcher to access patient details or medical records.

Details of the manner in which this will occur will be requested as part of an ethics committee application. REC application forms require evidence that the appropriate clinician has been consulted and agreed to carry out the work involved in recruitment. Problems can occur if, once the study is underway, a clinician may find that the work involved is greater than anticipated or that their regular workload has increased. As a result, well-meaning clinicians may be encouraged to 'pass on anonymised or nonanonymised data (to a researcher) without realizing the legal implications' (Strobl *et al.* 2000).

In 1997, the Caldicott Committee reported on their review of the use of patient-identifiable data in the NHS. A number of recommendations were presented and the intention declared to promote awareness of the issues at all levels in the NHS. 'Caldicott Guardians' were appointed in all Trusts and Health Authorities to oversee implementation of the Caldicott Committee's recommendations. How effective these initiatives have been remains untested. However, there certainly remain problems, as evidenced by Strobl *et al.*'s (2000) call for clear guidance for epidemiologists on confidentiality because of confusion, differences and difficulties in interpreting the Data Protection Act. Lack of policy guidance contributes to uncertainties regarding the roles of 'Caldicott Guardians' and ethics committees (Strobl *et al.* 2000). Similarly, guidance is required for clinicians who may, unknown to the REC, compromise the ethical conduct of a study by passing on information inappropriately.

### Consent

There is an increased emphasis on the importance of seeking patient's views regarding health policy (Department of Health 2000) and law (Guardian 2001, Public Inquiry into Children's Heart Surgery at Bristol Royal Infirmary 2001). There is an expectation that patient's consent will be sought in order to use their data for research purposes. The current



value placed on patient opinion and consultation contrasts with the historical attitudes of the medical profession. In the past, the medical profession has been accused of paternalism and jeopardizing patient autonomy by making decisions on patients' behalf (Savulescu 1995). It has already been stated that an environment of legal confusion exists in the UK health service regarding such issues as data protection (Strobl *et al.* 2000). It is possible that, in such an environment, a busy clinician may be tempted to fall back into a paternalistic attitude. If in their judgement a patient's participation in the research will cause no harm, they may be tempted to pass the patient details to the researcher without the consent of the patient.

The scandals at Alder Hey, Liverpool and Bristol hospitals has brought issues relating to consent to the forefront of the public mind. The Redfern and Kennedy reports have gone some way towards highlighting the action required to prevent future similar breaches in consent and to rebuild public confidence (Redfern *et al.* 2001, Public Inquiry into Children's Heart Surgery at Bristol Royal Infirmary 2001). The focus of these reports, as is appropriate, is on consent for treatment procedures. Discussion regarding confidentiality and consent relate to the use of patient data in research focus on epidemiological research (Mayor 2000). There is a risk, therefore, that issues of confidentiality and consent regarding identification and recruitment of patient subjects in other health research may be missed amongst within the existing debates and documentation.

## Summary

In brief, the ability of the new governance arrangements to address past criticisms of REC may be compromised by two factors. The first is insufficient funding. The second is confusion about confidentiality and consent requirements in clinical areas where research is conducted and where recruitment occurs. It is imperative that the public are not given further cause for concern and mistrust due to well-intentioned and busy clinicians passing on data to researchers without their consent.

In summary, this article has reviewed past criticisms of ethical review of health service research in the UK and the ability of new governance arrangements to tackle these. It might be argued that the paper has only looked at the framework within the UK and is therefore only of relevance there. However, there are at least two reasons to expect that lessons learnt from analysing the UK's ethical review process will be of much wider relevance.

The first is the near universality of the ethical committee review process. The need for ethical committees to review

biomedical research was identified at least as long ago as 1962, with the first Declaration of Helsinki (WMA 2000). However, it took a number of shocks to the system before the recommendation was widely implemented; important to this were the publications in the 1960s of Beecher (1966) and Pappworth (1967). Both showed an alarming level of unethical research by mainstream clinicians despite the Helsinki Declaration. Since that time, the review of health care research by ethical committees has become almost universal.

The second reason is that research into ethical committees in Europe shows that they have a fair degree of similarity in relation to their structure and function (Megone *et al.* 2001). For example, the UK's experience of the majority of REC members being medical doctors is shared in all the European countries surveyed by Megone *et al.* (2001).

## Implications for nurses

What then, are the implications for nurses of this analysis of UK ethical review procedures? In the research setting, nurses may act as researchers, REC members or clinicians where research is carried out. Points for consideration by nurses working in any of these capacities are as follows:

- Nursing is a relatively new academic discipline when compared with that of medicine. Nursing does not, therefore, have the equivalent volume of research knowledge and experience. As a result, nurses may find themselves applying to RECs as novice or inexperienced researchers. They may be unaware of the procedural delays they could experience. Nurses require awareness of the extent of potential delay in starting their research caused by REC approval process. This delay can then be built into the research timescale and planning.
- In the past, RECs have not always provided the experience and expertise in the range of methodologies used in nursing research (Dolan 1999). It is essential that nurses using less familiar methodologies are able to provide concise, clear and rigorous arguments supporting the use of their chosen methodology. They need to demonstrate the appropriateness of the methodology and its ability to meet the study aims, identify any methodological limitations and their impact, and exhibit their ability to carry out the study. It is worth considering that an application which appears to evangelize, or be extravagant in its vocabulary and jargon, is likely to drive those cynical about qualitative research further 'into their corner'.
- As with all health service researchers, nurses recruiting to research in the NHS need to consider carefully how they will identify, contact, recruit and gain consent from participants. Any potential threats to rights of confidentiality

or autonomy should be detected. This will require discussion with relevant clinicians, including the lead clinician responsible for the patients' care.

- If a nurse is acting as researcher but is not clinically involved in the area of study, the lead clinician needs to be acknowledged as a partner in the research and made aware of the ethical implications of the study. He or she will be responsible for ensuring that members of the appropriate clinical team introduce patient participants to the study. The researcher will then only receive patient details or contact patients after agreement is obtained.
- If a nurse is conducting research and are also involved in the clinical care of patient participants, she needs to consider potential role conflicts. Examples of these include the risk that patients would feel induced to participate in the study out of a sense of obligation to the nurse who cared for them. In addition, nurse researchers' clinical involvement may introduce bias in terms of selection, data capture, and analysis and interpretation of data.
- Nurses working in a clinical capacity in a research study setting, may be asked to help with identification and recruitment of patient participants. They should have had access to evidence that the research has undergone the required scrutiny and that the researcher has sought the appropriate approval from RECs, nursing management and lead clinician. Nurses should be aware that they must not make patients' details available to researchers without the processes appropriate to protect rights of confidentiality and autonomy being followed.
- Nurses appointed to a REC are advised to negotiate protected time to attend meetings, read proposals and access training. The decision to sit on a REC should be an informed one and nurses are advised to establish exactly what the time and workload commitments are. For some committees, this may be onerous.
- Whilst nurses are not on RECs to 'represent' the nursing profession, they do have a potentially invaluable role and can offer a unique perspective. The nature and continuity of their work and care can provide nurses with the ability to discern the implications of conducting a research study for patients as well as for the organization of work in health care settings. Such implications may not be apparent to other members with a more distant or episodic contact with patients or clinical environments.

## Conclusion

This overview of ethical review of health service research in the UK reveals certain challenges. The source of these challenges lies in a combination of factors, including

historical and procedural issues. A review of the past criticisms shows that the new governance arrangements for RECs may go some way to addressing the problems. They will, however, be hampered in doing this unless sufficient investment in RECs is made. It is important to realize that, where research ethics are concerned, this is a tripartite concern. Researchers, RECs and clinical research partners all contribute to the ethical probity of health service research. Nurses can act in any combination of the three roles of researcher, REC member and clinician. They need to be aware of their responsibilities and obligations in maintaining ethical integrity in research.

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## 'I'm still waiting...': barriers to accessing cardiac rehabilitation services

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'I'm still waiting...': barriers to accessing cardiac rehabilitation services

**Background.** The United Kingdom (UK) National Service Framework for coronary heart disease challenges health services to address existing problems regarding the quality and content of cardiac rehabilitation services. Concern also exists regarding inequalities in access to services. The South Yorkshire Coalfields Health Action Zone (SYCHAZ) funded this study to harness the views and experiences of staff and patients regarding existing services. The intention is to use the information gained to develop acceptable and accessible services for the future.

**Aims.** To explore what barriers exist for patients in accessing cardiac rehabilitation services within the South Yorkshire Coalfield locality.

**Ethical issues and approval.** Patients were identified and recruited with the assistance of staff responsible for their care. Informed consent was obtained prior to participation. Approval was obtained from the relevant Ethics Committees.

**Methods.** Qualitative methods were used, including semi-structured interviews and Framework Analysis techniques. Purposive sampling was used to select participants.

**Instruments.** Semi-structured individual interviews of 15 staff and 20 post-myocardial infarction patients. One group interview with seven health visitors and two with lay members of heart support groups.

**Outcomes.** Barriers to accessing cardiac rehabilitation.

**Results.** This study revealed a limited service capacity. Big gaps exist between patches of service activity that most patients appear to slip through. Problems in accessing the service were categorized into five themes: absence, waiting, communication, understanding, and appropriateness. Some groups fared worse in terms of access to services, for example women, the elderly and those in traditional working class coalfields communities. Professional and more affluent participants appeared better able to negotiate their way around the system by seeking out advice or 'going private'.

**Limitations.** The omission of medical staff and ethnic minority patients.

**Conclusions.** Cardiac rehabilitation in the policy targets in UK will only be met with substantial investment to address the barriers identified here.

Keywords: cardiac rehabilitation, barriers, access, inequalities, National Service Frameworks, qualitative research, framework analysis

## Introduction

This paper outlines the results of a study conducted as part of a programme of qualitative research funded by the South Yorkshire Coalfields Health Action Zone (SYCHAZ). South Yorkshire is a socio-economically deprived area in the north of England with high levels of chronic disease such as coronary heart disease. Health Action Zones are a United Kingdom (UK) government initiative to increase resources available to areas of deprivation and poor health. They aim to promote organizational partnerships to address inequalities in health.

This study is part of a wider programme of research examining access to heart health services (Tod *et al.* 2001). Cardiac rehabilitation was selected as the study for this study because of acknowledged limitations of national and local services (Thompson *et al.* 1997, Bethell *et al.* 2001). Health services in the study area are currently exploring ways to develop cardiac rehabilitation as directed in recent health policy (Department of Health [DoH] 2000). The research provided a vehicle to harness user and staff views. The intention is to use these to help redesign services for the future and reduce inequalities in access.

## Background

### *Coronary heart disease and access to services*

The human and financial cost of coronary heart disease is the priority concern for patients and health services alike. Every year approximately 150 000 people in UK survive a myocardial infarction (MI) (British Heart Foundation 1999). Some of the highest national coronary heart disease rates are experienced in the South Yorkshire Coalfields (South Yorkshire Coalfields Health Action Zone 2001). The link between coronary heart disease and deprivation is illustrated in these communities. Their health has been affected by long-term deprivation and exacerbated by the continuing decline in the traditional local industries such as coal and steel. Deprived communities also encounter inequalities in access to and uptake of heart health services (Payne & Saul 1997, Melville *et al.* 1999).

Heart disease, if not well managed and appropriately treated, may seriously impair their quality of life. One intervention which aims to benefit patients and relatives is cardiac rehabilitation. It is suggested that access to and uptake of cardiac rehabilitation is reduced in lower socio-economic groups (Melville *et al.* 1999).

The South Yorkshire Coalfields have identified coronary heart disease as a priority area. Improving delivery of and access to cardiac rehabilitation emerged as a question of concern within the SYCHAZ.

### *Cardiac rehabilitation*

Cardiac rehabilitation is a multidisciplinary, multifaceted intervention, which aims to benefit patients and relatives through exercise, education and psychosocial support

#### Box 1 Phases of Cardiac Rehabilitation

##### *Phase One*

In-patient cardiac rehabilitation, from admission to discharge.

Includes:

- reassurance
- information
- risk factor assessment
- education
- mobilization
- discharge planning
- involvement and support of partner/family

##### *Phase Two*

Immediate post-discharge, for up to 6 weeks.

Largely focused on education and resumption of physical activity.

Various models of delivery include:

- telephone follow-up
- telephone help line
- home visits by hospital based specialists or community nurses
- individual appointments in hospital or primary care
- group sessions

##### *Phase Three*

Intermediate post-discharge from 4 weeks post-discharge.

Traditionally service is hospital-based and exercise-focused. Recent efforts emphasize 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.

Adapted from: Brodie (2001), Jones and West (1995), Stokes *et al.* (1995).

(National Health Service [NHS] Centre for Reviews and Dissemination 1998). The aims of cardiac rehabilitation are to promote recovery, return to health and maximize quality of life and to reduce the risk of recurrence of cardiac illness (Bethell 2000). Four phases have been identified from the point of diagnosis to long-term maintenance (DoH 2000) (Box 1).

A comprehensive and individualized cardiac rehabilitation programme by suitably trained staff has been shown to reduce mortality by as much as 20% to 25% over 3 years (Oldridge *et al.* 1988, O'Connor *et al.* 1989). A recent systematic review revealed a 27% reduction in all cause mortality for exercise only cardiac rehabilitation (Jolliffe *et al.* 2001).

The nurse's contribution to cardiac rehabilitation has been identified as crucial (Noy 1998). Assessment, information giving, health promotion and psychosocial support are all components of cardiac rehabilitation delivered by ward, community or specialist nurses. The specialist nurse often emerge as the co-ordinator of cardiac rehabilitation programmes (Noy 1998). There is concern, however, regarding the variation and a lack of clarity in the nature of such nursing posts, ranging as they do from volunteer positions to full time and well trained specialists (Newens *et al.* 1995). There is also a call to integrate cardiac rehabilitation nursing interventions better in primary and secondary health care settings (Tod *et al.* 1998).

