

**Surviving cardiac arrest: patients' experiences of the in-hospital phase of recovery**

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This dissertation is dedicated to the memory of my grandparents  
Leonard Edward Ashton Spearpoint & Dorothy May Spearpoint

## **Abstract**

In the UK, cardiac arrest affects approximately 30,000 people in the community annually and the incidence of cardiac arrest in hospitals is currently reported as being 1.6 events per 1000 hospital admissions. Whilst survival to hospital discharge is variable, it is likely to be no more than 10% for out-of-hospital cardiac arrest and 19% for in-hospital cardiac arrest. The survivorship literature has suggested that patients experience a range of cognitive, functional and behavioural impairments, however, contemporary outcome data from the UK has indicated that the numbers of severely brain-injured patients surviving cardiac arrest is actually low. Furthermore a review of the literature revealed that little is known about the recovery experiences of those cardiac arrest survivors who were not apparently brain-injured.

This research inquiry intended to develop an informed understanding of the patients' experiences of recovery from cardiac arrest. This included their medical and nursing care, their response and adaptation to the extra-ordinary circumstances of their survival, their worries, fears and anxieties and any other matters that they chose to illuminate. Accordingly, an in-depth, unstructured, qualitative approach was used to interview sixteen patients during their recovery from cardiac arrest whilst they were still in-hospital patients.

Grounded analysis revealed that patients experienced a three-phase recovery process that commenced with (a brief) existentialist phase followed by a calmer, more rational period. During this second phase of recovery patients appeared to develop a coping strategy that followed the salutogenic model (Antonovsky, 1996) that included phase three, the development of recovery milestones which helped them to move away from a position of illness, towards a position of health. The narrative accounts of the patients suggested that the care provision of the medical gaze during the recovery process was variable and inattentive, being that it was principally constructed around its own operational workings, rather than being centred upon the patient.

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## Chapter 1: Introduction

### 1. Cardiac arrest survivorship

Cardiac arrest has been defined as “the cessation of cardiac mechanical activity as confirmed by the absence of signs of circulation” (Jacobs et al, 2004, page 236) and is considered to be a critical event both in the community setting and within hospitals (Buist et al, 2002, Cashman, 2002). Some have argued that cardiac arrest and cardio-pulmonary resuscitation (CPR) has become a signifier of the achievements of medicine, whilst being depicted as the ultimate challenge in both modern medical television dramas and documentaries (Bains, 1998). Despite increasing awareness, widespread educational programmes in CPR, continual advancements in knowledge, improvements in the organisation of the emergency response and technological advancement (Yeung et al, 2009) there has been little if any improvement in survival. The current reported incidence of in-hospital cardiac arrest in the UK has a reported frequency of 1.6/1000 hospital admissions (Nolan, et al, 2014) and there are approximately 28,000 out-of-hospital cardiac arrests in England (Resuscitation Council UK, 2014a). Less than 20% of patients who have a cardiac arrest in-hospital are discharged home alive (Tunstall-Pedoe *et al*, 1992, Gwinnutt *et al*, 2000, Peberdy et al, 2003, Cooper et al, 2006, Nolan et al, 2014). The survival figures for those who experience cardiac arrest in the community environment indicate that no more than 10% survive to be discharged home (Wissenberg et al, 2013, Resuscitation Council UK, 2014a).

The evidence regarding the quality of survival from cardiac arrest suggests that a minority of patients may experience a range of difficulties pertinent to their everyday lives. They appear to suffer cognitive, functional and behavioural impairment (Raina et al, 2008) and post-traumatic stress disorder is not uncommon (Gamper et al, 2004). For some, the extent of neurological damage is such that it affects their daily lives and that of their immediate carers (Lundgren-Nilsson et al, 2005). In the longer term, published evidence suggests that patients recovering from cardiac arrest have an additional risk of dying more prematurely than the general population in the first year following discharge from hospital (Kalbag et al, 2006).

The NHS Trust that hosted the research has a well-established resuscitation service and eighteen years experience of conducting detailed audit of resuscitation interventions and patient outcomes. The reported outcomes follow internationally recommended methods of data and reporting criteria (Cummins et al, 1997), known as the Utstein template, it includes a staged measure of survival from cardiac arrest that uses a non-linear temporal survival profile. The first outcome recorded is 'any return of spontaneous circulation' (ROSC), followed by ROSC greater than twenty-minutes, ROSC greater than twenty-four hours, discharge from hospital and one-year survival. The measurement points of discharge from hospital and one-year survival are considered critical long-term outcome points, and users are guided to record the patients' Glasgow-Pittsburgh cerebral performance category (CPC) score (Cummins et al, 1991) at the point at which the patient is discharged from hospital, irrespective of the final destination. Whilst being regarded as a crude method of assessing neurological recovery following cardiac arrest, the CPC scoring system is the most widely used neurological assessment tool in the resuscitation literature (Elliott, et al, 2010). It remains a routinely reported quality survival indicator amongst large national epidemiological data sets that form national cardiac arrest registries and audit programmes (Goldberger et al, 2012, Nolan et al, 2014).

The initial survival from cardiac arrest, arbitrarily recognised as a sustained ROSC for a period of greater than twenty minutes, has been reported at a rate of 50%. For these patients, this period heralds the commencement of a critical and unstable period of recovery. In recent years, the immediate post-resuscitation recovery phase has attracted significant attention from leading medical thought leaders in the resuscitation and intensive care fraternity (Nolan and Soar, 2008). In the context of conventional medical care, the longer-term well being of the patient is seemingly determined by the medical response to the physiological and psychological compromise consequential to such a condition and those patients that have co-morbid conditions may merit close attention in this regard (Sandroni et al, 2007). The complex interaction that defines critical care medicine as a multi-professional healthcare provision is considered to be significantly influential in the long-term well being of patients, an approach that has been widely disseminated in the form of a physiologically targeted post-resuscitation care bundle (Nolan and Soar, 2008).

Whilst it is evident that there is a significant quantity of literature pertinent to survival from cardiac arrest, there appear to be considerable limitations. Firstly, survival is largely framed from a medical / healthcare professional's perspective rather than from a survivor's view and the data is almost entirely gathered using quantitative methodologies. Secondly, it appears to have overlooked the important contribution from the patient experience. Thirdly, patient outcomes are routinely reported in a numerical context alongside crude and largely convenient neurological assessment tools (Glasgow-Pittsburgh Cerebral Performance Categories (Cummins et al, 1991)). Furthermore, follow-up studies with patients were conducted many months or even years after discharge from the hospital setting. The weight of published evidence provides a knowledge base of longer term recovery that is almost entirely negative and provides little in the way of knowledge of what patients' actually experience when recovering from cardiac arrest whilst in the hospital environment. The published literature indicates a concerning lack of 'holism', compassionate care and patient-involvement. This paucity of information therefore provides limitations upon our understanding of survivorship and recovery from cardiac arrest. As a consequence, clinicians are restricted in terms of being able to providing necessary, timely and effective therapeutic medico-sociological interventions.

## **1.1 Hearing the patient's voice**

Since the conservative government of John Major introduced the Patient's Charter in 1991 (Klein, 2006), there has been a declared intention to increasingly empower and involve patients in healthcare, both in terms of having a stronger voice in the planning of healthcare services and in being more autonomous in the decision making around care. This patient-centred ideal has been underpinned through a number of policy statements issued by a succession of neo-liberal governments. In the aftermath of the Bristol Heart Inquiry (Klein, 2006) the New Labour government of Tony Blair published the NHS Plan (Department of Health, 2000a), which became a landmark document that led directly to the establishment of a national, formalised, accountable clinical governance system. In conjunction with the existing professional regulatory statutes (British Medical Association, Nursing Midwifery Council, Healthcare Professions Council) this policy brought a previously unseen level of accountability to NHS management and clinical staff. Subsequently, the UK healthcare agenda

continued to positively engage with patients in the planning, implementation and evaluation of healthcare (Department of Health, 2008) at every level. More recently, government policy has placed considerable value on the opinion of the patient so as to act as a key driver in the improvement of services and in doing so it explicitly embraced qualitative and quantitative research methodologies in the quest for detailed, high quality patient feedback (Department of Health, 2009).

The patient agenda was further strengthened as a consequence of the mid-Staffordshire NHS Foundation Trust public inquiry (2013), which led to the publication of the document that became known as the Francis report. The report of Sir Robert Francis contained 290 recommendations, amongst which the most significant was the introduction of a statutory duty of candour, which required that all organisations that provide health and/or social care to openly and transparently inform patients and/or their representative's of any safety/care issues that may have arisen with the delivery of their care irrespective of whether any harm appeared to have occurred. Furthermore, all healthcare professionals are required to report to their employers any occurrence of treatment that causes serious harm or death with whistle-blowers safeguarded as a consequence of it becoming unlawful for any healthcare professional or manager to knowingly obstruct a healthcare professional from reporting harm to patients (Department of Health, 2013). This is considered to be one of the most significant changes to patient empowerment and patient safety in UK healthcare and came into law in November 2014 (Care Quality Commission, 2014). Two further national documents quickly followed the publication of the Francis Report, firstly the Berwick Report (National Advisory Group on the Safety of Patients in England, 2013) which explicitly recommended that the patient and their carers should be a powerful voice at every level of the healthcare delivery system (National Advisory Group on the Safety of Patients in England, 2013, page 18). Similarly, the Keogh report (2013) echoed the importance of patient involvement in improving the patient experience by being heard and involved in the planning, implementation and delivery of healthcare services and care.

Whilst this apparent shift in the balance of power represented an intended change to the current dominance of the medical gaze, it could be argued that it will take considerable time for these changes to actually penetrate the existing doctor/patient relationship, at least in the context of acute hospital based healthcare.