Despite evidence of effectiveness, cardiac rehabilitation provision in UK would appear to be patchy and unreliable (Bethell 2000). Allegations regarding inconsistent quality and content of services have been made (Thompson & Bowman 1997). There are also questions regarding inequalities in access to cardiac rehabilitation (NHS Centre for Reviews and Dissemination 1998, Melville *et al.* 1999). Current services are often hospital based, limited to low risk patients and operate strict exclusion criteria (Thompson *et al.* 1997). A low uptake exists amongst women, ethnic minority groups and the elderly which suggests that current services are either difficult to access or do not address their needs.

#### *The health policy agenda*

Reducing coronary heart disease rates and addressing health inequalities are currently a priority in UK health policy. The National Service Framework for coronary heart disease sets out standards to ensure the quality and content of heart health services as a way of realizing these targets (DoH 2000). This challenges the NHS to rectify the deficits and inequalities in existing cardiac rehabilitation services.

In the National Service Framework (NSF), NHS Trusts are expected to invite all patients admitted to hospital suffering from coronary heart disease to participate in a multidisciplinary programme of secondary prevention and cardiac rehabilitation (DoH 2000).

A limited cardiac rehabilitation service is available in the study area. The services differ slightly between the three areas. They are restricted in scope and capacity but all provided the following:

- Patients identified by a cardiac rehabilitation nurse or physiotherapist are seen pre-discharge for risk factor assessment, education and advice.
- A health visitor sees a small number of patients at home post-discharge.
- Phase three classes are available to some patients but services are tailored to the lower risk patients.
- A limited number of phase four classes were available across the Health Action Zone but require long distances to travel.

Local audit data indicate that services are inadequate to meet local need and to achieve NSF targets. More information was required to identify how this should be carried out in order to meet the needs of populations such as the South Yorkshire Coalfields, and those groups currently excluded from services. Previous studies on barriers to and preferences for services have been based in the USA (Evenson & Fleury 2000). Differences in culture and health services militate against transferring the results to an UK setting. A key factor in this is the underlying philosophy of UK NHS, where services should be available to all at the point of need. UK cardiac rehabilitation services have developed piecemeal, often funded by charitable or short-term sources, with variable commitment from mainstream funding.

#### The study

The study presented here was conducted to provide local information to identify what currently prevents people accessing cardiac rehabilitation in the South Yorkshire Coalfields. The intention was to include the views and experiences of populations who are often excluded from cardiac rehabilitation evaluation, for example the elderly, women and those from lower socio-economic groups. The data gathered is likely to be of interest to other health communities with similar levels of deprivation.

#### Aim

To explore what barriers exist for patients in accessing cardiac rehabilitation services within the South Yorkshire Coalfield locality.

#### Methods

##### *Method and design*

Qualitative methods were adopted utilizing semi-structured interviews and Framework Analysis techniques (Ritchie &

Spencer 1994). It has been suggested that in order to respond appropriately to the health needs of a community and address inequalities it is necessary to incorporate the views of that community. Traditional epidemiological techniques are ill suited to access this information. A more qualitative line of enquiry such as the one adopted here is recommended (Bowling 1997).

Data was collected between September 2000 and July 2001. Ethical approval was obtained from the three Local Research Ethics Committees in the SYCHAZ area.

#### Sample and Setting

The study was conducted in SYCHAZ. Purposive sampling was used to select people for individual interview to ensure a range of participants (Bowling 1997). Twenty patients were selected by the researcher from a sample of 23 who had agreed to participate. A range in terms of age, gender, employment, postcode, cardiac history and cardiac rehabilitation attendance was obtained.

Patient participants had all been admitted with an acute MI to one of the three acute hospitals in SYCHAZ area.

Patients' ages ranged from 43 to 76 years. Four women and 16 men with a range of employment history were

included. Twelve participants were retired, three were on sick leave, two were unemployed and three had returned to work. The nature of employment ranged from professional to various skilled and unskilled occupations. There was a range of home location in terms of area of deprivation and a mix of rural, urban and ex-mining community residents. All participants had a diagnosis of acute MI. Sixteen had had an MI less than 8 months prior to the interview. The remaining four had a more complex cardiac history. They were recruited to the study because their latest cardiac event was an MI but they had experienced an MI or heart surgery before. The National Service Framework requires all patients with coronary heart disease to be discharged with a programme of cardiac rehabilitation. This would include patients requiring surgery. For this reason, patients post-MI who were waiting for, or had experienced cardiac surgery were included. The sample incorporated those who had and had not attended cardiac rehabilitation (Table 1).

Patients were excluded if they were unable to participate in an interview as a result of any significant comorbidity, if participation may cause distress or they were unable to give informed consent.

Table 1 Patient sample and cardiac rehabilitation access

	Age	Gender	Cardiac Rehabilitation Health visitor home visit	Access to Phase 3 Hospital cardiac rehabilitation
1	63	Male	None	Excluded due to angina Waiting for angiography
2	51	Male	Visited twice	Started 14 weeks post-MI. Stopped 2 weeks later because of chest pain. Trying to get angiography privately
3	76	Male	None	Not interested in attending hospital
4	65	Male	Yes	Still waiting
5	60	Male	Yes	Excluded due to positive Exercise Tolerance Test
6	50	Female	Yes - 5 months post-discharge	Still waiting
7	58	Male	None	Started cardiac rehabilitation over 2 years post-MI. Re-accessed the system because of readmission to hospital with chest pain
8	72	Male	None	Started a year after cardiac surgery
9	66	Male	Yes	Excluded due to positive Exercise Tolerance Test. Waiting for cardiac surgery
10	65	Male	None	Started 9 months after cardiac surgery
11	55	Female	None	Still waiting
12	43	Male	None	Still waiting
13	58	Male	None	Currently attending
14	71	Male	None	Still waiting
15	68	Male	None	Start week after interview
16	52	Male	None	Still waiting. Trying to access cardiac rehabilitation through private health care
17	50	Male	None	Still waiting
18	48	Female	None	Still waiting
19	57	Male	None	Still waiting
20	71	Female	None	Excluded due to positive Exercise Tolerance Test

Table 2 Staff participants

Profession	Gender	Health care setting
Health Promotion Officer	Female	Health Authority
Health Promotion officer	Female	Health Authority
Public Health Doctor	Male	Health Authority
Exercise Development Officer	Male	Health Authority
Health Visitor	Female	Community
Practice Nurse	Female	General Practice
Dietician	Female	Community
Nurse	Female	Hospital
Nurse	Female	Hospital
Nurse Manager	Female	Hospital
Physiotherapist	Female	Hospital
Physiotherapist	Male	Hospital
Physiotherapy Manager	Female	Hospital
Dietetics Manager	Female	Hospital/Community
Fitness Instructor	Female	Leisure Services

Fifteen health professionals were selected for interview to ensure a range in terms of profession, age and health care setting. The sample included cardiac rehabilitation staff, nurses, dieticians and physiotherapists, health promotion officers, a public health doctor, health visitor, community exercise worker, hospital and community nursing managers. The majority of the participants were female, only three were male, which reflects the gender bias in the professions (Table 2).

Three group interviews were conducted to test emerging findings from the individual interviews. One was with seven health visitors and two with lay members of heart support groups.

#### Participant identification and recruitment

Patients were identified and recruited by hospital staff involved in their care. In two areas they were recruited retrospectively from the MI database. In the third hospital patients were recruited prospectively, during hospital admission, by cardiac rehabilitation staff. A detailed information sheet was distributed with a consent form which patients were asked to return if they were prepared to be contacted about the study. Consent was verified immediately prior to the interview commencing.

The health professionals were contacted by phone by the researcher, and the purpose and nature of the study explained. If they agreed to take part, an appointment for interview was made.

The group interviews were conducted within established training events organized by personnel external to the research study. The organiser and participants were approached by the researcher and consent obtained prior to the discussion to include the data in the study.

#### Data collection

The individual interviews took place in the patient's home or staff workplace. Interview schedule items included, well-being post-MI, help and support required and received, causation, views on cardiac rehabilitation, lifestyle modification and health uncertainties. Interviews lasted between 20 and 40 minutes, were tape recorded and transcribed and field notes taken. Patients were given the option of having someone with them during the interview. Many expressed a wish for their partner or spouse to be present as there was a strong sense that the heart attack affected the whole family. Eleven patients were interviewed with a partner present.

The group interviews were facilitated by the researcher and lasted between 20 and 60 minutes. They took the form of guided workshop discussions. Flipcharts lists and notes were taken to record the content of the discussion with the help of a scribe. The researcher and scribe discussed the interview immediately afterwards and field notes taken of these reflections.

#### Data analysis

The transcripts, diagrams and field note data were entered into QSR NVivo, a computer software package for the management of qualitative data. Participants were referred to by number in order to preserve anonymity. Framework Analysis techniques were adopted (Ritchie & Spencer 1994). This approach employs sifting, charting and sorting the material in a systematic manner in order to allow key issues and themes to emerge. *A priori* issues and other literature are integrated into the data analysis. 'Framework' provided a clearly defined analytical structure which contributed to the transparency and validity of the results.

The criteria of credibility, transferability, dependability and confirmability, outlined by Lincoln and Guba (1999) were



adopted as tests of rigor and 'trustworthiness'. A second researcher (FM) analysed a random sample of transcripts to check the theme identification and interpretation against these criteria. The group interviews were used to test the emerging results from the initial analysis thus adding to the 'trustworthiness' of the findings.

## Results

Staff participants reported an awareness of the limitations of existing cardiac rehabilitation services. The patient data revealed the extent of these limitations and confirmed that existing services met only the minority of patient's needs. Gaps were seen to exist between patches of service activity, with most patients slipping through the net. Access barriers fell into five themes; absence, waiting, communication, understanding, and appropriateness. The results are presented under these themes with an additional section identifying factors facilitating access.

### Absence

Absence was a theme interwoven in the responses of both patients and staff. Staff admitted that there had been a lack of commitment and investment in services in the past. Services were therefore limited and the resultant absence created a fundamental barrier to the many people accessing cardiac rehabilitation after a heart attack. The reported consequence of inadequate past commitment was the absence a clear strategy, funding, planning, enough adequately trained staff and agreed processes to support service delivery.

Clinical staff felt overwhelmed by the existing workload. There was serious concern at the prospect of having to try and expand the service to other groups of cardiac patients without additional resources, as required by the National Service Framework. Lack of time meant they were unable to think strategically and focused their attention on the one aspect and phase of the service they were trying to deliver, rather than the overall pathway.

I think when you haven't even got the basic stuff, it's hard to like visualize what you could go on and see (Staff)

The patients accounts of their heart attack and its effects on their lives revealed cardiac rehabilitation services were often absent when needed. People spoke quite powerfully of the abandonment, isolation and vulnerability experienced as a consequence of inadequate services.

Three time points were identified when the absence of cardiac rehabilitation services were most acutely felt:

- On transfer from the coronary care unit to the medical ward when people began to feel lost to the system.
- During the first 2 weeks post-discharge when participants thought help was needed to prevent fear and vulnerability developing.

### Box 2 Absence and abandonment

#### Time of absence

##### Transfer from CCU:

'I felt very, very vulnerable in there and they didn't know what was wrong with me'.

'you're thrown upstairs into a ward and it's totally different and you're on a ward and nobody seems to what shall I say? to care really!'

##### First 2 weeks post-discharge:

'I think as soon as you come out of hospital, you need some sort of guidance because that is the critical time not 6 months afterwards'.

##### 6-8 weeks post-discharge:

'Sister told me that "We're sending for you in about 6 weeks, Mr X, and we'll make an appointment for you to come back." I've never heard nothing from them!'

'I'd done as much exercise as I could and I was waiting for the next bit to kick in and obviously not hearing anything'.

#### Type of service absent

##### Advice and reassurance

'If I could have picked a phone up and said, "Look, you know, I'm feeling a bit ropy" that would have been good. Not necessarily visited by anyone, or visiting anyone'.

##### Psychological support

'...although you actually suffer the pain when you have the heart attack, I think the mental side of it is worse'.

'A lot of it is in your head, isn't it, the recovery and that. I was surprised how much it affected me, you know? But nobody actually came and sat with me'.

##### GP support

'He never came near us. Never came near us. Well, we sorted it out ourselves ...Yeah, but he never come near us. He's never been anywhere near us'.

##### Personalized information

'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'.

##### Support for the partner and family

'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?"'

- At 6–8 weeks post-MI, when, having relied on the written information given in hospital, people were left wondering what to do next (Box 2).

Participants singled out some specific components of cardiac rehabilitation as particularly important and the absence of these was emphasized. These included, advice and reassurance, psychological support, GP support, personalized information and support for the partner and family (Box 2).

### Waiting

Long waiting lists appeared to be the inevitable consequence of the limited cardiac rehabilitation service capacity. Waiting lists of up to 12 months created a delay and prevented people accessing services at a time when they needed them.

He hasn't been called for it yet because there's a long waiting list. I mean it's useless now, isn't it? (Patient's wife)

He says, 'Have you been to rehab yet?' I says, 'no' and he says, 'They'll be in touch.' But that's six months ago since my heart attack and the time's passed. I think really it'll be a waste of their time. (Patient)

Exclusion criteria for the hospital cardiac rehabilitation group also created a barrier. Exclusions were on the basis of age, a positive exercise tolerance test, postinfarct angina or heart failure, despite the fact they may have benefited the most from exercise cardiac rehabilitation.

Some participants were temporarily excluded until they had had an interventional cardiology or revascularization procedure. This created two waiting periods, first for the procedure, then for cardiac rehabilitation. In some instances it was the waiting, not just the illness, which impacted upon life satisfaction and well-being and created an inability to move on.

### Communication

Barriers because of poor communication fell into two categories; communication systems and the standard of information giving. Examples of failing communication systems included:

- Patients and community nurses unable to extract information about the availability of the hospital cardiac rehabilitation service.
- Inability to pass information regarding patients across health care settings creating delays of months in referral.
- Lack of clarity of how, when and who refers to the hospital cardiac rehabilitation classes and patients.
- Delays in receiving test results, e.g. exercise tolerance tests, which held up patients progress.

- No system to circulate information about the range of exercise and activity schemes available to patients in the community.

Big time gaps occurred between contact, allowing confusion about their recovery and services availability to grow. Staff reported that additional resources, especially information technology, would help to improve the current deficits in referral.