## 1.2 The research question

The apparent dearth of knowledge surrounding patients' experiences of recovery from cardiac arrest represents a weakness in the understanding of healthcare professionals as to what patients actually experience, how they cope with their recovery and how they see their future during the initial phase of recovery. Additionally, little is known of the strategies and situational assets that they may have available to them as they strive to overcome their challenges and difficulties; how do patients make sense of the situation in which they find themselves during what is a prolonged period of recovery and survivorship? How are they planning to cope with the mundane issues of daily life? Is their recovery care inadvertently partitioned by professional roles?

In consequence to this dearth of knowledge, we may be less able to optimize their circumstances and provide them with the most appropriate platform from which to recover, particularly in the initial phase of illness when they may be at their most vulnerable. The provision of high quality care is most likely to be enhanced through the involvement of patients, their families and carer's and the current UK healthcare agenda is committed to involving them in the planning, implementation and evaluation of healthcare (Department of Health, 2008).

The principal research question was to understand the emergent complexities associated with what patients actually experience during the recovery period following their initial survival from cardiac arrest. The methodology was designed to engage deeply with the patient, using open, non-structured qualitative interview strategies to talk with patients directly about their experiences of recovering from a life-threatening critical illness. In part this was informed by my personal experiences from a previous research study where I conducted semi-structured interviews with cardiac arrest survivors. During those interviews I had become aware that many of the participants had not known or understood that they had survived a cardiac arrest.

A number of other research questions, which are summarised below, were well-seated in the existing literature, had been considered and were expected to emerge during the interviews. These were focussed upon what the patient actually thought of their hospital care. For example, did patients perceive that having had a cardiac arrest

that they were susceptible to further immediate life-threats? What, if any, did the effects of such an event have upon their family and / or their carer(s)? Did the patient have any worries and anxieties that were specific to their condition? Did they have any thoughts or feelings about the end of their life? What or how did they perceive of their recovery? The interviews were conducted whilst they were recovering as in-patients within the hospital setting, still submerged in the work of the clinical gaze.

This dissertation reports on the findings consequential to an in-depth interview study that used a grounded approach to analyse the experiences of 16 patients who were recovering from cardiac arrest in hospital. Their experiences provided detailed insights into how patients perceive the complexity of care and their participatory interactions with the medical gaze. The emergent argument postulates a theoretical framework based upon a three-phase recovery model that could provide an enhanced recovery as part of a patient-centred, holistic, post-resuscitation care bundle.

In the chapters that follow, Chapter 2 presents a brief outline of the historical development of modern resuscitation medicine that was interlinked with a detailed critical analysis of the literature pertinent to survival and recovery from cardiac arrest. Chapter 3 details the rationale to support the methodological approaches utilised to acquire the data in this in-depth qualitative interview based research study and the grounded analysis that followed. Ethical approval and participant recruitment were also included in this chapter. The key findings that arose from the grounded analysis were presented in three findings chapters, being the search for coherence (chapter 4), recovery milestones (chapter 5) and illness and recovery – facets of the medical gaze (chapter 5). The final chapter (chapter 7) presents a detail discussion of the emergent thesis and the integral, crucial role played by the medical gaze in the recovery of patients who have survived cardiac arrest.



## **Chapter 2. Literature review**

### **2.0 Introduction**

The critical aim of the study was to explore in detail and gain an understanding of the experiences of patients recovering from cardiac arrest whilst they remained within the hospital setting. This study is not concerned with the technical interventions of resuscitation, accordingly, this chapter presents a critical review of the body of literature pertinent to survival and recovery, with specific focus on each of the three key themes that emerged from the data that were pivotal to the discussion of the findings and the derivation of the thesis.

An overview of the search strategies is presented in the first section of the chapter (2.1) followed by section (2.2) that outlines the historical development of modern resuscitation services in order to assist with the interpretive context of the study. Section 2.3 reviews the contemporary evidence regarding survival and recovery specific to cardiac arrest and highlights the considerable limitations with regard to the patient's experiences of recovery.

The significant gap in the dominant, medically focussed resuscitation literature regarding recovery from cardiac arrest had been identified early in the development of the research proposal. There was an almost complete absence of both patient recovery trajectories and the consequential biographical disruption (Bury, 1982) that had been evident amongst other types of illness recovery journey's that have been articulated within the medical sociology literature. Furthermore, it was apparent that the resuscitation literature was not well aligned with the patient experiences and the recovery themes that emerged from the interviews conducted in this research.

### **2.1 Search strategy**

The search strategy commenced with an extensive search of the published and un-published academic literature. This was conducted using the population intervention comparator outcome (PICO) method recommended for use by the Center for Evidence Based Medicine (2009) and lateral searching using reference lists, grey literature and

contact with experts. This method offered a systematic approach to acquire appropriately targeted and relevant literature, in order to form an established and contemporary knowledge base from which to conduct a critical analysis. Details of the literature search strategy are presented below in Table 1 and search terms in Table 2.

<b>Table 1. PICO Search strategy</b>	
<b>Search Terms</b>	
<b>Problem</b>	Cardiac arrest
<b>Intervention</b>	Resuscitation, basic life support, advanced life support, advanced cardiac life support, cardiopulmonary resuscitation
<b>Comparison</b>	Any
<b>Outcome</b>	Survival, recovery, quality of life
<b>Databases</b>	PubMed, Web of Science, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Cochrane, British Nursing Index (BNI), PsycInfo.
<b>Age range</b>	Adult
<b>Language</b>	English
<b>Time Range</b>	Unrestricted
<b>Subject</b>	Human studies
<b>Refined search</b>	Title and abstract

For the purposes of this doctorate and consequential to my job role, frequent and regular literature searching was conducted throughout the duration of the study period and a significant quantity of literature was acquired. Sources of literature came from attendance at local, regional, national and international resuscitation conferences, clinical policy development, academic inquiry, peer-reviewing journal articles and other research work. The PICO search identified 349 records from two database resources (Table 2). The searches conducted in the CINAHL, Cochrane, BNI, PsycInfo databases did not provide any additional resources.

**Table 2. Exploded search terms**

<b>PubMed</b>	<b>Hits</b>
((("heart arrest"[MeSH Terms] OR ("heart"[All Fields] AND "arrest"[All Fields]) OR "heart arrest"[All Fields] OR ("cardiac"[All Fields] AND "arrest"[All Fields]) OR "cardiac arrest"[All Fields]) AND ("cardiopulmonary resuscitation"[MeSH Terms] OR ("cardiopulmonary"[All Fields] AND "resuscitation"[All Fields]) OR "cardiopulmonary resuscitation"[All Fields])) AND recovery[All Fields] AND "quality of life"[All Fields] AND (("1993/01/01"[PDAT] : "2013/12/31"[PDAT]) AND "humans"[MeSH Terms] AND English[lang] AND "adult"[MeSH Terms]))	5
((("heart arrest"[MeSH Terms] OR ("heart"[All Fields] AND "arrest"[All Fields]) OR "heart arrest"[All Fields] OR ("cardiac"[All Fields] AND "arrest"[All Fields]) OR "cardiac arrest"[All Fields]) AND ("cardiopulmonary resuscitation"[MeSH Terms] OR ("cardiopulmonary"[All Fields] AND "resuscitation"[All Fields]) OR "cardiopulmonary resuscitation"[All Fields])) AND ("quality of life"[MeSH Terms] OR ("quality"[All Fields] AND "life"[All Fields]) OR "quality of life"[All Fields]) AND (("1993/01/01"[PDAT] : "2013/12/31"[PDAT]) AND "humans"[MeSH Terms] AND English[lang] AND "adult"[MeSH Terms]))	127
((("heart arrest"[MeSH Terms] OR ("heart"[All Fields] AND "arrest"[All Fields]) OR "heart arrest"[All Fields] OR ("cardiac"[All Fields] AND "arrest"[All Fields]) OR "cardiac arrest"[All Fields]) AND outcome[All Fields]) AND (systematic[sb] AND "2008/11/12"[PDat] : "2013/11/10"[PDat] AND "adult"[MeSH Terms])	86 (Cardiac arrest, outcome, systematic reviews)
<b>Web of Science</b>	
Cardiac arrest AND recovery AND 'quality of life' AND 'survival'	27
'Resuscitation' AND recovery AND 'quality of life' AND 'survival'	23
Heart arrest' AND 'recovery' AND 'quality of life' AND 'survival'	21
'Cardiac arrest' AND 'recovery' AND 'quality of life'	60

The following sections summarise the evidence from 75 relevant sources derived from 14 policy papers, 22 reviews / editorials, 17 evaluations / audits, 14 primary research articles and 8 books.

## **2.2 The development of resuscitation medicine**

Cardiopulmonary resuscitation (CPR) and resuscitation medicine is a 20th century concept which has developed and diversified to become a global phenomenon in little more than fifty years (Robertson, 2001). CPR is a simple life-saving concept that is readily taught and easily provided which has, as evidenced by television news coverage, reached even the most impoverished economies, promulgated by a truly global network of well-intentioned charitable and voluntary bodies and in some cases, professional healthcare systems (Eisenberg et al, 2007). Modern society has embraced the use of CPR to treat unexpected and reversible death and it has become a widely used and expected medical and lay technique, perhaps with unrealistic expectations of success (van den Bulck, 2002).