Sister told me that 'We're sending for you in about six weeks, and we'll make an appointment for you to come back.' I've never heard nothing from them!...So it's gone haywire in the hospital somewhere I think. and I still haven't heard 'owt, so whether it's their end or what or in between us I don't know. (Patient)

Inconsistency of advice giving and occasions the information didn't make sense to the patient also constituted barriers to accessing cardiac rehabilitation. Problems with communication were highlighted with those patients who could not speak English. This included people whose first language was sign, as well as another spoken language. Examples included the inadequate availability and use of interpreters, difficulty in accessing information in a group situation, the tendency for staff to make decisions regarding care without consulting the patient and the lack of availability and use of communication aids, for example, computer assisted learning.

### Understanding

Staff understanding and definitions were dominated by reference to the phases of cardiac rehabilitation. This meant a focus on patches of activity rather than pathways, processes and content of care.

Patients and carers expressed a lack of understanding of what cardiac rehabilitation is, which influenced their decision of whether to access the service or not. For example, some people had unmet expectations as a result of misunderstanding. If expectations were not met this could lead to a loss of confidence in the service.

Probably I was expecting too much...I probably read it wrong. It probably wasn't for that, but there again if there's a help line, why have a help line if they're not going to help you? (Patient)

Some patients interpreted cardiac rehabilitation as exercise only. This was a barrier when people did not see exercise for them.

I mean I don't want to do anything too strenuous. I'm getting lazy in my old age! (Patient)

There was still perception amongst some that exercise is for fit people only and isn't good for you after a heart attack.

I wasn't looking forward to it. I can tell you that. I'd have gone as it happens, but I didn't know what it entailed. You know? I can't see me jumping up and down on the bars and all this, could you? After an heart attack, I don't know. (Patient)

Patients understanding of coronary heart disease and their heart attack appeared to influence whether they accessed cardiac rehabilitation. Patients attributing the heart attack to one factor instinctively focused on resolving that one issue. Where raised cholesterol was blamed, diet was changed, cholesterol-lowering drugs taken and blood levels improved. There was then little motivation to access cardiac rehabilitation or look at overall heart health.

Patient's heart attack experience sometimes differed from their expectations. When the symptoms were not as severe or enduring the instinct was to minimize the severity of the illness. The patient then perceived they did not need cardiac rehabilitation. This inclination was also identified by staff who linked it to a cultural tendency in the South Yorkshire Coalfields, not to admit to weakness.

A lot of people don't appreciate exactly what's gone off, that they turn round and say 'Well I've had a heart attack and I'm all right now...' Certainly in this area there's an ego image with the fellows. (Staff)

### Appropriateness

The final barrier identified in this study relates to the extent to which cardiac rehabilitation services, as they are currently delivered, are perceived to be appropriate by patient.

Some participants advocated the delivery of education and exercise in a group setting. Others found it inappropriate and unappealing. People were deterred from attending groups because they found them stressful socially, lacked privacy or were put off by dominant members in the group. There also appeared to be an expectation that they would be the odd one out, with other group members being older, younger, more or less ill than them.

I mean there might have been people there who'd had really bad heart attacks and it could have made me worse, you know, by talking to them. (Patient)

Those who considered hospital-based services inappropriate valued the choice of a local service. Reasons given for this preference included not wanting to travel, problems with transport, parking at the hospital and also a reluctance to revisit the hospital. The latter was explained by a fear or intense dislike of hospitals and also its association with what had been a terrifying event, the heart attack.

Actually I mean I detest hospitals to be quite honest. (Patient)

It were quite stressful going [to cardiac rehabilitation] anyway. Like re-visiting the scene of the crime! (Patient)

Both patient and staff participants reported that women were precluded from attending a cardiac rehabilitation by other commitments. These included childcare, paid employment, housework and family responsibilities. Delay in service availability places an additional barrier upon women because of the speed with which they resume responsibilities in the home and family. The commitments were more acutely felt in areas of high male unemployment and traditional Coalfields communities because,

It's the women that sort of bear the brunt of the caring role. (Staff)

The elderly also experienced specific barriers in accessing cardiac rehabilitation. Staff and patient participants thought existing services inappropriate for the elderly, often because of the hospital base. Frailty because of age or comorbidity may exacerbate problems with travel, transport and distance to services. Elderly participants also emphasized the importance of routine in their lives and the security this offered. If cardiac rehabilitation attendance disrupted their routine, they would not attend.

I refused help from the hospital...I said, 'Well, what's the times?' He said, 'Mornings.' I said, 'That's out. (Patient)

### Facilitating factors

Facilitators in accessing services were also identified. 'Going private' or paying for private health care, was considered the only option by some who found NHS services deficient.

I have got a lot of questions...I need to sort myself out. and I couldn't see me waiting that length of time. So I said, 'Well, I'll go private. (Patient)

'Finding alternatives' was the only option open to some when faced with delay in accessing NHS facilities. These alternatives included accessing leisure clubs for exercise and friends and family who have had a heart attack for information and advice. 'Being in control' over aspects of their lives provided patients with more opportunity to access services. For example, having control over their own time and their own transport enabled them to access services whatever the time and location.

It's fortunate that I'm a company director so, you know, to a great extent I can suit myself, but not everybody is as fortunate. (Patient)

Having the knowledge, skills and assertiveness to take control when communication systems fell down also marked

some patients out as being able to access services when others couldn't.

Things that happened have all been in my favour...I'm not an average national health patient. You see?' (Patient)

## Discussion

This study provides a snapshot of the cardiac rehabilitation provision in the South Yorkshire Coalfields as experienced by the patients and staff participants. Many of the barriers identified relate to problems with service capacity. The level of service required by patients and families in this study varied but limited capacity and inflexibility prevented staff offering an appropriate range of services to ensure access. As a qualitative study these experiences can only claim to relate to the study population. It is, however, interesting when the national situation is considered. Bethell *et al.* (2001) reported between 14% and 23% of patients post-MI are enrolled onto cardiac rehabilitation programmes. This raises broader questions about the adequacy of services in UK.

Staff participants echoed the view of Bethall (2000) and Fearnside *et al.* (1999) that lack of investment and omitting cardiac rehabilitation from services commissioned in the past has contributed to the problem. As reported by staff in this study, services can then become reliant on the enthusiasm of dedicated individual practitioners, often nurses, who provide a programme restrained by the limitations of their individual resources and skills (Bethell 2000).

The results add strength to the findings of previous research regarding the importance of certain aspects of cardiac rehabilitation. These include the needs of partners and families (Frederickson 1989, Hilbert 1994), the importance of timely and appropriate information giving (Scott *et al.* 2001), appropriateness of services for women (Radley *et al.* 1998, Halm *et al.* 1999) and people from deprived communities (Melville *et al.* 1999), communication and hospital based services (NHS Centre for Reviews and Dissemination 1998). This study illustrates how ill equipped the services are to provide the menu driven programme and individualized care that were valued by patient participants and have been recommended elsewhere (Oldridge 1991).

One of the study aims was to identify barriers which contributed to any inequality of access to cardiac rehabilitation. It should be noted that access to services was poor across patient groups. The indication was, however, that the professional and more affluent participants appeared better able to negotiate their way around the system by seeking out advice or 'going private'. This patient group were also in more control over their time and workload and so could

access hospital-based programmes regardless of distance to travel or time of day.

Certain participants, such as women, the elderly and those in traditional working class coalfields communities, were likely to have more complex needs or social expectations regarding recovery. For these, barriers in accessing services had a more severe impact.

Reasons for returning to role related behaviour, and not attending cardiac rehabilitation, were revealed by the South Yorkshire Coalfields participants. Women were under pressure to return to their house, work and family responsibilities. Men living in traditional ex-mining communities were sometimes reticent about the impact of their illness. The prevailing 'macho' culture reduced the perceived necessity for cardiac rehabilitation or support. Some of the more elderly participants sought comfort in their previous routines, which they did not want disturbed by attendance at cardiac rehabilitation in the hospital.

These views echo the findings of a recent study. King *et al.* (2001) speculate that patients 'erroneously believe that returning to their role related activities showed that they did not need a "rehabilitation" programme' (p. 293).

These inequalities in access to services are of particular concern in state funded health care systems, such as the UK NHS, which strive to offer equality of access at the point of need. Further research is required to establish if the barriers documented here are replicated in other similarly deprived communities.

The barriers identified here do differ slightly from those identified in a recent USA survey (Evenson & Fleury 2000) reflecting differences in cultural influences in health care access as well as health care provision. The US study identified finance and lack of patient motivation as the most significant barriers. Congruency with the USA study was found in the small minority of SYCHAZ participants who had resources. They opted out of the NHS system and pursued private provision. Work and time conflicts and problems with referral processes were similar for both study samples.

However, the SYCHAZ participants highlight service limitations and inappropriateness of services as additional barriers to accessing cardiac rehabilitation.

## Limitations of the study

The results of this qualitative study can only claim to relate to the study population. The main sampling limitations were the omission of GPs and hospital doctors. This was as the result of time constraints of the overall research programme. In the patient group, there was no ethnic minority representation.

This reflects the low numbers of people from ethnic minority groups living in the South Yorkshire Coalfields. Only a small number of women were included which was a feature of the patients admitted during the period of recruitment. It is hoped that future studies will include those groups.

## Conclusion

It is now some years since the limitations of cardiac rehabilitation services in UK were first acknowledged. This small study reveals that from the perspective of the participants, lack of investment and planning and the resultant limited service capacity, create a basic structural barrier to patients and carers accessing post-MI cardiac rehabilitation in the South Yorkshire Coalfields. Other barriers reflect the nature of the South Yorkshire Coalfields, for example, the distance between the ex-mining villages and the hospital where cardiac rehabilitation services were based and the stoicism of the local communities and their early return to role related behaviour.

The study reflects the range of issues which influence access to services and which need to be addressed by cardiac rehabilitation nurses and other staff working in a variety of roles across health care settings.

## Acknowledgements

This study was funded by the South Yorkshire Coalfields Health Action Zone. We are grateful to the participants of the study for giving their time so generously.

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***Appendix 2.***

***Conferences arising from this study***

## **Appendix 2. Conference presentations arising from this study**

2005 International Conference on Community Health Nursing (Tokyo, Japan)

*“Watchful insecurity”: heart attack recovery experience and implications for community cardiac rehabilitation*

2005 International Society of Critical Health Psychology. (Sheffield)

*“Watchful insecurity”: using grounded theory to explore the meaning of recovery after a heart attack*

2005 RCN International Nursing Research Conference (Belfast). Two concurrent sessions.

1. *The meaning of recovery after a heart attack: implications for nurses*

2. *“Get me out of here.....” cardiac patients experiences of transfer to a general ward*

2004 10<sup>th</sup> Qualitative Health Research Conference, (Banff, Canada):

*An exploration of recovery and rehabilitation experiences after a heart attack: implications for service delivery*



2003 Royal College of Nursing International Research Conference  
(Manchester):

*Combining qualitative data analysis methods: pros and cons for health services research*

2002 International Conference of Public Health Nursing (Belfast):  
*Access to cardiac rehabilitation: the public health nursing role*

2002 Royal College of Nursing International Research Conference  
(Exeter):

*"I'm still waiting..." barriers to accessing cardiac rehabilitation*

2002 UK Public Health Association Annual Public Health Forum (Glasgow):  
*Overcoming barriers to accessing cardiac rehabilitation*

2001 British Association of Cardiac Rehabilitation Annual Conference  
(Blackpool):

*Barriers to accessing cardiac rehabilitation*

***Appendix 3. Summary of ethical issues addressed in the Ethics Committee proposal.***

***Ethics committee approval letters***

### **Appendix 3. Ethical Issues Addressed in Ethics Committee Proposal and Ethics Committee approval letters**

#### ***Ethical Issues Addressed in Ethics Committee Proposal***

- Local Research Ethics Committee approval will be sought from each Health Authority.
- Patient autonomy and confidentiality. First contact with the patient will be i) for the individual interviews a member of hospital staff involved in their care and ii) for the group interviews by a support group co-ordinator. The researcher will only make contact if agreed to by the participant.  
Agreement to initial contact by the researcher will be via the return slip.
- Those patients contacted by letter will not be approached until the appropriate databases have been searched to check the patient has not died since discharge.
- Informed Consent. Written consent will be obtained prior to participation in the interviews, following the provision of written and verbal information. This consent will include agreement to be audio taped.
- The researcher will verify consent prior to the interview taking place.
- The audio tapes will be transcribed and anonymised. The tapes will then be destroyed and transcripts kept in a locked and secure room or cupboard.
- If any medical concern is identified as part of the interview, or the patient becomes distressed, they will be referred back to the patients GP, Practice Nurse or cardiac rehabilitation nurse, as appropriate.

- If the researcher is conducting interviews in the patient's own home, the Practice staff will be consulted to ensure there is no concern for personal safety. The researcher will inform a member of the Health Authority of location and expected time of completion. A mobile phone will be carried for additional security.

## ***Ethics Committee Approval Letters***

Rotherham General Hospital  
Moorgate Road  
Oakwood  
Rotherham  
S60 2UD

**LOCAL RESEARCH ETHICS COMMITTEE**

**Acting Chairman:**

Dr T Patterson  
Director of Public Health  
Rotherham Health Authority  
Bevan House  
Moorgate Road  
Rotherham  
S60 2UN

Main switchboard: 01709 820000

**Administrator:**

Mrs J Pickard - 01709 304177  
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5 December 2000

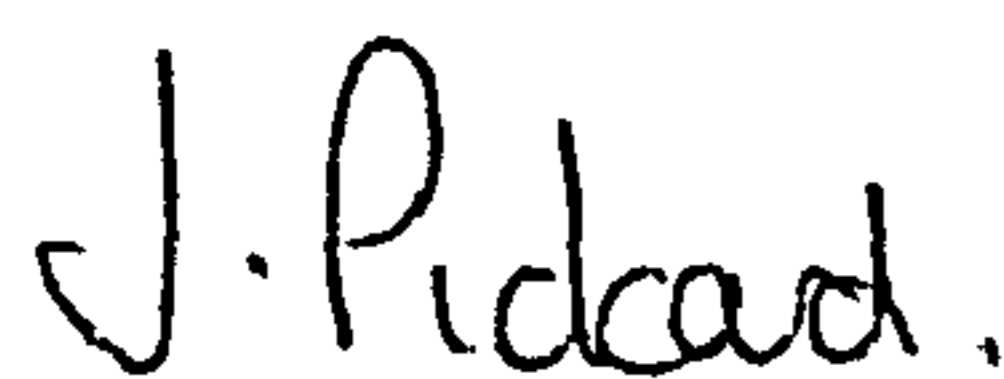
Angela Tod  
Heart Health Researcher  
Rotherham Health Authority  
Bevan House

Dear Ms Tod

**Overcoming barriers to access to heart health services: cardiac rehabilitation**  
**LREC No: 00/20**

I am pleased to confirm that, following your response to the issues raised concerning the above study, members of the Local Research Ethics Committee ratified Chairman's approval at the meeting on Monday 27 November 2000.

Yours sincerely



Jackie Pickard  
**Administrator**

## DONCASTER LOCAL RESEARCH ETHICS COMMITTEE

Medical Teaching Centre, Doncaster Royal Infirmary, Armthorpe Road, Doncaster S Yorks DN2 5LT

Secretary: Mrs C Cooper Tel: 01302 366666 Ext. 3704 Fax: 01302 553113

Hours of Work: Wed. 8.30 – 4.30 Thurs. 8.30 – 10.30 am

Chairman: Mr N Thomas

11 October, 2000

NT/CRC/F:\USERS\CCOOPER\MISCELLAETHICS\00.43ATa.doc

Ms A Tod  
Heart Health Researcher  
Public Health  
Rotherham Health Authority  
Bevan House  
Oakwood Hall Drive  
ROTHERHAM  
S60 3AQ

Dear Ms Tod,

**Re: Study No: 00/43 - Overcoming barriers to access to heart health services:  
cardiac rehabilitation**

Thank you for your letter which satisfactorily addressed the concerns raised by the Committee in their letter of the 9<sup>th</sup> August 2000. Your study was again considered at our meeting held on the 10<sup>th</sup> October 2000 and I am happy to report that we can now approve your project.

Yours sincerely,



Mr N Thomas  
Chairman  
Doncaster Local Research Ethics Committee

Your Ref:

Our Ref: AJT/AJ

Please ask for:

Mr A J Thorpe  
01226 777034

**BARNSELY RESEARCH ETHICS COMMITTEE**

4 August 2000

Ms A Tod  
Heart Health Researcher  
Department of Public Health  
Rotherham Health Authority  
Bevan House  
Oakwood Hall Drive  
Rotherham  
S60 3AQ

Dear Ms Tod

**OVERCOMING BARRIERS TO ACCESS TO HEART HEALTH SERVICES:  
CARDIAC REHABILITATION**

Thank you for attending the Barnsley Research Ethics Committee meeting on 2 August 2000 to discuss your application in connection with the above proposed study. I am pleased to confirm that the Committee has agreed to approve your application.

Would you please note that in the event of any unforeseen changes or new information which would raise questions about the continued conduct of the research this must be notified to the Committee immediately. The Committee would also wish to be provided with an end of study report of the trial in due course.

Yours sincerely



Dr W E Rhoden  
Chairman





***Appendix 4.***

***Participant documentation for  
group interviews***

## GROUP INFORMATION SHEET

### Overcoming Barriers to Access to Cardiac Rehabilitation Services

***You are invited to participate in a research study to evaluate peoples experiences of recovering from a heart attack and identify what help and support they require.***

#### ***“Why have I been asked to take part in this study?”***

The South Yorkshire Coalfields Health Action Zone is a partnership of Health Authorities, Local Authorities and other organisations. It aims to find new ways of delivering services in order to improve the health of residents of Rotherham, Barnsley and Doncaster. One of the target areas is heart disease.

This study has been funded by the South Yorkshire Coalfields Health Action Zone. The aim is to gather information about peoples' experiences of recovering from a heart problem and the opinions of staff regarding what sort of help and support they need. This information will be used to develop and improve services, such as cardiac rehabilitation.

You have been invited to take part because you are a member of a heart support group.

#### ***“How long will the study last?”***

One year, but your involvement will take no more than two hours.

#### ***“What will it involve?”***

If you agree to participate in the study, you will be asked to take part in a group interview.

The discussion is about what sort of problems you think people encounter in recovering from a heart problem, what their cardiac rehabilitation needs may be, what services they are currently offered and what services you think should be on offer.

With your permission, the discussion will be tape recorded. This will avoid the interviewer having to take notes while you are talking. The tapes will then be transcribed, but the information will be anonymised so that, where possible, you will not be identifiable. The tapes will be destroyed when the study is complete.

***“What if I do not wish to take part?”***

Your participation is entirely voluntary. You are under no obligation to participate.

***“What if I change my mind during the study?”***

You are free to withdraw from the study at any time without affecting your treatment.

***“What will happen to the information from the study?”***

All information will be entirely confidential and anonymised where possible. You will be informed of the results of the study if you wish, although the full analysis may not be available for 2 years.

It is anticipated that the information from both studies will be helpful in developing services in the future. The research will also contribute towards the post graduate study of one of the researchers.

***“What if I have further questions?”***

You should contact the researcher Angela Tod on 07714-766661

**GROUP CONSENT FORM**

**Overcoming Barriers to Access to Cardiac Rehabilitation Services**

I ..... agree to take part in the study to examine peoples experience of recovery from a heart attack, the care they need and receive.

I confirm that:

I have read the information sheet about the research study

I agree to participate in the research

I understand that Angela Tod, will interview me for up to an hour at my workplace.

I understand that my participation is entirely voluntary

I understand that the discussion will be tape recorded, the recording transcribed and then destroyed.

I understand that I am free to change my mind about taking part in the study without having to give a reason and without it affecting my care in any way

Participant Name: .....

Signature: .....

Date: .....

Researcher Name: .....

Signature: .....

Date: .....



# GROUP INTERVIEW – INTRODUCTION

## GROUP INTERVIEW SCHEDULE

What are the physical effects of the heart problem?

*Prompts*

- ♥ What factors affect your well being?
- ♥ What upsets you about your condition?
- ♥ How helpful is your current medication?
- ♥ How far do you believe your condition can be treated / cured?
- ♥ Do you have exacerbations? If yes what effect do they have?

What are the social or emotional effects of the heart problem?

*Prompts*

- ♥ Relying on those close to you?
- ♥ Where / how do you get emotional support?

Relationships?

*Prompts*

- ♥ How did/does your heart problem effect relationships?
- ♥ Do you feel you contribute the same in relationships as you did before your heart problem?

## Psychological health issues?

### *Prompts*

- ♥ Do you feel you are the same person as you used to be before the heart problem?
- ♥ Did / do you suffer from anxiety and depression – influencing factors?

## Experience of health services?

### *Prompts*

- ♥ How effective was your early treatment?
- ♥ Were you satisfied with the level of care?
- ♥ Did you receive any cardiac rehabilitation?
- ♥ What would have been ideal?
- ♥ Were health services better or worse than you imagined?

## Financial implications?

### *Prompts*

- ♥ Did your heart problems effect your employment?
- ♥ Benefits, sick leave?
- ♥ Can you describe how the illness has effected you financially?
- ♥ Did you receive any advice or support to help with employment /money issues?
- ♥ Any housing worries related to your health?

***Appendix 5.***

***Example of a group interview  
summary***



## **Appendix 5. Example of group interview summary**

### ***Setting***

Boardroom of the hotel where the group normally have their support group meetings. Sandwiches and drinks had been supplied. Setting not bad but not ideal. Large boardroom table which meant people were spread quite far apart. Difficult to prevent more than one discussion occurring at once.

### ***Attendance***

Seven patients and five carers had originally agreed to attend. One couple phoned to say they were ill and couldn't attend. One patient cancelled as they were due to move out of the area the following month and no longer thought it relevant that they attend. This left four couples and three carers - a total of nine.

### ***Atmosphere and discussion***

People arrived gradually, staggered start. Very difficult group to keep focused. Apart from one very quiet couple, group members had quite strong opinions and were happy to share them. I was able to engage and capture the views of the quieter participants.

They used humour quite a lot to make a point. Humour used especially when talking about the emotional trauma of a heart attack and recovery.

One woman was a bit of a "loose cannon" in that she had had a heart attack, but had had surgery since. Her emphasis was therefore on her surgery rather than the heart attack. Her experience illustrated how different the needs of these two patient groups can be. Surgery being a planned event unlike a heart attack.

Two members of the group had been involved as users in cardiac rehabilitation service planning groups. They talked as if they had been round the block a time or two. There was some cynicism about whether services would change and develop.

Participants numbered in transcript to preserve anonymity.

Sample description will be numbered pairs, patient will be (a), carer will be (b):

- 1a - male patient
- 1b - female carer
- 2a - male patient
- 2b - female carer
- 3a - male patient
- 3b - female carer
- 4a - female patient
- 4b - male carer
- 5a - female patient

### ***Participants characteristics***

All those present were retired.

1a

Quite a mild mannered Irish man in his 70's. Looked quite well. Tended to contribute if questions were directed to him specifically. That may have been as much to do with the dominance of 2a and 3a. Fairly quietly spoken but he spoke with some emphasis. Irish chap with a Geordie wife. Retired tradesman.

1b

Also very mild mannered. Wanted to contribute but like her husband tended to answer questions directed at her or started conversations with those near her. Quietly spoken with gentle Geordie accent, difficult to decipher at times.

2a

Professional man in his 60s. Rather domineering. Had been involved as a user in the service development/planning group. Rather cynical about the impact of all the consultation and concerned that things won't change.

2b

Wife of 2a. Rather quiet. Deferred to her husband a lot but was able to contribute at times.

3a

Man in his 60's. Ran the heart support group. Both him and his wife were "big" characters both physically and verbally. A salesman in the past. Now retired.

4a

70 year old woman. Contributed quite a lot once she got her confidence. Able to compare her experience with others. Was a housewife.

4b

Man in his 70s. Only male carer. Had been very shaken by his wife's illness. Very capable in the home.

5a

Woman in her 60's. Had heart surgery. Had a very different clinical experience to the others and was keen at times to make that point. Some of this appeared to be due to the fact her surgery was a planned event, unlike a heart attack. Her other difference was that she was separated and lived on her own.

### ***Key points / quotes***

Life interrupted by heart attack. Everyone different after the heart attack

"Mentally lost"

Why me? Am I allowed?

Lose control – have to give control to others

Need individual information but also need to be part of a "community" of people in same situation – comparison and reassurance.

Rehabilitation / recovery is about the first time you do something again.  
Looking for permission, not sure what you can do.

Relationship problems, irritable, don't want to upset him, the kids can't  
handle it. Role reversal, not just partner, kids as well.

Change priorities. Measure fitness by getting on with it and doing what you  
used to – even if it takes longer.

Emotional impact means at first very lacking in confidence despite doing the  
reading. "I'd read all the books, I could pronounce all the clever words, I  
knew all the drugs, all the things like that, but a heart attack is an extremely  
emotional thing. You know, it is the, you are probably more likely to drop  
dead from a heart attack than any other disease or illness you can have"  
Couldn't plan the future or arrange things. "I've started buying long playing  
records"

***Appendix 6.***

***Participant documentation for  
individual interviews***

## PATIENT INFORMATION SHEET

### Overcoming Barriers to Access to Cardiac Rehabilitation Services

***You are invited to participate in a research study to evaluate peoples experiences of recovering from a heart attack and identify what help and support they require.***

#### ***“Why have I been asked to take part in this study?”***

The South Yorkshire Coalfields Health Action Zone is a partnership of Health Authorities, Local Authorities and other organisations. It aims to find new ways of delivering services in order to improve the health of residents of Rotherham, Barnsley and Doncaster. One of the target areas is heart disease.

This study has been funded by the South Yorkshire Coalfields Health Action Zone. The aim is to gather information about peoples' experiences of recovering from a heart attack. This information will be used to try to develop services, such as cardiac rehabilitation. It may improve services.

You have been invited to take part because you have recently had a heart attack.

#### ***“How long will the study last?”***

One year, but your involvement will take no more than an hour.

#### ***“What will it involve?”***

If you agree to participate in the study, you will be asked to take part in an interview at your own home. The researcher will telephone and make arrangements for this, and will carry clear identification.

The interview will take place six months after you are discharged from hospital. It will involve a discussion about your recovery, your general health and your use of any cardiac rehabilitation services.

With your permission, the interview will be tape recorded. This will avoid the interviewer having to take notes while you are talking. The tapes will then be transcribed, but the information will be anonymised so that you will not be identifiable. The tapes will be destroyed when the study is complete. The transcripts will be kept in a locked cupboard.

Unless you object, the anonymised and transcribed interview data may also be compared with the data collected in a study being conducted in Sheffield. The Sheffield study is evaluating a community cardiac rehabilitation scheme. By combining the interviews from both studies a more detailed and meaningful picture can be created.

You do not need to attend rehabilitation classes or clinics in order to take part.

The interview will last about half an hour. If you would prefer it, the interview can take place at your GP surgery or at the hospital.

***“What tests will I receive and how often will I have to visit the hospital?”***

There are no additional tests or treatments associated with this research. You will not need to attend any rehabilitation classes or clinics unless you wish to do so.

***“What if I do not wish to take part?”***

This will in no way affect your treatment.

***“What if I change my mind during the study?”***

You are free to withdraw from the study at any time without affecting your treatment.

***“What will happen to the information from the study?”***

All information will be entirely confidential and anonymised. You will be informed of the results of the study if you wish, although the full analysis may not be available for 2 years.

It is anticipated that the information from both studies will be helpful in developing services in the future. The research will also contribute towards the post graduate study of one of the researchers.

***“What if I have further questions?”***

You should contact the researcher Angela Tod on 01709-302069 or 07714-766661

***If you are prepared to participate in the study please sign the attached consent form and return it to the researcher in the envelope provided***

# PATIENT CONSENT FORM

## Overcoming Barriers to Access to Cardiac Rehabilitation Services

I ..... agree to take part in the study to examine peoples experience of recovery from a heart attack, the care they needed and received.