The foundation stone of what has become modern resuscitation was laid with the (re) discovery of the technique of closed chest compressions (Kouwenhoven, Jude and Knickerbocker, 1960). This ground-breaking research identified that the simple technique of pushing on the chest wall (external cardiac massage) could successfully restart an arrested heart. According to Baskett (2001), Safar and colleagues were conducting research work examining simple manual methods of opening the airway and delivering artificial ventilation at the same time, but independent to the work of Kouwenhoven, Jude and Knickerbocker. Baskett's historical account suggested that modern CPR was fully realised when, in 1961, Safar published the results of his experimental work which combined airway management (airway) and expired air ventilation (breathing) with closed chest compressions (circulation) to form what became known as the Airway, Breathing, Circulation (ABC) of resuscitation (Baskett, 2001). Prior to this juncture resuscitation had been an open-chest, internal cardiac massage technique limited to the operating table conducted by elite highly trained surgeons or crude methods of expelling water from the lungs of drowning victims (Bains, 1998).

The practical methodological simplification offered by the ABC approach brought CPR and the prospect of reversing premature death out of the operating theatre and into the rest of the hospital, but Safar had ensured that CPR reached out beyond the boundaries of the hospital by taking it into the community (Safar, 1981). From its modest beginnings, CPR, resuscitation medicine and its clinical application developed very quickly; incorporating electrical therapy (defibrillation and cardiac pacing), advanced airway techniques, drugs and post-resuscitation care aimed at limiting vital organ damage following successful reversal of cardiac arrest (Bains, 1998).

Further progress would have been difficult without a number of key factors. Firstly, through conferences and meetings, the research work undertaken by Jude's group and Safar's group had reached a wider audience and many were inspired to replicate their findings and apply them to their own patient groups, for example, in 1960 Blalock published his results following the successful application of the closed-chest massage technique to children (Baskett and Baskett, 2001). Just a few years later, provoked by high mortality rates from research into myocardial infarction, Pantridge introduced the first cardiac arrest team to a hospital (Royal Victoria Hospital, Belfast in 1964) and the first cardiac care ambulances into a local community in Belfast in 1966 (Baskett and Baskett, 2001). The first comprehensive manual of resuscitation was written in 1968 by one of the pioneers of modern resuscitation, Dr Peter Safar (Baskett and Baskett, 2001).

Following this inspirational initiative, thought leaders in the United States had by the early 1970's introduced similar systems of emergency cardiac care and CPR into communities and hospitals, firstly, in New York and Miami, and then as the concept gathered momentum and further results were published, it was adopted in other parts of the United States including Seattle (in Baskett and Baskett, 2001). Pantridge received criticism from many colleagues in the United Kingdom who were sceptical of his results and concerned about costs, consequently it was not until many years later that the first community cardiac care and resuscitation schemes were introduced into mainland Britain. These were lead by Chamberlain in Brighton (in 1973) and by Baskett in Bristol in 1976 (in Baskett and Baskett, 2001).

During the later 1970's it was recognised (by an increasingly larger group of critical thought leaders in the both the United States and the United Kingdom) that organised resuscitation training was required for hospital doctors and nursing staff in an attempt to further improve the efficacy of resuscitation and improve patient outcomes. This occurred side-by-side with the development of training ambulance personnel in CPR and advanced emergency techniques. During the same period, the American Heart Association had begun to develop formal national educational strategies centred upon resuscitation medicine, which included the formation of the Advanced Cardiac Life Support Course (ACLS) and the development of ACLS and basic life support instructors (American Heart Association, 2008), a situation that came to be replicated by other disciplines, for example, trauma, paediatrics and neonatal medicine.

The origins of the development of organised resuscitation in the United Kingdom commenced in earnest with the coming together of a group of like-minded, enthusiastic individuals from an array of medical specialities including cardiology, anaesthesia, emergency medicine, primary care and paediatrics. By 1981, this group had founded the Community Resuscitation Advisory Council (CRAC) as a charitable organisation committed to developing community CPR programmes, which by 1983 had become the Resuscitation Council of the United Kingdom (RCUK) (Fisher, 2003).

The first blueprint for the co-ordination and organisation of resuscitation services was published by the Royal College of Physicians (1987) in collaboration with the recently founded RCUK. The report was a comprehensive document designed as a directive to guide hospitals, ambulance services and the voluntary aid societies as to how to establish the organisation of resuscitation services, including resuscitation training. In the early 1990s the RCUK had established the first national life support courses (including instructor training) which were delivered across the United Kingdom and Europe, following the earlier American model (Moretti et al, 2007). Continued development and refinements to those national life support courses and resuscitation services has brought us to the position that we find today. Attendance and participation in emergency life support courses has become firmly established in the junior doctor curricula and all are recognised across the respective specialist Royal Colleges. It is expected therefore that all participants in resuscitation interventions and treatment in UK hospitals should be appropriately trained and

certificated whilst being supported by robust, organised resuscitation systems (Resuscitation Council UK, 2013).

The next part of the literature review considers the evidence regarding survival and outcome from cardiopulmonary arrest and how those survival outcomes have been measured.

### **2.3 Survival outcomes from cardiopulmonary resuscitation**

Little was known or evident about the survival prospects of patients who suffered cardiac arrest in hospitals in the United Kingdom (UK) until the publication of the BRESUS study (Tunstall-Pedoe et al. 1992). Up until this point publications of patient outcomes from cardiac arrest were restricted to infrequent single hospital reports or pre-hospital studies from the United States (US) (Tunstall-Pedoe et al. 1992). It had also been recognised that due to considerable variability in data collection methods and the reported outcome parameters regarding survival the published data was unreliable. Accordingly, a number of influential senior healthcare professionals developed and published the Utstein template (Cummins et al, 1991), which attempted to standardise the data collection criteria and the reporting mechanism of cardiac arrest outcomes for adult out-of-hospital cardiac arrest in order to provide more reliable outcome evidence whilst enabling service delivery comparisons.

The Utstein template as a utility was designed to examine a range of complex organisational, technical and outcome performances within the respective resuscitation services. It has provided a definitive platform for uniform reporting of cardiac arrest outcomes that has enabled standardised comparisons of services and outcomes. Alongside a series of survival outcome milestones, including sustained return of spontaneous circulation (ROSC), 24 hour survival and discharge from hospital, attempts were made to measure the quality of survival through the use of the Glasgow-Pittsburgh cerebral performance category outcome scoring system (Table 3) (Cummins et al, 1991), which had been previously developed as a simple surrogate marker to assist clinicians in their assessment of the severity of brain injury. The Utstein approach required researchers and clinical auditors to record the best

performance achieved at the time of hospital discharge and to take additional note of the discharge destination, such as home, residential care home, rehabilitation centre or another hospital.

<b>Table 3. Glasgow-Pittsburgh cerebral performance categories (Cummins et al, 1991)</b>		
<b>Score</b>	<b>Cerebral Performance Categories</b>	<b>Overall Performance Categories</b>
1	Good cerebral performance. Conscious. Alert, able to work and lead a normal life. May have minor psychological or neurological deficits (mild dysphagia, non-incapacitating hemiparesis or minor cranial nerve abnormalities)	Good overall performance. Healthy, alert, capable of normal life. Good cerebral performance (CPC1) plus no or only mild functional disability from non-cerebral organ system abnormalities.
2	Moderate cerebral disability. Conscious. Sufficient cerebral function for part-time work in sheltered environment or independent activities of daily life (dressing, traveling by public transportation and preparing food). May have hemiplegia, seizures, ataxia, dysarthria, dysphasia or permanent memory or mental changes	Moderate overall disability. Conscious. Moderate cerebral alone (CPC2) or moderate disability from non cerebral system dysfunction alone or both. Performs independent activities of daily life (dressing, traveling and preparing food). May be able to work part-time in sheltered environment but disabled for competitive work
3	Severe cerebral disability. Conscious. Dependent on others for daily support because of impaired brain function (in an institution or at home with exceptional family effort). At least limited cognition. Includes a wide range of cerebral abnormalities from ambulatory with severe memory disturbance or dementia precluding independent existence to paralytic and able to communicate only with eyes, as in the locked-in syndrome.	Severe overall disability. Conscious. Severe cerebral disability alone (CPC 3) or severe disability from non-cerebral organ system dysfunction alone or both. Dependant on other for daily support.
4	Coma, vegetative state. Not conscious. Unaware of surroundings, no cognition. No verbal or psychological interactions with environment.	Same as CPC 4
5	Death. Certified brain dead or dead by traditional criteria.	Same as CPC 5

### 2.3.1 In-hospital cardiac arrest survival outcomes

The first Utstein template for analysis of in-hospital adult cardiac arrest was published in 1997 (Cummins et al, 1997) and in 2004 it was further refined and simplified (Jacobs et al, 2004). Suffice to say, the in-hospital Utstein template has been extensively utilised to report outcome survival data for the reporting of outcomes from many large national datasets, including the national registry of cardiopulmonary resuscitation (NRCPR) (Peberdy et al, 2003) and more recently the national cardiac arrest audit (NCAA) in the UK (Nolan et al, 2014).

It is evident from conference presentations (personal experience) and the (limited) number of publications of Utstein compliant in-hospital cardiac arrest that there



are three headline outcome measures frequently reported upon. These were the sustained return of spontaneous circulation (ROSC), survival to discharge from hospital and the Glasgow-Pittsburg cerebral performance category (CPC) score.