***I confirm that:***

I have read the information sheet about the research study

I agree to participate in the research

I agree to the researcher, Angela Tod, contacting me to arrange an interview

I understand that Angela Tod, will interview me for about an hour, either at home or at my GP Practice

I understand that my participation is entirely voluntary

I understand that the interview will be tape recorded. The recording will be transcribed. The transcript will be anonymised, that is, your name and that of anyone else you refer to will be removed. In this way, you can not be identified from the transcript. The transcript will be kept in a locked cupboard. The tape will be destroyed.

I understand that the anonymised results from this study will be compared with a similar study being conducted in Sheffield.

I understand that I am free to change my mind about taking part in the study without having to give a reason and without it affecting my care in any way

I understand that if I say anything about my health which causes concern, with my permission, Angela will let either my GP or Practice Nurse know.

Patient Name: .....

Signature: .....

(please sign here and return the form to Angela in the envelop provided)

Date: .....

(To be completed by the researcher immediately before the interview)

Researcher Name: .....

Signature: .....

Date: .....



South Yorkshire Coalfields Health Action Zone Research Proposal

OVERCOMING BARRIERS TO ACCESS TO HEART HEALTH SERVICES

CARDIAC REHABILITATION

Patient Interview Schedule

It has now been six months since you had your heart attack. Can you tell me how you have been? (ice breaker)

Did you need or get any help with understanding what had happened to you?

In hospital?

After discharge?

Expand: who, what, when, where, why?

Did you attend any rehabilitation classes at the hospital after you were discharged from hospital?

If yes – type, venue, number attended

If no – any reason why not?

*Prompts:*

Physical access problems (transport, distance, hills)

Content and format of class?

Have you attended any other forms of rehabilitation programmes or classes?

*Prompts:*

Exercise classes, slimming, diet classes, smoking cessation?

Who and where delivered?

Did you experience any problems in getting to the classes?

If you were not offered any cardiac rehabilitation classes, would you have attended them if invited?

Did you get any other help and support from elsewhere?

How important do you think cardiac rehabilitation classes are after a heart attack?

What sort of lifestyle changes have you made since your heart attack?

**Did you need help in making those changes?**

*Prompt:*

Smoking, exercise, diet, medication, job, family roles.

**Could anything have been done to make your recovery and rehabilitation easier?**

**What sort of cardiac rehabilitation services do you think should be available?**

**Do you know what to expect in the future as regards your heart health and your medical care for your heart?**

*Prompt:*

GP / Practice Nurse follow up, secondary prevention?

Hospital OPD

Future tablets, tests and investigations?

**Are there things you are still uncertain about, concerning your health?**

**Lastly a few questions about yourself?**

**How old are you?**

**(Gender)?**

**(Postcode)?**

**Do you have a job?**

If yes, what?

If no, what was your last job?

**Do you drive a car?**

**Do you have access to a car?**

**What is your highest level of education?**

**What medication do you take?**

**Has this medication changed since you left hospital?**

**Is there any other comments you would like to add regarding your recovery?**

**Is there anything you would like to ask me?**

Thanks you for agreeing to be interviewed for this study.

***Appendix 7.***

***Recovery paradigm model***

## Appendix 7. Recovery: Paradigm model

*Taken from: Strauss A. Corbin J. (1990) Basics of Qualitative Research Sage. Newbury Park.*

Open coding: breaking down, examining, comparing, conceptualising and categorizing data. Developing properties and dimensions of categories.

Axial coding: putting categories together in a relational form, making connexions.

Paradigm model:

CAUSAL CONDITIONS → PHENOMENON → CONTEXT → INTERVENING CONDITIONS →

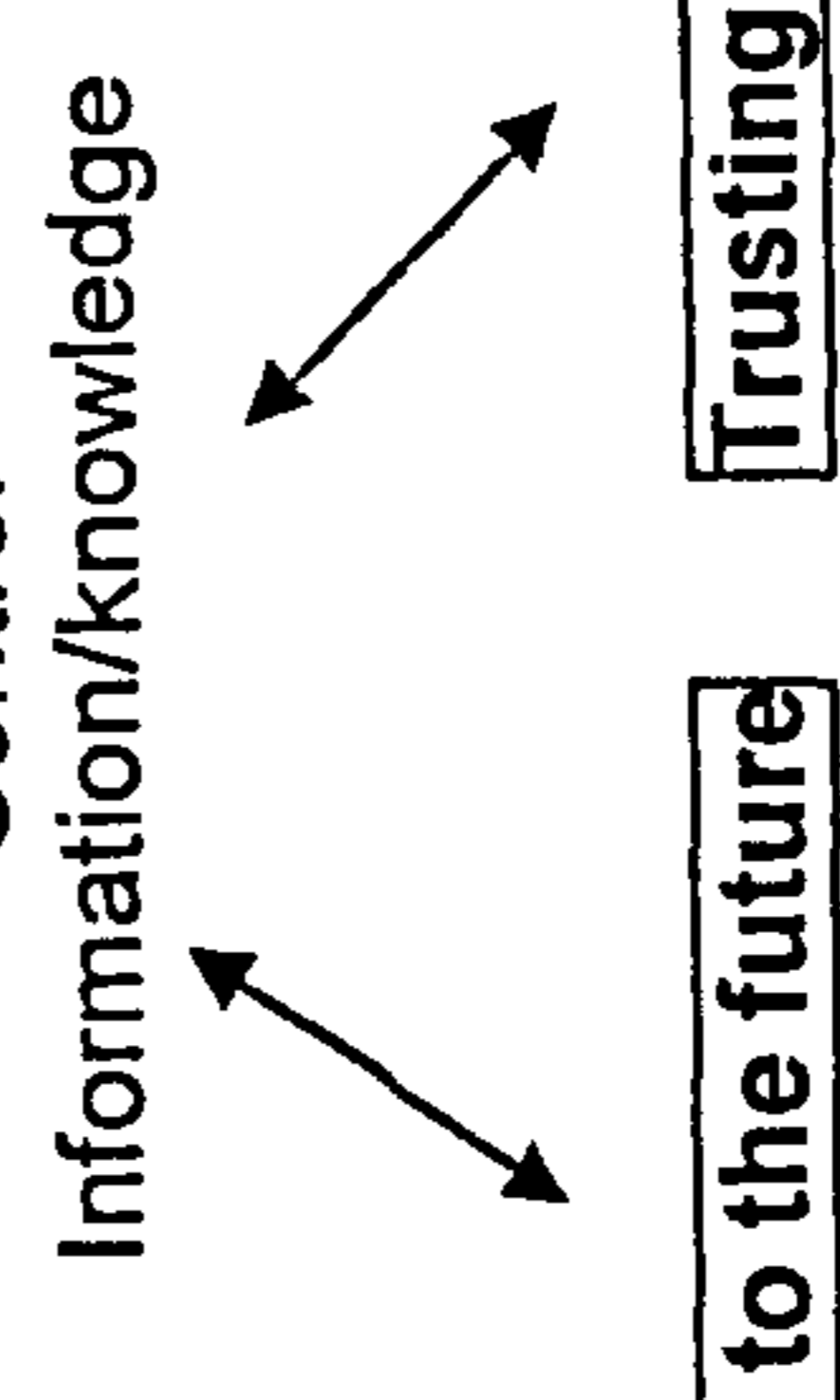
ACTION / INTERACTIONAL STRATEGIES → CONSEQUENCES

Study summary:

Stage 1 revealed that people saw themselves as “a different person” after the heart attack than they were before. A key concept in terms of whether the difference was positive or negative seemed to be where people saw themselves on the pathway to recovery.

Stage 2 explored what people mean by recovery, how do they conceptualise and define it, (i.e. when do you know you've got there) and what strategies do people adopt to try and move towards this. The justification for this is that, by understanding the recovery experience, cardiac rehabilitation services can provide the support people need get there. Grounded theory techniques were used. The paradigm model is used to illustrate axial coding and relationships between categories.

Components of the paradigm model	Categories	Sub-categories
<p><b>Causal conditions</b> The events or incidents that lead to the occurrence or development of a phenomenon.</p>	<p><b>Heart attack (M.I.)</b></p>	<p>How the M.I. experience is categorised, described by patients  <b>1/ Sudden</b>  <b>2/ Loss</b>  <b>3/ Unexpected</b></p>
<p><b>Phenomenon</b> The central event / happening, about which a set of actions / interactions is directed at managing or handling.</p>	<p><b>M.I. recovery</b></p>	<p><b>Recovered, recovering, not recovered</b> People see themselves as different after the heart attack. This is described in terms of recovery.</p>
<p><b>Context</b> 1/ The specific set of properties that pertain to the phenomenon along a dimensional range. 2/ The set of conditions within which action/interactional strategies are taken to manage, handle, carry out or respond to a specific phenomenon</p>	<p><b>Recovery experience</b></p>	<p>1/ M.I. —————&gt; <b>Recovery</b>   2/ <b>Emotional</b>  <b>Physical</b>  <b>Understanding</b>  <b>Social</b></p>
<p><b>Intervening Conditions</b> The broader structural context pertaining to the phenomenon. The broad, general conditions bearing upon actional/interactional strategies.</p>	<p><b>1/ Society and culture of the South Yorkshire Coalfields</b>   <b>2/ Services to support recovery and rehabilitation</b></p>	<p>Conditions that influence whether people can mobilise action/interactional strategies.  <b>1/ Coalfields communities and households</b>  <b>Demographics and epidemiology</b>  <b>Stoicism</b>  <b>Commitments</b>  <b>2/ Gap between service need / experience (service nature, service content, staff attitude)</b></p>

<p><b>Action / Interactional Strategies</b>          Directed at managing, handling, carrying out, responding to a phenomenon. They are:</p> <ol style="list-style-type: none"> <li>1/ processual and evolving i.e. moving and changing over time</li> <li>2/ purposeful, goal orientated i.e. done for a reason in response to or to manage the phenomenon</li> <li>3/ Failed action/interaction also important</li> <li>4/ There will be intervening conditions that facilitate or constrain action/interaction</li> </ol>	<p><b>Recovery / coping mechanisms</b></p>	<p><b>1/ Taking control</b>          Getting information          Getting on with it / resuming activities</p> <p><b>2/ Attribution</b>          Seeking explanations          Comparing</p> <p><b>3/ Redefining</b>          Reset limits          Reprioritise          Set new targets / goals</p>
<p><b>Consequences</b>          The consequence to taking action/interactional strategies.</p>	<p><b>Recovery</b></p>	<p>Confidence          Control          Information/knowledge</p>  <p><b>Looking to the future</b>      <b>Trusting the body</b></p>

***Appendix 8.***

***Examples of codes, categories and analysis techniques.***

## **Appendix 8. Examples of codes, categories and analysis techniques.**

### **Open coding**

#### ***Initial coding and categories***

##### *Heart attack experience*

- Loss
- Alone
- Sudden
- Disbelief

##### *Recovery experience*

- Isolated
- Restricted
- Fear
- Confusion
- Frustrated
- Not understanding
- Emotional
- No control
- Mollycoddled
- Uncertainty
- Humiliated
- Irritable
- Depressed
- Lack of confidence
- Vulnerable
- Forgetful
- Confused
- Questioning
  - Am I allowed?
  - Ought I to?
  - Why me?

##### *Coping*

- Seeing everyone as different
- Comparing to others in the same position
- Having a recovery goal
- Advice from others
- Role change
- Attribution and explanation
- Comparing
- Seeking understanding



### *Adjustment*

- Different person
- Physical
- Emotional
- Accepting
- Seeing the future
- Confidence
- Control
- Different priorities
- Different attitudes
- Resuming activity
- Getting on with it
- Realistic goals
- Understanding

### *Service need*

- Continuity
- Explanation
- Home visit
- Someone to talk to
- Information
- Individualized care
  - Listening
  - Taking time
  - Personalized information
- Reassurance
- Honesty
- Empathy
- Encouragement
- Staff who know and care
- Assessment
- Other people in the same position

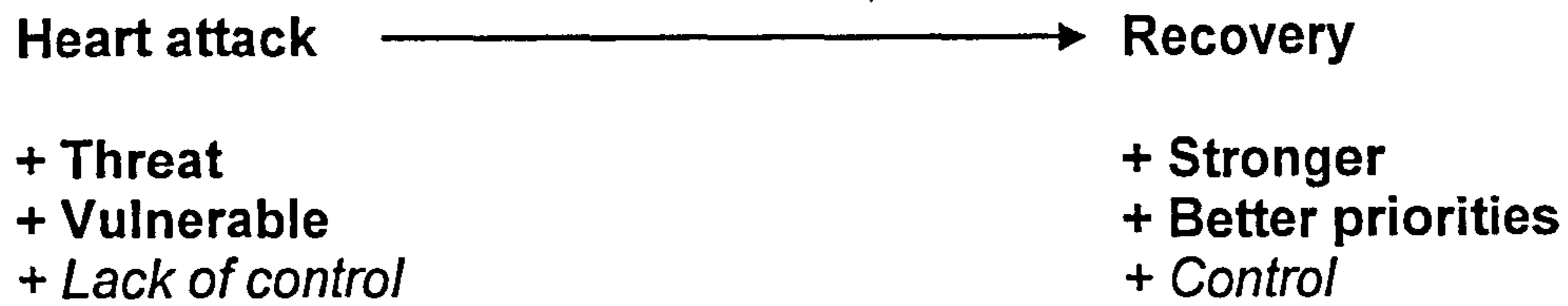
### *Service experience*

- Unmet expectations
- Lack of continuity
- Poor communication
- Lack of time
- Limited capacity
- Exclusion
- Waiting lists
- Delay

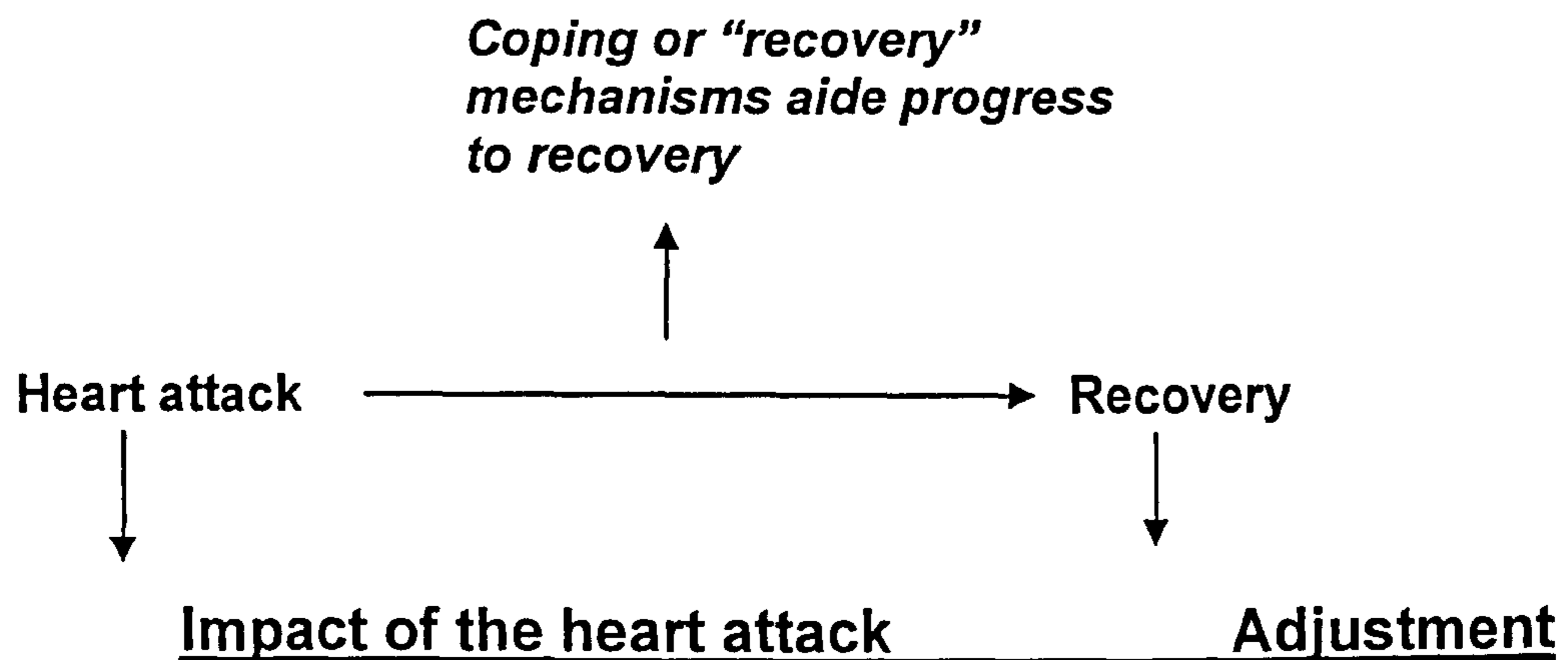
## Axial coding

### Diagrams that helped map out model

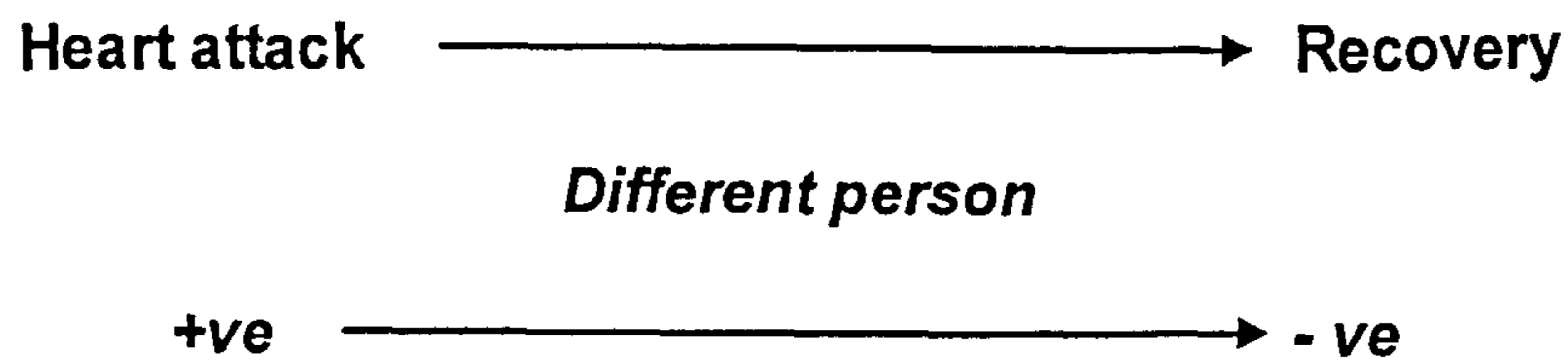
1.



2.



3.



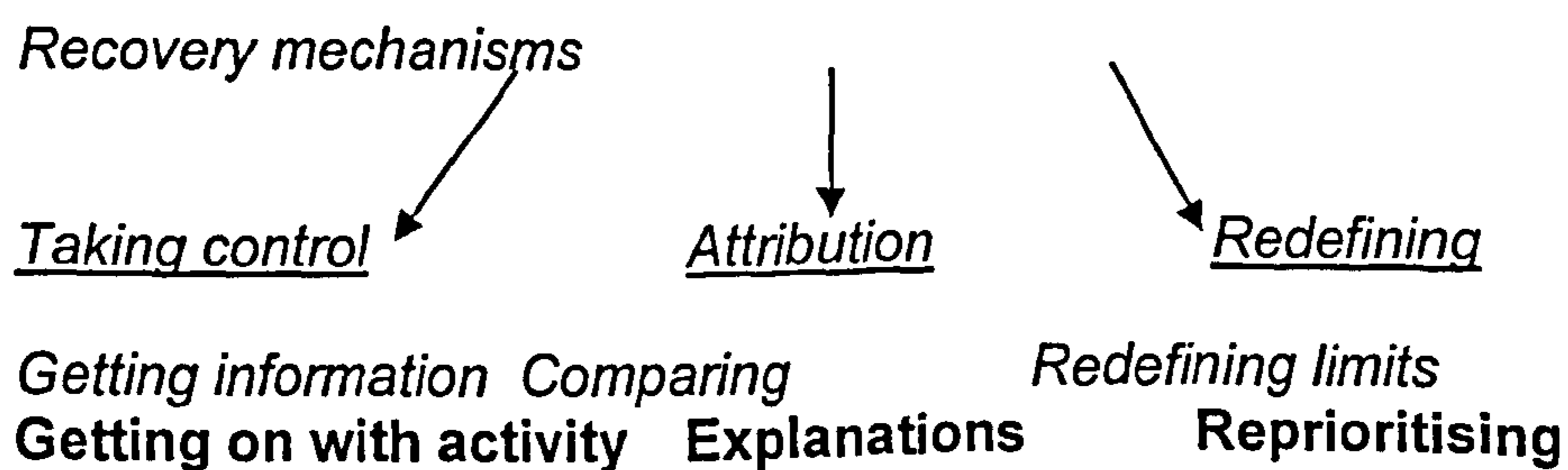
*People saw themselves as different. Stage of recovery influenced whether they experienced the difference positively or negatively.*

4. Defining and refining sub-themes

a) Recovery experience

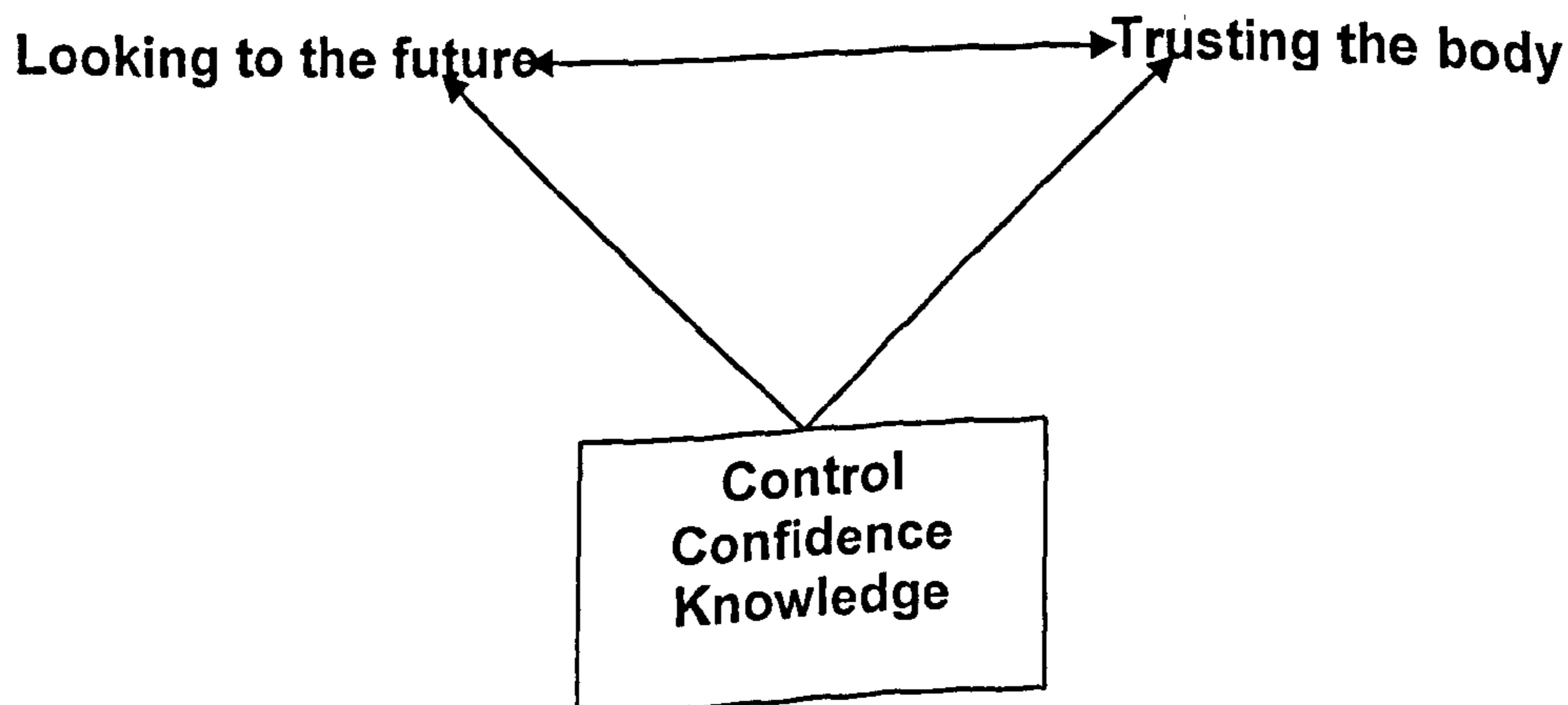
Emotional	Physical	Understanding	Social
<i>Frightened</i> <b>Vulnerable</b> <i>Irritable</i> <b>Depressed</b> <b>Anxious</b> <b>Frustrated</b> <b>Unconfident</b>	<b>Tried</b> <b>Fatigued</b>	<b>Uncertain</b> <b>Confused</b> <b>Forgetful</b> <b>Questioning</b> <ul style="list-style-type: none"> <li>• Why</li> <li>• Am I allowed</li> <li>• Ought I</li> </ul>	<i>Isolated</i> <b>Mollycoddled</b> <b>Restricted</b> <b>No control</b>

b) Recovery mechanisms



c) Precursors of recovery

*Confidence, control and knowledge emerging as precursors to recovery*



d) Service need

Nature	Content	Staff attitude
<b>Continuity</b> <b>Individualised</b> <ul style="list-style-type: none"><li>• <b>Listening</b></li><li>• <b>Time</b></li><li>• <b>Personalized information</b></li></ul>	<b>Explanations</b> <b>Someone to talk to</b> <b>Assessment and monitoring</b> <b>Meeting others</b>	<b>Honesty</b> <b>Knowledgeable</b> <b>Reassuring</b> <b>Caring</b>

## 5. The paradigm model

CAUSAL CONDITIONS → PHENOMENON → CONTEXT  
 → INTERVENING CONDITIONS → ACTION / INTERACTIONAL STRATEGIES → CONSEQUENCES

Components of the paradigm model	Categories	Sub-categories
<p><i>Causal conditions</i>            The events or incidents that lead to the occurrence or development of a phenomenon.</p>	<p><b>Heart attack (M.I.)</b></p>	<p>How the M.I. experience is categorised, described by patients  <b>1/ Sudden</b>  <b>2/ Loss</b>  <b>3/ Unexpected</b></p>
<p><i>Phenomenon</i>            The central event / happening, about which a set of actions / interactions is directed at managing or handling.</p>	<p><b>M.I. recovery</b></p>	<p><b>Recovered, recovering, not recovered</b>            People see themselves as different after the heart attack. This is described in terms of recovery.</p>
<p><i>Context</i>            1/ The specific set of properties that pertain to the phenomenon along a dimensional range.            2/ The set of conditions within which action/interactional strategies are taken to manage, handle, carry out or respond to a specific phenomenon</p>	<p><b>Recovery experience</b></p>	<p><b>1/ Heart attack → Recovery</b>  <b>2/ Emotional</b>  <b>Physical</b>  <b>Understanding</b>  <b>Social</b></p>

<p><i>Intervening Conditions</i> The broader structural context pertaining to the phenomenon. The broad, general conditions bearing upon actional/interactional strategies.</p>	<p><b>1/ Society and culture of the South Yorkshire Coalfields</b></p> <p><b>2/ Services to support recovery and rehabilitation</b></p>	<p>Conditions that influence whether people can mobilise action/interactional strategies.</p> <p><b>1/ Coalfields communities and households</b> <b>Demographics and epidemiology</b> <b>Stoicism</b> <b>Commitments</b></p> <p><b>2/ Gap between service need / experience (service nature, service content, staff attitude)</b></p>
<p><i>Action / Interactional Strategies</i> Directed at managing, handling, carrying out, responding to a phenomenon. They are: 1/ processual and evolving i.e. moving and changing over time 2/ purposeful, goal orientated i.e. done for a reason in response to or to manage the phenomenon 3/ Failed action/interaction also important 4/ There will be intervening conditions that facilitate or constrain action/interaction</p>	<p><b>Recovery mechanisms</b></p>	<p><b>1/ Taking control</b> Getting information Getting on with it / resuming activities</p> <p><b>2/ Attribution</b> Seeking explanations Comparing</p> <p><b>3/ Redefining</b> Reset limits Reprioritise Set new targets / goals</p>
<p><i>Consequences</i> The consequence to taking action/interactional strategies.</p>	<p><b>Recovery</b></p>	<p>Confidence Control Information/knowledge</p> <p style="text-align: center;">↓</p> <p><b>Looking to the future</b> <b>Trusting the body</b></p>

## The storyline

The story concerns people's experiences after a heart attack and how they move from the distress and crisis of the acute event to a point when they consider that they have recovered. How did they manage or not manage the process? What is it they are working towards and how do they know they have got there?