The early results from 17,420 patients, the NRCPR in-hospital cardiac arrest data, which was a large, suitably reliable national cardiac arrest registry, indicated that 44% of patients achieved sustained ROSC and 17% were discharged home. Of these patients, 86% were regarded as having good neurological outcome, where the CPC score was one for the majority of survivors, or at worst, two (Peberdy et al, 2003). The first publication from the NCAA data reported survival outcomes from a large, highly reliable sample of 22,628 patients, where 45% of patients achieved sustained ROSC and 18.4% survived to be discharged home. The quantitative outcomes scores for crude neurological recovery in the NCAA report indicated that 97.5% were considered to have a good neurological outcome (CPC of 1 or 2) (Nolan et al, 2014). Despite the organisational variability within the respective healthcare systems the results were remarkable similar and have been considered to be reliable. The NHS Trust where the research participants in this study experienced their cardiac arrest recovery has contributed to the NCAA database and the local results will be presented in the methodology chapter.

### **2.3.2 Out-of-hospital cardiac arrest survival outcomes**

The most recently published systematic review and meta-analysis of out-of-hospital cardiac arrest (Sasson, Rogers, Dahl and Kellerman, 2010) analysed 79 studies, which spanned a period of 30 years and revealed a discharge survival rate of just 7.6%. Against this background, a small number of more recent publications from comprehensive, national and regional Utstein compatible databases of large data sets from out-of-hospital cardiac arrest registries have reported encouraging results that have indicated improving survival outcome data from out-of-hospital cardiac arrest that have been attributed to the placement of publicly accessible automated external defibrillators (Lijovic et al, 2014).

The resuscitation outcome consortium, which manages a large dataset of out-of-hospital cardiac arrest in North America, indicated that survival was enhanced in

patients who had witnessed cardiac arrest followed by bystander or professional CPR, this contributed to a discharge survival rate of 8% (Hostler, et al, 2010). In a large study of 19,468 patients from ten years of out-of-hospital cardiac arrest data published from the Danish national cardiac arrest registry (Wissenberg et al, 2013), survival outcomes gradually increased as more and more bystanders conducted CPR and indicated that thirty-day survival improved from 3.5% in 2001 to 10.8% in 2010. Similar numerical improvements have been reported from the London Ambulance service NHS Trust (Fothergill et al, 2013). This retrospective, observational study was based on a well-established clinical audit and reporting system that included a cardiac arrest registry which has conducted (and reported) annual activity and survival outcome data for a number of years. In total the London Ambulance Service was called to 49,746 cardiac arrests, indicating a cardiac arrest incidence of 117.8 / 100,000 persons in London. In order to effect better comparison with other published studies of out-of-hospital cardiac arrest studies, the authors excluded those events that fell outside of the standard Utstein reporting template. This meant that only on those cardiac arrests where bystander CPR was attempted and were treated with electrical therapy using a defibrillator were included. The reported discharge survival rate during the five-year period of the study indicated a continual increase from 12% in 2007 to 32% in 2012. Whilst this data was informative, this group have not reported neurological outcomes.

Current evidence has indicated that a small but important group of survivors suffer gross neurological deficits, which are reflected by CPC scores of three or four. The national cardiac arrest audit (Nolan et al, 2014) reported that 2.5% of patients who are discharged following in-hospital cardiac arrest had poor neurological outcomes and according to data from the Danish national cardiac arrest registry, as many as 6% of patients who were discharged from hospital after out-of-hospital cardiac arrest experienced significant neurological compromise (Stromsoe, 2013). Conversely, it could be considered reasonable to surmise (if one takes an epidemiological, positivist position) that grossly disabling neurological damage is largely minimised by timely and effective CPR and more informed approaches towards the complex management of post cardiac arrest syndrome, including therapeutic hypothermia (Nolan et al, 2010). Nevertheless, it is evident that whilst a small number of patients are affected by a degree of cognitive neurological damage, many more patients may also experience

other illness sequelae as they recover from cardiac arrest, which may also disrupt the anticipated biography of their lives.

The next section of this chapter reviews and critically analyses the published evidence pertinent to the range of conditions and circumstances that have been reported to arise and affect the quality of patient recovery in terms of the cognitive and behavioural effects, following cardiac arrest.

## **2.4 Survival and recovery outcomes – beyond cognitive impairment**

Mild to severe cognitive impairment secondary to brain injury that is attributed to low levels of oxygen in the brain has been widely acknowledged and reported in studies of survival outcome within the resuscitation community for many years. More recently reports of psychological and behavioural disturbances began to appear in the literature, including anxiety, depression, post-traumatic stress disorder (PTSD) (Wilder-Schaaf et al, 2013). The apparent plethora of survival outcome publications has drawn the attention of interested researchers and three key systematic reviews emerged which have provided a rich source of data pertinent to this study and are discussed chronologically in this section of the literature review.

Moulaert and colleagues (2009) presented an informative systematic review of the published literature that concentrated upon the cognitive deficits apparent amongst survivors of out-of-hospital cardiac arrest. Twenty-eight articles (systematically filtered from an initial sample of 286) were closely analysed to reveal that cognitive dysfunction (particularly memory loss) affected between 40 to 50% of out-of-hospital cardiac arrest survivors, which the authors attributed to complex physiological damage consequential to cerebral hypoxia and the response to reductions in cerebral blood flow. The authors commented on the general low quality of the evidence reviewed, noting considerable confirmation bias in the way that study sample populations were selected, small sampling sizes in the majority of papers studies and significant heterogeneity in the application and measurement of cognitive function assessment tools. Confounding variables were also not accounted for in the majority of the studies and the authors acknowledged their own inherent bias, which they attempted to overcome methodologically.

A more recent paper from Elliot, Rogers and Brett (2011) was the first systematic review to closely examine the published evidence that reported quality of life outcomes in survivors from cardiac arrest. The authors also attempted to include patient-centred outcomes in their review, including depression, anxiety, PTSD and social functioning. They also included widely used quantitative health assessment tools such as Short Form-36, EQ-5D and the Health Utilities Index within their search strategy. Seventy articles were extracted from over 5000 obtained from the primary literature searches.

An overview of the results indicated that 46 papers supported the hypothesis that following discharge from hospital, patients had a good quality of life, 17 held a neutral position and seven indicated that patients had a poor quality of life. However, a number of limitations were noted. Much of the literature reviewed overlapped with that used by Moolaert and colleagues (2009) and the authors also identified significant heterogeneous sampling across the selected papers, which included mixed populations of in-hospital and out-of-hospital patients, some excluded patients with catastrophic neurological damage, others excluded patients with no overt neurological deficits and a number included children and sub-sets of very elderly patients. Most importantly, the assessment methods regarding the measurement of quality of life, psychological and cognitive outcomes were also markedly variable, in the 70 papers reviewed there were 65 different neurological tests documented. The CPC was the most widely used (20%) whereas other validated tests were used in less than 5%. The authors also recognised that none of the reviewed evidence included surviving patients who required in-hospital care that were never discharged from hospital.

This made comparative analysis difficult and challenged the authors to arrive at an informative conclusion, consequently they engaged in a detailed discussion of the extensive diversity of the outcome measures used and argued a case for a range of standardised patient-centred quality outcome measures to be established within an Utstein style format. Despite the identified limitations contained within the literature, Elliott and colleagues (2011) concluded that surviving patients had experienced a reasonable quality of life, albeit one that may have been different than that experienced before their cardiac arrest.

The systematic review conducted by Wilder-Schaaf and colleagues (2013) aimed to specifically target the resuscitation literature that was concerned with psychological consequences following survival from cardiac arrest. It was the opinion of the authors that these important behavioural and mental health disturbances had been largely overlooked and that opportunities for therapeutic intervention during recovery were being missed. The authors also intended to examine the methodological strategies deployed within this body of evidence. The search strategy contained the following parameters, cardiac arrest, therapeutic hypothermia, depression, anxiety, quality of life, post-traumatic stress disorder, psychological outcomes, hospital anxiety and depression scale and Beck depression inventory. Furthermore, papers that did not include at least one quantitative measure of psychological outcomes were excluded. From an initial sample of 2200 papers, just 11 met the author's inclusion criteria.

The authors concluded that general assumptions could be made from the resultant literature in that psychological dysfunction frequently occurs and when it does it is present throughout the recovery phase following survival from cardiac arrest. The author's noted considerable methodological heterogeneity in the literature that they reviewed and were critical of the quality of the data. Consequently they felt compelled to provide a succession of advisory directives aimed at improving the academic rigour of the quantitative methodology used in the studies. Rather disappointingly, the appreciation and inclusion of a more appropriate, informative, patient-centred, qualitative methodology did not appear to have been considered.

This systematic review concluded that a quarter of patients who survive cardiac arrest are likely to experience some form of behavioural / psychological disturbance during their recovery. It was therefore considered important for clinicians to recognise (through early screening) that patients are susceptible to psychological difficulties and recommended (without any practical detail) that appropriate supportive interventions should be provided in order to improve the recovery period and overall well being of patients when anxiety, depression or PTSD are manifested. Whilst the authors recognised that further studies are needed, there was no overt consideration towards research that actively encourages and includes patients who are recovering from cardiac arrest and provide a level of perspective from the patient's point of view.

In summary, the results obtained by these three systematic reviews have indicated that patients recovering from cardiac arrest may experience a range of cognitive, psychological and behavioural dysfunctions. Cognitive difficulties were apparent in 40 – 50% of patients, anxiety present in between 13 – 42% of patients, depression detectable in between 8 – 45% and finally, PTSD evident in between 19 – 27% per cent of patients. The evidence also suggested that appropriate therapeutic interventions were limited meaning that it was likely that when patients experienced these difficulties, therapeutic opportunities were missed, which may have compromised the quality of their recovery.

It is of further interest to this study to note that the three groups of systematic reviewers conducted their final critical analysis on papers extracted exclusively from the medically constructed resuscitation-based literature. Moreover, with the exception of two studies which included outcomes obtained during the in-hospital phase of recovery, the outcomes were determined days, weeks, months and often years after discharge from hospital. Consequently none of the studies addressed the patient experience of recovery. It was also noticeable that amongst the literature, only one qualitative paper was included. This was in part due to the scarcity of appropriate qualitative publications, but also the inherent bias from search methodologies that only included quantitative studies. Finally, the searches deployed in the systematic reviews appeared to have discounted any possibility that patients may experience beneficial psychological outcomes associated with survival from cardiac arrest, such as the spiritual uplift reported by some survivors of cardiac arrest who have a near-death experiences (Fenwick and Fenwick, 1995). The next part of this literature review has examined the limited qualitative evidence and the near-death experiences evidence that emerged from the literature search conducted for this study.

#### **2.4.1 Survival and recovery – qualitative literature**

The amount of publications employing qualitative methodologies within medical literature is disappointingly sparse. Only three papers were identified that directly address elements of the recovery from cardiac arrest through qualitative inquiry, two of which include accounts of the recovery experience of patients who received implantable cardioverter defibrillators (ICD) following survival from out-of-hospital

cardiac arrest (Kamphuis et al, 2004) and recovery experiences and well being of nine survivors from out-of-hospital cardiac arrest in Sweden (Bremer, Dahlberg and Sandman, 2009). Finally, Lau and colleagues (2010) conducted an interview-based inquiry amongst a small group of patients who had recovered from cardiac arrest recovery to consider advanced care planning. To commence with, Kamphuis and colleagues (2004) conducted semi-structured interviews with twenty-one patients who received implantable cardioverter defibrillators (ICD) following survival from out-of-hospital cardiac arrest in the Netherlands. Four themes that the authors elucidated from the pre-existing evidence base were applied to a content analysis approach. The themes that they started with were centred on stress, social support, physical condition and personal well being and the resultant themes from the content analysis were presented in the following order.

Firstly, participants expressed disappointment with the progress of their recovery and found it difficult to accept the physical limitations they had experienced. Secondly, many were challenged by their cognitive deficits and were unsure as to whether these faculties would be regained over time. Thirdly, some recipients of ICDs experienced positive support from their family's, which for some was influencing factor on their agreement to have the ICD fitted, for others social support was disappointingly absent. The fourth factor was the time limited contact with medical staff that they had experienced whilst in hospital, which continued even when attending follow-up appointments in the outpatient clinics.

The authors identified a number of additional themes that had not surfaced when they had conducted the literature review. One of the most surprising and interesting findings that arose was how some members of this research cohort had responded positively to having come face-to-face their own mortality. Many experienced a renewed zest for life and a determination to enjoy the moment, for some there was no longer a fear of death. However, not all of the participants viewed their encounter with death favourably, for some the survival from cardiac arrest seemed to devalue their previous life experiences in some way.

Another unanticipated finding came from participants who expressed anxieties when anticipating the experience of actually receiving a shock when the ICD is

activated, some expressed concerns as to how others (family, friends and / or bystanders) might react when witnessing their collapse and the see the physical response to the electric shock. This suggested an element of stigmatism associated with having an ICD inside their bodies, a body that had failed and one that was reliant upon a small implanted device to maintain well being. In the first few days and weeks following discharge home, some patients moderated their physical activities in the belief that vigorous exercise might trigger an arrhythmia. In the longer term, some were grateful for the extension of their lives, but those who experienced complications were less positive. The authors also commented that patients were progressively less reliant upon their social support network that had been so crucial to them in the earlier phase of recovery. As patients became more accustomed to their situation they appeared to have gained confidence in the device. For those that had experienced cognitive challenges and memory loss, they also noted an improvement in the longer term.

Whilst many of the issues raised by this group of patients were directly related to the receipt of an ICD, all of the patients had recovered from out-of-hospital cardiac arrest and this study was one of very few that used qualitative inquiry to provide a more richer, more holistically positioned, patient-centred account of the experiences associated with recovering from cardiac arrest. The authors confidently postulated that the recovery experience and the pathway towards well being following cardiac arrest and receiving an ICD would be enhanced through closer attention to all of the recovery challenges experienced and alluded to by the participants in the study, those being the holism that encompassed the physical, cognitive, behavioural and psychological aspects of recovery.

These important points regarding a more holistic, patient-centred approach were echoed in the work of Bremer, Dahlberg and Sandman (2009) who used a phenomenological methodology to study the recovery experiences and well being of nine survivors from out-of-hospital cardiac arrest in Sweden. This paper presented a demonstrably robust and convincing argument that the patient's voice should be heard when contemplating the complex and often devastating outcomes that are congruent with initial recovery from out-of-hospital cardiac arrest. The engagement in an in-depth qualitative research process with survivors of cardiac arrest, conducted with the intention of bringing real patient experiences into the consciousness of those



responsible for the provision of care who make very difficult, stressful, life-changing ethically challenging decisions should provide for a more knowledgeable, better informed, patient-centred and holistic perspective to those who contemplate such difficult and stressful ethical dilemmas. The authors also make the point that associated survival literature from patients recovering from myocardial infarction is not necessarily applicable unless the participants have experienced the same life-threatening situation that is presented by cardiac arrest. They also pointed out that little (if any) of the preceding literature took account of the patient's experiences of recovering from cardiac arrest.

Recruitment was achieved through the publication of a newspaper article and sampling from the National (Swedish) Register of Out-of-Hospital Arrests. Purposive sampling was used to identify survivors of cardiac arrest of known cardiac aetiology who were discharged from hospital no less than six months prior to their interview (one participant had their cardiac arrest 15 years previous to their interview). The sample of nine participants included eight men and one woman and were aged between 44 and 70 years, all nine survivors were retired and living in their own homes.

Presented in a chronological sequence from the moment of the event to the patient's current position, the resultant narratives provided a unique and very detailed analysis of the lived experiences of the survivors. The authors discussed in detail seven main themes that arose from the data. These were as follows, the sudden life threat, awakening in perplexity, the memory gap and loss of coherence, memory recall, searching for coherence, distressing and joyful understanding, existential understanding and well being through coherence.

The theme of the sudden and elusive life threat concerned the patients' feelings of disbelief and total surprise that the cardiac arrest had happened and their difficulties in understanding that such a thing had actually happened to them. The next theme, that of awakening in perplexity, explained the cognitive and psychological chaos that accompanied the patients' return to consciousness and their struggle to regain their sense of self and position in the world. The memory gap was seen as a signifier of the cardiac arrest event, alongside a sense of total loss of the

linear time for the duration of the period of unconsciousness. The author's felt that in order for the patient to move forward this memory gap required coherence. The filling in of the gaps by others, including healthcare professionals, family and friends, was regarded as essential to the reconstruction of the missing events of the lives of the patient and enabled them to gain a semblance of understanding as to what had happened to them.

The theme of distressing and joyful understanding was perceived as a consequence of gaining coherence and was borne out of timely reflection upon the fortunate circumstances that led to their survival, whilst acknowledging that survival in these circumstances is uncommon. Patients experienced existential feelings of general vulnerability linked to a fear that they may experience a further cardiac arrest that they might not survive. Despite the presence of existential fears, patients searched for coherence and generally desired a return to a normal life, one of well being in the comfort and safety of one's family and friends. The paper concluded by recognising that having the knowledge of the psychological complexities that patients actually experience during their recovery (in all of its manifestations) would better prepare healthcare professionals to address the real needs of their patients enabling a more proactive, supportive, more complete recovery experience.

Whilst Bremer, Dahlberg and Sandman (2009) have provided what is probably the most informative and a rich account of the experiences of patients recovering from cardiac arrest that has been published thus far, the work did not appear to develop the themes pertaining to two important contemporary recovery concepts. Specifically, the authors did not link the unanticipated life-threat and sustained altered life-world trajectory experienced by patients to the literature regarding biographical disruption from chronic disease (Bury, 1982), which would appear to support their findings. Secondly, in their interpretation of the search for coherence, no account was taken of the body of evidence surrounding salutogenesis and the search for coherence (Antonovsky, 1996). Both of these issues are addressed in the final section of this literature review.

A team of researchers from Pennsylvania conducted a qualitative interview inquiry aimed at eliciting an understanding of the recovery experiences of patients

recovering from cardiac arrest and consider advanced care planning (Lau et al, 2010). This paper aimed to explore four key themes (derived entirely from a medical perspective), namely the patient's and their family's perception of medical prognostication in the immediate post-resuscitation phase, the patients definition of death, the use of advanced directives and perceptions of health and organ donation. The authors utilised a semi-structured questionnaire that was developed by a group of experienced doctors. Sampling was conducted through self-selection of participants who expressed a wish to discuss their experiences for a separate project following attendance at a national conference for survivors of sudden cardiac arrest (SCA) and nine survivors (from out-of-hospital cardiac arrest) were recruited to the study. The post recovery period at the point of the telephone interview ranged between one and eleven years. The interviews lasted between 20 and 60 minutes and each one was digitally recorded and transcribed verbatim. A second investigator then reviewed the transcripts and produced the narrative themes. Unfortunately, the analytical coding methodology was not described within the paper.

Participants had been asked to recall how the doctors had approached the difficult question of prognostication and unsurprisingly their experiences were varied and regarded by some as inaccurate, others recalled receiving mixed messages and conflicting information. The results also revealed a range of responses from survivors about the definition of death and how patients perceived the term cardiac arrest, some accepted and understood that they had technically died, whereas others preferred not to think of cardiac arrest as being associated with death. It clearly emerged that advanced care planning and end of life care had not been discussed with any members of the sampled group, but the patients themselves identified that perhaps they should have been. It was also interesting to note that during their recovery period patients significantly relied upon the support from the sudden cardiac arrest organisation to which they belonged and the authors noted that doctors had provided little in the way of psychological support. Most of the participants considered that they were now healthy and few had considered registering as potential organ donors.