Everyone saw himself or herself as a different person after the heart attack than they were before. Whether this difference was positive or negative depended where they were on the spectrum of recovery. The process of recovery involved overcoming a number of emotional (frightened, vulnerable, anxious, irritable, humiliated, unconfident), physical (tired, fatigued), social (isolated, no-control, restricted, mollycoddled) and cognitive (uncertain, confused, forgetful, questioning) experiences that were encountered along the way.

The initial experience of the heart attack was one of shock and vulnerability. There was a universal experience of feeling out of control, lack of confidence and sense of loss. To move towards recovery required the ability to mobilize a number of recovery mechanisms. Some were impeded in doing this by social and cultural norms, for example, the emphasis on resuming traditional gender specific roles and the expectation to be stoic and put a brave face on things. In addition, many had difficulty getting the information, support and reassurance necessary to employ the recovery mechanisms at different

points along the recovery pathway. As a result of this and other disruptions, for example, new symptoms, failed tests, frustrated communication and overprotection, some moved backwards and forwards along the recovery pathway. The journey was not linear.

The mechanisms people employed to help with recovery fell into three categories. 1) Taking control: by acquiring information and by gradually increasing or resuming activity. 2) Redefining life and identity: by setting new and achievable targets (which may involve giving up some activity like work), reprioritising what is important (such as not worrying about small things and spending more time doing what you enjoy) and redefining physical limits (this may mean keeping active but if necessary not in the same way). 3) Seeking attribution: by finding an explanation or meaning for what the heart attack, for some this meant comparing themselves to others in a similar position.

The above mechanisms emerged from accounts from people who had achieved and not achieved recovery. Those who were struggling were still trying to understand why the heart attack had happened and its implications for their life. These people lacked the precursors to recovery, which were control, confidence and knowledge. As a result they could not see their future but were constantly looking over their shoulder, worried about the threat of further symptoms or heart attack. Those who saw themselves as recovered commented on the length of time it had taken and the difficulty of the emotional and psychological aspects of recovery. Recovery was



experienced as “trusting the body”. Two components emerged from this; trust and looking to the future.

Participants found access to services to support movement along the recovery process and help mobilize recovery mechanisms to be lacking. They described core characteristics of services that they thought would facilitate recovery. The nature of the service was such that it would offer continuity and be individualized. The content of the service should include someone to talk to and listen, assessment and monitoring, meeting others in the same position and provide explanations. Staff attitude was crucial and being honest, knowledgeable and caring was viewed as reassuring.

## **Core category and dimensions**

**Core category = Trusting the body**

**Dimensions**

**a) Trust:**

**Trusting → Not trusting**

**b) Looking to the future**

**Able → Not able**

## **Appendix 9. Analytical induction process**

## **Appendix 9. Analytical induction process**

In this study the process of analytical induction involves the constant development and checking of conceptual and theoretical propositions in order to generate the grounded theory of Watchful Insecurity. Constant comparison was consistently used to apply inductively derived propositions to the data and test them deductively. Memos were used throughout to record and support theoretical development throughout this process. The three data sets of group, individual and informal interviews provided many and varied opportunities to constantly compare emerging results across participants and sections of coded text. This triangulation added to the theory verification.

### **Constant comparison**

The initial codes and categories depicted in Appendix 8 were generated after first reading and familiarization of the group interview transcripts. The codes and categories were then first applied to the group interview data. Sections of text were coded in QSR NVIVO. This was to test and expand on the codes. Constant comparison of the text was done by interview and by code (or node – the term used in QSR NVIVO). Memos were used to record, develop and build categories and theoretical propositions.

Following this, individual interviews were also coded. Individual interviews were selected using theoretical sampling. The two data sets were then compared. Sections of text from both data sets that were coded the same were selected and compared to check i) the conceptual integrity of the codes and categories and ii) further expand or condense categories.

An example of this coding is provided below. Sections from Group interview 3 and individual interview 4 are used.

### Group Interview 3

Text	Codes
<p>P3.1 The first two years were... it's rough, it really is, its no good saying its not because it really is!</p>	<p><i>Recovery experience Vulnerability Different person</i></p>
<p>P3.4 I think a lot of that you know is down to the medication taken!</p>	
<p>P3.3 Probably, I've always said that, in fact it's a standing joke that you know, it's the tablets were're on</p>	<p><i>Attribution Explanation Understanding</i></p>
<p><i>Everyone laughs</i></p>	
<p>2a Well we blame that for everything... well that's true.</p>	<p><i>Attribution Understanding</i></p>
<p>C3.2 I think you look at life different.</p>	<p><i>Different priorities Different person</i></p>
<p>C3.3 Oh yes you do!</p>	
<p>C3.1 Well you do after you've got over it!</p>	
<p>C3.2 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".</p>	<p><i>Reprioritise Different goals Getting on with it</i></p>
<p><i>This strikes a cord and everyone talks at once</i></p>	
<p>P3.2 We live from day today and if we want to do something and feel like doing it, then we do it!</p>	<p><i>Resuming activities Different priorities</i></p>
<p>C3.2 We do it</p>	
<p>P3.2 Forget the cost. Forget the other things, if you like doing it, do it!</p>	
<p>P3.4 That's why we've just gone and booked a holiday today! We've just booked for..... we wouldn't normally have done that, we've only just got back from Jersey. We might as well spend the money and go!</p>	<p><i>Acceptance Reprioritise Different goals Getting on with it</i></p>

## **Codes and categories generated**

*Recovery experience*

Vulnerability

*Coping/recovery mechanisms*

Attribution

Understanding

*Adjustment*

Different person

Different priorities

Reprioritise

Different goals

Getting on with it

Resuming activities

Acceptance

## Individual interview 4

Text	Codes
<p>INTERVIEWER Did anybody sit down and explain what a heart attack was?</p>	
<p>PATIENT 4 Yeah. Yeah. One doctor told us. He sat down and told me.</p>	
<p>INTERVIEWER So when you went home, did you feel that you'd understood what it was and how to get over it I suppose?</p>	
<p>PATIENT 4 I knew what had happened, but I were ... Ain't it silly? I were scared. Yeah. I were really, erm, I were afraid somehow. It upset me. Yeah. I had no confidence at all ....</p>	<p><i>Understanding</i> <i>Fear, Vulnerability</i> <i>Lack of confidence.</i> <i>Precarious</i></p>
<p>INTERVIEWER And there was nobody really who talked to you about those sorts of things, that you were frightened?</p>	
<p>PATIENT 4 No. No. No. I were given a book.</p>	<p><i>Information</i></p>
<p>INTERVIEWER Right.</p>	
<p>PATIENT 4 And I saw a little video.</p>	<p><i>Information</i></p>
<p>I think the worst thing anyone can have is a heart attack.... But your heart somehow, I don't know, it's.... 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.</p>	<p><i>Knowledge</i> <i>Fear, Vulnerability,</i> <i>Insecurity</i> <i>Lack of confidence</i></p>
<p>I came out in June. I was told that this health visitor would come to see me. I got no contact from the health visitor. Me husband rung up and the nurse had arranged for it one of the nurses, staff nurses, had phoned somebody and I told you we went on for three week. 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 and more you see?</p>	<p><i>Advice seeking</i></p> <p><i>Confusion</i> <i>Lack of information</i></p> <p><i>Insecurity</i> <i>Uncertain</i></p>

<p>No. I've had no support. I've been left in ignorance really. In fact, I got to the point where when I went for the exercise test, I asked the man who were doing it if I'd had a heart attack, 'cos I just felt like it ... 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, you seem to be ... ooh, for months and months I were frightened! Oh yeah! I were terrible!</p> <p>Me life style had been changed completely anyway. You know? I've never been back to normal living again,</p>	<p><i>Lack of information Isolated</i></p> <p><i>Denial, avoidance</i></p> <p><i>Vulnerability, Insecurity Lack of confidence Lack of control</i></p> <p><i>Different person Adaptation</i></p>
<p><b>INTERVIEWER</b> Are there things that you still feel uncertain about in terms of your health, but more particularly your heart health?</p>	
<p><b>PATIENT 4</b> Yeah. I do feel .. 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!"</p>	<p><i>Uncertain Vulnerability, Insecurity, Looking to the future. Lack of confidence Getting on with it Coping</i></p>



## **Codes and categories generated**

### *Recovery experience*

Vulnerability

Precarious

Fear

Denial

Lack of / Information

Uncertainties

Lack of confidence

Lack of control

Isolated

Insecure

Confusion

Vigilance

### *Coping / recovery mechanisms*

Avoidance

Getting on with it

### *Adjustment*

Different person

Trusting the body

Confidence

Understanding

Theoretical propositions were then applied to both the data sets. The questions emerged from the constant comparison and memos written during this analysis.

Examples of these propositions include:

- People describe themselves as different after a heart attack.
- People were frightened after the heart attack, which led to preoccupation with their bodies.
- People seek to attribute their heart attack to something that makes sense to them.
- People develop a different sense of priorities after the heart attack.

*QSR NVIVO* facilitated this process as it allowed the separate data sets to be searched by individual participant, interview or code. For example, data from people of different ages, gender, time points from their heart attack, or experience, were selected as appropriate. In other situations, data from all the data sets that were coded to a particular node were selected for constant comparison, to test the integrity of a conceptual or theoretical component of the emerging theory. Memos and diagrams were also used to facilitate this process.

Codes and categories were refined and condensed. For example, “coping” evolved into “recovery mechanisms”. Links and relationships between the codes and categories began to emerge from further application of propositions to the data and constant comparison of the data.

Examples of these propositions include the following:

- Recovery is defined as “trusting the body” and “looking to the future”.
- Precursors of recovery (using this definition) are, control, confidence and information.
- People adopt mechanisms to facilitate recovery.

The axial coding results that emerged from this have been given in Appendix 7 and 8.

## Conceptual selective coding

At this stage of the analysis the emerging results were recognised to be descriptive. The data sets were left completely alone at this point. The analysis was conducted conceptually. It was at this point that the core category of Watchful Insecurity was identified. It was only by thinking conceptually, rather than describing the content and nature of the data, that the core category emerged. The analysis took on a new focus at this point as relationships and conceptual links between categories and with the core category were explored and tested.

Definitions and meanings of existing codes and categories were explored and were minuted in memos. The focus of this is reflected in the following memo that was written after discussion with the mentor.

### ***Selective coding memo: Watchful Insecurity***

Need to revisit the aim of the study i.e. to explore the meaning of recovery after a heart attack

So far the analysis has revealed the following statements and questions:

- People described themselves as a different person after the heart attack than they were before.
- Services describe recovery and return to normal to be a goal.
- If people are different, what is normal for them and how can they return to it?
- i.e. What does recovery mean? How do they know when they have got there?

Axial coding, as depicted in the paradigm model, memos and diagrams, is only descriptive.

Now need to do selective coding to identify core category

In order to do this I need to lose "Trusting the body" as a core category and stop thinking of the concept of recovery as a spectrum or having an endpoint.

By defining and rethinking codes, the emerging core category to summarize recovery experience = Watchful insecurity

This was arrived at via conceptual consideration of, vigilant insecurity and biographical insecurity.

Recovery means moving beyond watchful insecurity.

Watchful insecurity is a state where people are hyper aware that they are different.

***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. An event that is a reminder of how fragile your place is in the world***

Recovery markers e.g. resuming activity, achieving goals, regaining positions

Steps to expand and test theory:

- Generate a theoretical understanding of watchful insecurity
- Identify the theoretical properties of watchful insecurity
- Dimensions of the properties
- Develop theoretical understanding of a state i.e. what are the theoretical properties of state? What makes such a state emerge? Are there critical points or junctures that produce it? Is it constant? Are there different 'types' of watchful insecurity? Where else do you see it?
- Look at codes. How do they relate to watchful insecurity?

Examples of how memos and diagrams were developed and helped in undertaking this process are provided in Appendix 10.

Having undertaken the selective coding, the theoretical propositions were again applied across the data sets. Particular attention was paid at this point to negative case analysis. For example, data from people and interviews and nodes that did not seem to initially fit Watchful Insecurity were analysed. This was helpful in developing the concept of affirming Watchful Insecurity. It was also used to explore why exercise and activity was viewed positively by some and appeared to aggravate Watchful Insecurity for others. In this instance negative case analysis contributed to the development of the concept of challenging Watchful Insecurity, routine Watchful Insecurity and the tools to manage Watchful Insecurity.

Sections of text were recoded to test the application of the theory. Examples of this follow using the same text as earlier i.e. Group Interview 3 and Individual Interview 4. Illustrative quotes from these sections of data were used to illuminate the concepts in the thesis.

A quote from P3.4 was used to illustrate “Generating meaning/Seeking explanations”.

A quote from individual interview 4 was used to illustrate how, if challenging Watchful Insecurity by trying to get information goes wrong, it can further aggravate Watchful Insecurity.

## Group Interview 3 – selective coding

Text	Codes
<p>P3.1 The first two years were... it's rough, it really is, its no good saying its not because it really is!</p>	<p><i>Different person Aggravated Watchful Insecurity</i></p>
<p>P3.4 I think a lot of that you know is down to the medication taken!</p>	<p><i>Generating meaning, Seeking explanations</i></p>
<p>P3.3 Probably, I've always said that, in fact it's a standing joke that you know, it's the tablets were're on</p> <p><i>Everyone laughs</i></p>	<p><i>Generating meaning, Seeking explanations</i></p>
<p>P3.1 Well we blame that for everything... well that's true.</p>	<p><i>Attribution</i></p>
<p>P3.4 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 its higher rate.</p>	<p><i>Generating meaning, Seeking explanations</i></p>
<p>C3.2 I think you look at life different.</p>	
<p>C3.3 Oh yes you do!</p>	<p><i>Different person Redefining</i></p>
<p>C3.1 Well you do after you've got over it!</p>	
<p>C3.2 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".</p> <p><i>This strikes a cord and everyone talks at once</i></p>	<p><i>Redefining, Different goals Taking control, Getting on with it</i></p>
<p>P3.2 We live from day today and if we want to do something and feel like doing it, then we do it!</p>	<p><i>Taking control, Resuming activities Reprioritise</i></p>
<p>C3.2 We do it</p>	
<p>P3.2 Forget the cost. Forget the other things, if you like doing it, do it!</p>	<p><i>Taking control, Resuming activities Reprioritise</i></p>

<p><b>P3.4</b> That's why we've just gone and booked a holiday today! We've just booked for..... we wouldn't normally have done that, we've only just got back from Jersey. We might as well spend the money and go!</p>	<p><i>Acceptance</i> <i>Reprioritise</i> <i>Different goals</i> <i>Getting on with it</i></p>
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## Individual Interview 4 – selective coding

Text	Codes
<p>INTERVIEWER Did anybody sit down and explain what a heart attack was?</p>	
<p>PATIENT 4 Yeah. Yeah. One doctor told us. He sat down and told me.</p>	
<p>INTERVIEWER So when you went home, did you feel that you'd understood what it was and how to get over it I suppose?</p>	
<p>PATIENT 4 I knew what had happened, but I were ... Ain't it silly? I were scared. Yeah. I were really, erm, I were afraid somehow. It upset me. Yeah. I had no confidence at all ....</p>	<p><i>Aggravated Watchful Insecurity Loss of confidence, Fear, Vulnerability Lack of confidence.</i></p>
<p>INTERVIEWER And there was nobody really who talked to you about those sorts of things, that you were frightened?</p>	<p><i>Precarious</i></p>
<p>PATIENT 4 No. No. No. I were given a book.</p>	<p><i>Getting information</i></p>
<p>INTERVIEWER Right.</p>	
<p>PATIENT 4 And I saw a little video.</p>	<p><i>Getting information</i></p>
<p>I think the worst thing anyone can have is a heart attack.... But your heart somehow, I don't know, it's.... 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.</p>	<p><i>Triggers, meanings of the heart, Knowledge, Aggravated Watchful Insecurity, Fear, Vulnerability, Insecurity</i></p>
<p>I came out in June. I was told that this health visitor would come to see me. I got no contact from the health visitor. Me husband rung up and the nurse had arranged for it one of the nurses, staff nurses, had phoned somebody and I told you we went on for three week. 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 and more you see?</p>	<p><i>Lack of confidence</i></p> <p><i>Tools, Taking control, Getting information Challenging Watchful Insecurity</i></p> <p><i>Confusion Lack of information</i></p>



<p>No. I've had no support. I've been left in ignorance really. In fact, I got to the point where when I went for the exercise test, I asked the man who were doing it if I'd had a heart attack, 'cos I just felt like it ... 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, you seem to be ... ooh, for months and months I were frightened! Oh yeah! I were terrible!</p> <p>Me life style had been changed completely anyway. You know? I've never been back to normal living again,</p> <p><b>INTERVIEWER</b> Are there things that you still feel uncertain about in terms of your health, but more particularly your heart health?</p> <p><b>PATIENT 4</b> Yeah. I do feel .. 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!"</p>	<p><i>Watchful Insecurity</i> <i>Uncertain, lack of understanding</i></p> <p><i>Watchful Insecurity</i> <i>Vigilant</i> <i>Lack of information</i> <i>Isolated</i></p> <p><i>Different person</i> <i>Tools, Avoidance</i></p> <p><i>Watchful Insecurity,</i> <i>Symptoms Lack of confidence</i> <i>Lack of control</i></p>
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## **Informal interviews**

The ten informal interviews were used for verification of the theory in the final stages of selective coding. At this stage the theory of Watchful Insecurity was nearly finalized. They were used to explore unresolved issues from the data. They were also a type of peer debriefing, where “peer” was defined as a friend or colleague with certain personal or professional expert knowledge or experience.

They were guided discussions the content of which was steered by emerging conceptual thinking and theoretical propositions. These were recorded in memos. A brief summary of the theory of Watchful Insecurity was given to participants and then a discussion commenced. The memo was used as the interview guide.

## **Informal interview memo: triggers**

It will not just be a heart attack that induces Watchful Insecurity. Theoretically other unpredicted, sudden, frightening events will also prompt Watchful Insecurity e.g. other illness, trauma/accident, bereavement, crime.

In what way is Watchful Insecurity distinctive after a heart attack compared to other situations? e.g. level, characteristics, causes, symptoms, meaning, impact.

In other situations are there conceptual associations with difference, loss, change, confidence, control? Is this different to a heart attack?

Distinguish the difference between Watchful Insecurity after a heart attack and other situations.

Does Watchful Insecurity occur in situations where a person has had an opportunity to assess risk prior to the event e.g. cancer where the person is ill prior to diagnosis?

Need to discuss with someone with expert knowledge of accident, cancer, bereavement.

The informal interviews were not initially going to be formally included in the research process. After reflection at the end of the study their crucial role was realized. It is possible that more could have been made of the informal interviews if their inclusion was planned from the beginning. For example,

data from the discussions could have been recorded, transcribed and be used as an additional dataset. This was not, however, possible.

Field notes, that were made anonymous, were recorded in the informal interviews. These were written up as further memos. These memos were not included in the electronic data set but were kept as hand written memos. The memos were then sorted into piles with the entire set of memo written throughout the analysis. They were sorted according to the components of the theory i.e. triggers, types, trajectories and tools. Comparison was made of the memos across time to check that there was a clear concept development and the theory components were supported. Data was also compared to check and test the characteristics of theory i.e. that Watchful Insecurity emerges from a sense of difference, is enduring and undulating. In this way the memos provided another form of data triangulation.

#### **Post-informal interview memo 4**

Watchful Insecurity occurs after a threatening event, if it occurs in a context where it has not been possible to assess the extent of the risk and danger prior to the event. This may occur in a cancer diagnosis.

Why is cancer different to a heart attack when it comes to Watchful Insecurity?

Cancer:

1. Build up a range of symptoms. Diagnosis is preceded with a symptom requiring reporting to a doctor.
2. Diagnosis may be positive – enable people to make sense of things. It may mark the start of treatment and feeling better.
3. Maybe watchful and insecure about a wide range of symptoms not just the few often associated with a heart attack e.g. chest pain and breathlessness.
4. The emphasis in cancer is on cure, unlike a heart attack, which has a chronic implication.
5. Activity may be positive not threatening.
6. Cancer may be of a part of the body where you are not immediately aware of the implications.

Now need to discuss the above with people who have experienced or witnessed accident.

As their inclusion was only decided in retrospect, only verbal consent for the informal interviews was obtained. Consent was initially obtained for the conduct of the discussion. Nothing the participant said was used verbatim, only the conceptual and theoretical memos that were written afterwards were used. After the decision was made to include the informal interviews into the analysis and thesis, the researcher went back to the participants to obtain their agreement for their inclusion.

As a final stage of analytical induction, after the informal interviews the components and characteristics of the theory of Watchful Insecurity were once again checked against the three datasets. Data coded to certain nodes were checked for sense and conceptual coherence. Relationships of the categories to the core category (Watchful Insecurity) were checked and verified. No further advantage was to be gained from further sampling and analysis. It was decided that theoretical saturation had been reached.

## **Appendix 10. Memos made during selective coding**

## **Appendix 10. Memos made during selective coding**

This appendix is a composite of some of the conceptual memos made during selective coding and development of the theory of Watchful Insecurity. The content of the appendix serves to illustrate the conceptual thinking and exploration that was conducted and underpins the theory. Examples of the exploration include i) the examination of the concept “state” in order to determine whether Watchful Insecurity was a state, ii) questioning what being different meant in the context of Watchful Insecurity iii) expanding upon the theoretical properties of Watchful Insecurity.

### **Theoretical properties of “State”**

“State” is an absolute not relative condition. You are in or not in a state.

It describes a sense of physical and emotional being, way of being, mode of existence

One “experiences” being in a state – matches the purpose of the research, which was to capture patients’ experience of recovery / discover their meaning of recovery.

“State” embodies two concepts.

#### **1. A way or condition**

Physical  
Objective  
Measured  
Relative  
State of repair  
Untidy state  
State of health

#### **2. Being, existence**

Emotional  
Subjective  
Experienced  
Absolute  
State you are in  
Depressed/emotional state

This study concerns the personal state, subjective experience, as represented by participants in interview and interpreted by researcher (2).

***How does this fit with objectivity emphasized by Glaser?***

## **Being different**

Experiencing change due to loss of control, confidence, role, position, responsibilities, activities and identity.

Consequences of being and feeling different include disbelief (denial); confusion because of not understanding the difference (seek an explanation, attribution); frustration due to restriction and fear; humiliation because they feel a lesser person; lack of self esteem; depression.

If people feel different are there implications of being 1) altered, unstable and 2) divergent i.e. out of step?

Become preoccupied by the difference, want to compare how you are different and have changed with others experiences of difference.

## **Loss**

Loss describes a state where 1) one has been deprived or dispossessed of something resulting in feeling bereaved or 2) one experiences or becomes aware that something is missing and feels irretrievable.

## **Change**

Describes an experience of variation in circumstances, feelings, settings. Implies discord or improvement i.e. "becoming a new man".

## **Theoretical properties of “watchful insecurity”**

“Watchful insecurity” is a state, a way of being that is experienced because of encountering a sudden or frightening event associated e.g. crime, accident. The event induces loss and change to an individuals’ biography.

It is caused by, a consequence of, the impact or result of a sudden unpredicted, dangerous, threatening event.

The event is associated with loss of control. It creates a state of being hyper-aware of loss, change and a sense of being different.

Preoccupied, precarious and perilous

It is perpetuated by a lack of knowledge, meaning and understanding.

Links to codes = What prompts it? Crisis, sudden, danger, threat, fear, loss of control, confidence and trust in the body

## **Watchful**

Embodies 2 concepts, both apposite to the study; vigilance and cautiousness

### ***Vigilant (preoccupied)***

A state of awareness of being different, vigilance implies a condition of being watchful, protective, careful, attentive (overly) of your body such that you restrict what you do. It implies a state of wakefulness, 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. Looking backwards, not forwards.

### ***Cautiousness (precarious)***

This implies a state of being wary and heedful as a result of an event, and the related change and difference. Care is taken due to doubt. Links to questioning e.g. Ought I to? Am I allowed? People are tentative, taking no risks.

Being on guard, knowing when to stop, playing safe, once bitten/twice shy

Being vigilant and cautious means being preoccupied – link to data on memory loss and irritability



## **Insecurity (perilousness)**

Insecurity implies a lack of safety, feeling unprotected, defenseless and therefore vulnerable and susceptibility e.g. to have experience one heart attack and therefore be susceptible to another. It embodies the concept of precariousness and the lack of control and confidence e.g. hanging by a thread, skating on thin ice, hovering on a brink. Makes fear understandable.

### **Dimensions of watchful insecurity**

<b><i>Watchful insecurity</i></b>	<b><i>Recovery</i></b>
Vigilant	Unaware
Preoccupied with self	Engaging with others/life
Protective of self	Protected
Attentive	Inattentive
Cautious	Confident
Precarious	Reliable
Wary	Assured
Doubtful	Certain
Distrusting	Trusting
Insecure	Secure
Perilous	Unthreatened
Unsafe	Safe
Vulnerable	Protected
Susceptible	Resilient

### **Markers / characteristics of recovery**

<b><i>Watchful insecurity</i></b>	<b><i>Recovery</i></b>
Bewildered	Knowledgeable, have meaning (attribution)
Confused	Clear
Uncertain	Understanding
Precarious	Confidence, control
Not achieving / failing to reach goals	Achieving goals
Losing positions/roles/ responsibilities	Regaining positions/roles/ responsibilities
Mistrust, doubt	Trust, have confidence

Preoccupied  
Restricting activity  
Denial, disbelief

Focused  
Resuming activity  
Acceptance

Recovery is not constant but fluid. People move in and out of state of recovery / WI according to events and experiences.

Recovery is a balance of understanding, resuming and accepting.

### **Understanding**

Attribution

Meaning – of the event and its impact on life

### **Resuming**

Mental and physical control  
Activity  
Goals  
Positions/roles/responsibilities  
Self-esteem  
positions/roles/responsibilities

### **Accepting**

Loss and change  
Limitations/restrictions  
Different priorities  
Different attitudes  
Different

Maybe reassurance is about:

1. Recognizing who they were before the illness and what this means now
2. Facilitate understanding
3. Helping in negotiating the balance between resuming and accepting
4. Doing this in an informed way with honesty, empathy, encouragement and care. Time to listen / staff who know and care

May reach a point of resuming and accepting but then something happens to throw you back into “watchful insecurity”. Therefore it is not constant.

### **Different person**

Who is being cared for by health services?

The person they were or the different person they are now?

The person they were needs to be recognized in order to create meaning for people.

**What is required to move beyond watchful insecurity?**

**Need to do**

Resume / restrict activity

Seek advice

Personalized knowledge

Accept change and loss where necessary

Set goals

**Need to have**

Confidence

Understanding

Meaning

Acceptance

Control

**Service implications**

Need continuity (monitoring and assessment) and personalized service that recognizes the person they were and are. Acknowledge and address the difference and achieve balance between resumption and acceptance.

Achieved via: someone who knows and cares; time; advice; assessment; information