Elements of the medical gaze were inadvertently incorporated into the questionnaire and this paper reflected the results from an inquiry established to provide information to the benefit of the medical view of recovery and survival, however it did identify several important inadequacies in the provision of post-resuscitation care of patients recovering from cardiac arrest. Whilst the authors took account of the (limited) patient perspective, there was conspicuous absence of recognition that other, non-medical health care professionals may play an important and integral role in the provision of post-resuscitation recovery care of vulnerable people who had survived a significant life threat.

The study published by Kamphuis and colleagues (2004) discussed earlier in this section, alluded to positive psychological effects experienced by some patients during recovery from cardiac arrest. These included a feeling of being lucky to be alive and that death was not necessarily something to fear. Similar positive experiences have been noted in the near-death experience survival literature, for example in a questionnaire based study of over 350 patients who provided accounts after so-called near death experiences, many had a reduced fear of death and many felt spiritually uplifted (Fenwick and Fenwick, 1995). Furthermore, it has been argued that the near-death experience itself is largely positive and appears to confer a level of long-term psychological protection to those who experience it (Parnia, Spearpoint and Fenwick, 2007).

Despite the limited amount of qualitative literature, the research provided helpful insights into the recovery experiences of patients. It was evident from Bremer, Dahlberg and Sandman (2009) that patients who are recovering from cardiac arrest and face an existential challenge and that they embark upon a search for coherence, seeking to make sense of what has happened to them. For many, the confrontation with their own mortality provides a modicum of spiritual uplift, for others the opposite was experienced.

A considerable volume of outcome / survival publications has been subject to critical analysis through the process of systematic review, almost exclusively from a quantitative, medical perspective. In all of the systematic reviews the respective teams of authors made similar conclusions and revealed a diverse, heterogeneous methodology that has made for difficult and challenging interpretation in the search

for definitive and beneficial care targets. The lack of consensus towards a standardised set of parameters from which to acquire reliable outcome metrics regarding experiences that patients face in their struggle to survive and recover optimally has been further undermined by a lack high quality, patient centred research. For the time being we appear reliant upon a very small number of qualitative patient-centred studies to provide the very best knowledge of the how patients experience recovery and survival from cardiac arrest.

The literature drawn from the cardio-pulmonary resuscitation arena makes it clear that inadequate attention is paid to the provision of patient-focussed, holistic professional care, particularly to the psychological well being of patients. Much could be learned if medicine widened its interpretive gaze to consider and accommodate related literature from a broader evidence-base and include research from related disciplines such as nursing and medical sociology. There is a significant body of literature that provides detailed insights into the recovery experiences of survivors from medical care or conditions associated with critical illness and cardiac arrest. For example, Wiles (1998) reported upon the experiences of patients recovering from myocardial infarction, similarly, Erikssen et al (2009) reported on patients and their families experiences of returning home following myocardial infarction and Prinjha and colleagues (2009) revealed an interesting variety of experiences of patients recovering from a period of stay within intensive care. The medical sociologist David Rier's paper "*The missing voice of the critically ill*" provided a detailed and very insightful post-hoc critical review of his own admission to an intensive care unit and Lawton's review (2003) of the lay person's experiences of health and illness provided a contemporary critique of the doctor / patient relationship.

## **2.5 The medical gaze, coherence and recovery**

Constructivist grounded theory argues that analytical processing produces the resultant codes and the thematic categories that lead to the findings, rather than the findings being derived from a pre-conceived hypothesis. It is at that point that the relevant literature should be critically reviewed to examine how it complements, contradicts and integrates with the findings (Charmaz, 1996).

### 2.5.1 The medical gaze

The quality of the doctor / patient relationship could be considered to be a fundamental influence upon the patients experience of recovery. The seminal work of Talcott Parsons (1951) defined the sick role as one that placed the person experiencing the illness into a position of social deviancy, subject to therapeutic control and therapeutic interventions that were designed to recover and return the person into a healthy, functional state and that within this context the patient is passive. Wallach Bologh (1981) considered that the sick role had evolved and was consequential to increasing control by physicians (largely through the power of their superior medical knowledge) to the point of almost complete disregard towards the patient. Her findings included a number of patient-centred issues, for example, a failure to communicate effectively with patients, the conduct of unnecessary treatment, an intentional avoidance of providing patients with difficult information and the loss of patient autonomy. Sadly, these behavioural traits are ones that many consider as common-place more than thirty years later, and the avoidance strategy (in the context of prognostication) taken by physicians was alluded to by Lau et al, (2010).

The experiences endured by Rier (2000) in his recovery from a 15 day stay in the intensive care unit (ICU) provided the stimulus for him to conduct an intensive review of the post-Parsonian medical sociological literature and it was apparent to him that medical sociology had averted its gaze from acute and critical illness. His personal experience of critical illness led him to re-classify his previous theoretical standpoint that regarded the Parsonian context of healthcare as being out-dated when he discussed how the critically ill are by necessity or through choice, happy to hand themselves over to the medical team and take a passive Parsonian role, albeit it temporarily.

Some forty-four years ago, Eliot Freidson (1970, page 205) postulated that *“medicine may be engaged in the creation of illness as a social state which a human being may assume”* and that it (medicine) does so from a position of authority that was conferred through its professional stature and its desired status within society. Friedson (1970) also recognised that illness had a duality as it represented a biological deviance away from the desired, stable position of health as well as a social deviance away from functional activity and the provision of a net contribution to society. This position placed

illness as a necessary social and political (capitalist) construct that required regulation through the profession of medicine. A profession, supported by significant infrastructure that merited the development of its own governmental department, which became valued, respected, afforded and positioned as hierarchically superior to those under its increasingly penetrative gaze.

Whilst nursing, as a profession is not generally referred to in the linguistic narrative of the medical gaze, it has become an integral, collaborative partner in this construct. The work of the nursing gaze, which takes places alongside the gaze of the doctors and the gaze of the professions allied to medicine, had formed its own professional niche. Consequently, nursing has become subject to similar levels of professional regulation, public accountability and social status as that experienced by doctors (Gastaldo and Holmes, 1999).

Foucault (1973) provided a significant treatise on the historical social construction of the profession of medicine and its regulatory function, but he also paid close attention to the biological model of disease and illness through regulation at the individual level. Foucault (1973), in recognition of the physically intimate work of the physician, labelled the demeanour of this meticulous, learned role of diagnosis and treatment as being a gaze specific to that of the medical practitioner. However, he argued that the medical gaze is not only focussed upon the diseased constituents of the body and the symptoms that manifest themselves through that body. The gaze is also concerned with referencing the symptomatic disease against a body of medical knowledge that had been historically accrued, where necessary, it added to new information to that body of knowledge. Therefore, in a Foucauldian context, as a representation of population-wide surveillance and societal control, epidemiological studies of disease entities became the most highly regarded assertions of what Foucault called power/knowledge.

Furthermore, Turner (1987) helpfully summarized the Foucauldian concept of the macro-construction of society, which holds that the derivation, balance and maintenance of power/knowledge required regulation and surveillance, through the establishment of an array social control constructs, such as the judiciary and prisons, the medical profession and the hospitals, which Foucault (1977) had termed panopticism. Drawing on the historical, societal management of the plague, where every

person, in every dwelling, in every affected community was placed under strict, marshalled surveillance that monitored every move, Foucault (1977) argued that society preferred to bring these deviants under the control of society, rather than exclude them and isolate them extraneously to the main community (as had previously happened with leper colonies).

Nettleton (1995), in an outline of Foucault's panopticism indicated that the efficacy of the panopticon initially wrested upon the premise that there was a physical structure that supported complete hierarchical observation. Foucault (1977) used the example of a contemporary prison to illustrate the concept. Bentham's Panopticon had a radial design, which provided a centrally positioned prison warder with a theoretical opportunity to view all of the prisoners at once. In the words of Nettleton (1995, page 113), this design offered "*total surveillance*" of the incumbents. Whilst it was not actually possible for all prisoners to be watched simultaneously, the prisoners felt as though they were under continuous surveillance and the fear of being caught when misbehaving was sufficient to ensure conformity with the regime. Therefore, this power over the incarcerated was achieved through a deliberately constructed behavioural auto-regulation. Nettleton (1995) also reminded us that Foucault had identified further benefits of the panopticon, in that those held under the all-encompassing gaze provided a potentially rich substrate for the production of knowledge – captive subject matter that was suitable for scientific inquiry through empirical research for the development and acquisition of knowledge.

In the context of modern healthcare, Armstrong (1995) detailed the emergence of what he termed 'surveillance medicine', within which he saw an increasingly powerful lens for the utility of the medical gaze. This higher magnification of the gaze looked beyond the limitations of the physical space of the buildings of the hospitals, surgeries and clinics as it penetrated the communities and homes of the entire population. Simultaneously, the new medical gaze embraced the psychosocial contributions to illness. Armstrong's construct of surveillance medicine (1995) had echoed the Foucauldian premise that the establishment of hospitals changed the spatial alignment of illness beyond symptoms and lesions to include screening and investigations. Surveillance medicine extended the boundaries of the gaze - modern medical health care changed the spatial relationship of illness further in that it now concerned itself with



additional regulation that included the *potentially* unwell, that is, all person's considered to be healthy. In doing so, the twentieth-century clinical gaze recognised the inadequacies of a health care system that was limited to tackling illness and disease, usually within the confines of the medical space of the hospital and the clinics. Instead it turned its gaze towards communities, becoming a panopticon without walls and embarking on a programme of preventative health care that aimed to keep people healthier and for longer. This targeted regulation would in time, reduce the incidence of disease and illness (deviance) across the whole population.

Scambler (1997), in his support for Armstrong's concept of surveillance medicine, alluded to the rigorous relentless measurement and regulation of health and illness that have pervaded modern society. Synonymously, this has been accompanied by an increasingly risk averse societal construction of illness that is clearly evident from the publication of national public strategy documents, for example 'Healthy Lives, Healthy People' (HM Government, 2010). This type of large-scale regulation is a common approach used by neo-liberal governments and has been subject to criticism from some quarters, many libertarians consider that such edicts are contradictory to the principles of personal freedom, autonomy and the right to self-determination that are synonymous with democratic society (Tengland, 2012).

In recent years government policy has sought high quality patient feedback (Department of Health, 2009) and placed considerable value on the opinion of the patient in an attempt to act as a key driver in the improvement of services, which commenced with the publication and implementation of the Patient's Charter in 1991 by the government of John Major (Klein, 2006). These first steps towards a patient-centred national health service and provided a platform for what was to follow during New Labour's first term of office. The UK healthcare agenda, initially driven by the NHS Plan (Department of Health, 2000a) aimed to positively engage with patients in the planning, implementation and evaluation of healthcare (Department of Health, 2008) at every level.

The NHS Plan (2000a) was to place patients at the centre of the new NHS, furthermore, the establishment of a UK wide clinical audit programme which followed the publication of 'An Organisation with a Memory' (Department of Health, 2000b), the

patient-safety agenda was to take a significant step forward as stronger lines of patient accountability were formalised. This paper, through its far-reaching recommendations, sought to place the patient at the core of healthcare delivery. A series of measures were established which included the setting up of a standardised, accountable, patient-focused, pan-NHS clinical governance and risk management mechanism. This placed the patient at the centre of the healthcare delivery hub and gave patients a modicum of control not previously experienced. This was in stark contrast to what was seen previously, being the traditional Parsonian / Foucauldian position that placed the patient as a deviant lurking at the periphery of healthcare delivery, un-involved and largely compliant with the system.

Examples of Armstrong's model of surveillance medicine (1995) are many and varied. The document 'From "Health of the Nation" to "Our Healthier Nation" (Hunter, Fulop and Warner, 2000, page 4) is one such example and it contained in the opening sentence of its introduction an explicit statement that indicated the intention to address health and illness of populations beyond customary regulatory boundaries.

*"Many governments around the world, including the United Kingdom government, are turning their attention from an exclusive focus on health care systems to the wider social and economic determinants of health strategies"*

This extended clinical gaze is clearly aligned to the Foucauldian narrative in that it (the medical gaze) remains a socially constructed, auto-regulated and a largely effective panopticon, however, as previously discussed, the concept of the medical gaze is integral with the intricate work of the physician upon the body of the patient (Foucault, 1973). However, alternative models of care have also been postulated, for example Szasz and Hollender (1956) (as cited in Kaba and Sooriakumaran, 2007) identified three elements to the doctor-patient relationship, a) activity-passivity - for example, the patient is passive and the doctor is active, this is usually the situation in medical and surgical emergencies or acute illness; b) guidance cooperation, whereby the doctor provides the advice and the patient is compliant, as happens more commonly in the management of illness that is planned or less acute and finally c) mutual participation, where there is dual role, such as that seen during rehabilitation programmes or in chronic illness management where a rapport and a longer-term

relationship can develop, that may lead to inclusive decision making regarding the care trajectory. In their review of patient-centredness, Mead and Bower (2000) indicated that this third component of the Szasz and Hollender model is further supported by the work of Michael Balint, who in the 1960's added the psycho-dynamic element to our understanding of the doctor-patient relationship which was previously seen only in a bio-medical context. Crucially, Balint considered that the patient's viewpoint of their illness is intrinsically valuable to the therapeutic intervention (Mead and Bower, 2000) and is one that fits the current (theoretical) paradigm.

### **2.5.2 The medical gaze and the individual during resuscitation**

It has been argued that, amongst health care delivery situations, the medical emergency that occurs when a patient's heart stops beating effectively, commonly referred to as a cardiac arrest, is amongst the most demanding of circumstances that befall the medical gaze (Bains, 1998). In the modern healthcare system in the UK it is conventional for critically ill patients to be placed under continuous surveillance within purpose built ward areas within the hospital such as the intensive care unit (ICU), coronary care unit (CCU) or in similar high-dependency unit (HDU). It is conventional for continuous physiological monitoring to take place, which is overseen by specially trained nurses who are at the patient's bedside (or very close by), similarly, doctors are also readily available. Patients who collapse in other parts of the hospital would not normally be placed under such close surveillance, therefore the response to a sudden collapse is a little slower, but national standards recommend that in modern healthcare systems, delays in providing advanced life support should not be more than three minutes (Nolan et al, 2010).

The urgency and the intensity of critical attention that is placed upon the patient at from the point of unexpected collapse is considerable. Speaking from my own clinical perspective, which incorporates 27 years experience as an active member of a hospital-based cardiac arrest team, it is typical for the attendant cardiac arrest team to be composed of a group of no less than six (and often more than ten) appropriately trained clinicians of varying levels of knowledge, skills and experience. This body of expertise is summonsed rapidly from all corners of the hospital by an electronic group call alert system and within two to three minutes the team will have gathered around the

collapsed patient, intent on reversing the dying process that the patient is currently experiencing. This usually involves a highly co-ordinated, cohesive team approach that requires the provision of intensive, physically active, highly technical and cognitively complex work.

In the community setting the delivery of advanced life support is very similar, however there are fewer personnel, as such care was normally provided by two to three specially trained ambulance paramedics or emergency medical technicians, who have been summonsed to the scene of the collapsed person via the national emergency call system. Ordinarily the ambulance personnel would take more than five minutes to arrive at the scene of the patient's collapse and there is a London standard of eight minutes from receipt of 999 call to arrival at the patient (London Ambulance Service NHS Trust, 2014), data reported in the most recent publications indicated a median response time of 7 minutes (London Ambulance Service NHS Trust, 2013). The guidelines that form the basis of the technical, organisational and human factors approaches deployed by cardiac arrest teams (which are subject to audit and research) are conventionally reviewed and revised in five year cycles, accordingly those used upon the patients recruited to this study were the most detailed and evidence-based thus far produced (Nolan, et al, 2010).

Following successful resuscitation the intensity of the gaze continuously changes as the patient moves into the critically important post-resuscitation phase of recovery (Nolan and Soar, 2008). During this period it is almost inevitable that patients require high-dependency care, either within an ICU, CCU or similar facility. As the patient continues their recovery and becomes less dependent, their reliance on close surveillance lessens and they move into more conventional ward environments as they prepare to leave the hospital and return to their home environment. The forthcoming section of the literature review examines the evidence base pertaining to coherence and recovery following cardiac arrest.

### **2.5.3 Recovery from critical illness and coherence**

In addition to the paucity of patient-centred research concerned with recovery from cardiac arrest, it is evident that there is a similarly limited voice from the critically ill, but there are notable exceptions. The final part of this literature review has considered the publications that have reflected the patient experience of recovery from illnesses associated with cardiac arrest.

Wiles (1998) conducted in-depth interviews with a group of 25 patients who were recovering from myocardial infarction. The two main objectives of the study were to generate data about people's experiences of recovering from a heart attack and their experience of the care they received thereafter, which was conducted to provide an improved, better informed recovery programme. The participants were interviewed a few weeks following discharge from hospital and then again about five months later. The findings from the initial interviews indicated that patients had feelings of disbelief and surprise at having suffered a heart attack as it was something that they had not foreseen, even though many understood that a heart attack was usually a sudden event.

During the in-hospital period of recovery patients had been provided with an information leaflet entitled 'Back to Normal', which had been published and provided by the British Heart Foundation. In addition to this reading material, cardiac liaison nurses and other healthcare professionals provided more generalised information about recovery and indicated to patients that they should make a full recovery after about three months. Whilst it was interesting to note that six patients had no recollection of receiving said input about their recovery, those that did recall receiving information and support, the information that they received was at odds with their personal views and expectations. Generally, patients appeared to have a pessimistic view regarding their recovery, as they would have expected to die or at least be permanently debilitated after having a heart attack, but many patients were surprised by how quickly they recovered and how well they felt. Accordingly, they came to terms with this by regarding their heart attack as mild (rather than serious). However, those who had suffered cardiac arrest as a consequence of the heart attack did indeed perceive that they had experienced a serious heart attack.

At the second interview patients considered that they had fully recovered if they reached the three-month period without any further symptoms or reliance upon healthcare interventions (other than routine follow up). Those who were reliant upon further healthcare interventions did not consider themselves fully recovered and both groups recognised that lifestyle adjustments would be necessary, some of the more seriously affected patients endured considerable physical impairment and their heart attack was seen as life-changing. With the exception of the most severely affected (who perceived that they were dying) all intended to make lifestyle adjustments in order to minimise the risks of further heart attacks.

Another study of patients recovering from myocardial infarction (MI) was published in Sweden by Eriksson, Asplund and Svedlund (2009), who conducted a series of in-depth interviews with 15 patients and their partners 4 – 8 weeks following discharge from hospital with a view to capturing their views and experiences of going home after MI. The main results revealed that the majority of patients and their partners viewed the return home from hospital as a major recovery milestone that signified a return to normal life and feelings of security, safety and a return to ordinary social activities. However, for others they were less confident and retained anxieties about their physical frailties and vulnerability and the work offered helpful insights towards improved, patient-centred discharge planning.

Rier (2000) discussed his own experiences within the context of his involvement in his care and the issues he experienced with regards to the information disclosed to him. His review of the literature provided useful clarity in that he differentiated critical illness from the *critical phase* of illness, which implied that this was a necessary component in the patient's recovery. Rier was keen to state that the critically ill have a story to tell and indicated that it was one that had not previously been told from the perspective of the patient and provided uniquely informative insights that are pertinent to the research participants in this study who collapsed into unconsciousness as their heart ceased to beat effectively and arrested. Rier identified that his rapid deterioration offered him little or no time to contemplate or ready himself for what was to happen. In his recovery Rier also noted that barring his limited contact with hospital visitors, his social interactions were almost entirely confined to engaging with the healthcare professionals who provided his medical and nursing care, upon whom he was largely dependent.

Rier's work goes some way to accommodate and position Bury's (1982) biographical disruption work into an acute recovery model. But, one must also remain mindful that Rier was in a dual role, as a patient and a medical sociologist and cannot be considered to be a layperson. Bury (1982) had recognised how patients had experienced illness in that it disturbed and disrupted the structure of the sufferer's everyday life. Whilst, he reported that many patients with chronic illness did at times conform to the Parsons model of the 'sick role' (Parsons, 1975), many subtly asserted their independence and concealed their illness, moreover they were capable of developing and utilising their own coping strategies, incorporating elements of self-determined rehabilitation; some may have even chose to completely opt out of formal rehabilitation programmes.

In her commissioned review, Lawton (2003) brought together the work of Bury with that of Charmaz (1983) and Williams (1984), all of whom who published similar insights into patient's experiences of living with chronic illness. Charmaz (1983) conceptualised the loss of self as a psychological deficit that was associated with isolation, dependency and loneliness that often accompanied debilitating chronic illness. Williams (1984), who used narrative reconstruction to add a temporal, real-world context that considered the array of positive assets that people with long-standing chronic illness used to make sense of their position in the world and to re-establish a degree of order to their lives in the wake of their biographical disruption.

In terms of how patients are able to develop a sense of coherence, working in the field of health promotion, Antonovsky (1996) argued that people in (a health orientated) crisis develop a resilience that helps them to move towards a more stable healthy state and away from less stable, illness state. Antonovsky developed his positive assets model of resilience from two key constructs; generalised resistance resources and a sense of coherence. As a contrast to the origins of illness (pathogenesis) Antonovsky conceptualised the origins of health, which he labelled salutogenesis.

Antonovsky (1996) suggested that a person's generalised resistance resources are a positive stress response to a cascade of internal and external stimuli that are sub-consciously constructed from their personal life experiences and incorporates an array of cognitive, physical, psychological, cultural and / or societal factors. Furthermore,

Antonovsky suggested that it is a person's ability to harness and utilise the generalised resistance resources that determines the strength of their sense of coherence that subsequently influences their return to health. In other words, a person that is motivated to cope (meaningfulness), understands the challenge (comprehensibility) and has the resources available (manageability) is one that is more likely to return to health.

Prinjha, Field and Rowan (2009) undertook a qualitative study of the experiences of patients attending follow-up clinics after a period recovering in ICU. Despite the lack of an evidence-base, ICU follow-up services had been strongly recommended and introduced into policy in the early 2000's as a support to patients who may have experienced physical and / or psychological difficulties after discharge from ICU. Additional service evaluation had also been planned and was seen as a key performance indicator of ICU as a service. Thirty-four patients were interviewed as part of the Healthtalkonline project (<http://www.healthtalk.org>) and all had been admitted to ICU as emergency cases, notably, none had experienced cardiac arrest.

The authors conducted a grounded approach to the analysis of the transcripts and remarked that the emergent themes produced data that had not previously featured in health related quality of life assessment tools. The four key themes of the patients' experiences were continuity of care, the receipt of information, the importance of expert reassurance and giving feedback to staff on the ICU. Generally speaking, patients afforded value to the ICU follow-up clinic and felt that having the service available had helped with the physical and psychological elements of their on-going recovery, however there were a number of patients who chose not attend as they had not wanted to return to ICU as they did not want to be reminded of the difficulties experienced therein.

#### **2.5.4 Chapter review**

In the course of the last 50 years society has come to accept and expect that CPR will be rapidly deployed to treat sudden cardiac arrest. The published evidence regarding outcomes, expectations of recovery and survivorship appear to be incomplete and poorly understood. The patient's voice and its experiences of recovery and survivorship from cardiac arrest during the critical phase of illness is conspicuous by its



absence, and we are reliant upon a myriad of studies framed from the perspective of the medical gaze as it was demonstrably clear that researchers of resuscitation outcomes have rarely interacted inclusively with contemporary medico-sociological evidence regarding recovery trajectories, recovery from illness, biographical disruption or health-seeking behaviours.

Despite the identified failings we have come to understand that survival (to discharge from hospital) following cardiac arrest remains dismal at 19% for in-hospital patients and at best 10% for those events that occur in the community setting. For a minority of patients who survive there is a range of physical, psychological and behavioural deficits that present the survivors with biographical challenges to their life-world. Cognitive brain damage, including memory loss, anxiety, depression, PTSD, social dysfunction and quality of life issues have all been reported in the post-discharge recovery phase, whilst positive outcomes from survival, such as a reduced fear of death and appreciation of an extended life have been largely overlooked.

## **Chapter 3. Methodology**

### **3.0 Introduction**

The principle and fundamental aim of this research was to understand and articulate the experiences of hospitalised patients who are recovering from cardiac arrest prior to being discharged from secondary medical care. The research was also intended to elucidate their fears, anxieties, concerns and what they thought about their immediate and longer-term future. The literature review that preceded this chapter clearly identified that the patient's voice, as an important, informative influence upon which to construct and direct care during the challenging journey of recovery, survivorship and well being, had not been sought.

This chapter provides a detailed account of the rigorous methodological process that was undertaken and is divided into three distinct sections. It begins with an account of how and why the chosen methodology was selected, including the underpinning philosophical construct and the supporting theoretical frameworks. The second section is concerned with the research setting, the ethical issues that arose around participant recruitment and the how the fieldwork of interviewing the participants was conducted. Within this, contextual attention is paid to the dual role and the potential clinical professional / researcher conflicts that I had anticipated that I may experience in the field. The final section details the grounded approach that was utilised in the analysis of the data that led to the generation of the theoretical outcome that is postulated in the discussion chapter. This section also provides the necessary underpinning to support scientific rigor, reliability and trustworthiness with regards to the conduct of the research and the development of a robust concept of recovery from cardiac arrest. This chapter provides a suitable platform to lead the dissertation into the findings discussed in detail in chapters 4-6 that generated the resultant grounded theory of critical phase recovery.

### **3.1 Qualitative methodology: rationale**

In order to reliably answer the research question it is an academic necessity to be theoretically informed (Silverman, 2005). Subsequently, prolonged consideration was given towards a range of suitable research methodologies. My initial thoughts were

directed to look at a quantitative approach to the acquisition of data. This was particularly appealing as I had both previous experience of working with quantitative data and a publication history in the field of resuscitation outcomes (Spearpoint, McLean and Zideman, 2000; Treanor, Spearpoint, and Brett, 2005; Kalbag, Khotyra, Richards, Spearpoint and Brett, 2006). Whilst I felt that I possessed a good working knowledge of the published literature, I felt compelled to conduct an exploratory and focussed literature review to address some of the gaps in the evidence highlighted in the literature review.

The literature review identified a number of quantitative assessment tools that merited consideration as suitable data collection instruments and a number of these were examined in detail. The literature had indicated that using the Glasgow-Pittsburgh cerebral performance category system (CPC) (Cummins et al, 1991) as a crude numerical metric to gauge quality of survival from cardiac arrest was entirely inappropriate, but serious consideration was given towards more sophisticated questionnaires that had been used comparatively less frequently, namely the short-form-36 instrument (Ware and Sherbourne, 1992) and the hospital anxiety depression score (HADS) (Spinhoven, et al, 1997). After close examination and having reviewed the literature it became clear that such an approach would not be suitable to answer the research questions as intended. Whilst all of these tools would generate data, it would have been framed through an entrenched positivist medical gaze (Hilton and Southgate, 2007). A positivist perspective is considered as a central tenet of evidence-based medicine and is reflective of the current philosophical paradigm within medicine (Goldenberg, 2006). Additionally, a positivist approach often takes a reductionist, epidemiological position that excludes outliers in the data and pays little attention to the individual (Little, 1998). I concluded that taking a positivist ontological position that was largely concerned with the derivation of facts, the testing of verifiable hypothesis and the formation of *absolute, unbiased truths* (Denzin and Lincoln, 2008) would not have been conducive to the development of a patient-centred perspective that would genuinely address the research questions and reliably echo the patient's voice. Furthermore I felt that if I used any of the said tools I would have been prone to replicating the demonstrable inadequacies that my literature review had unearthed.

In making the decision to embark on a qualitative study, I felt it necessary to consider a mixed-methods approach, but I decided that the utilisation of quantitative and qualitative data would have introduced unnecessary methodological complexity and data collection / patient participation issues as outlined by Bryman (2006). Accordingly I concluded that an in-depth interview approach represented the most effective method of acquiring data that would address the research questions, nevertheless it was important to consider other interview-based strategies.

I briefly considered a focus-group interview approach, however this would have been problematic for several reasons. Firstly, a deep exploration of the patient's very personal recovery experiences was integral to the study aims, therefore patients would have been required to discuss personal matters, and as Kitzinger (1994) acknowledged, participants would be likely to feel inhibited in revealing their inner-most feelings when reflecting upon their experiences in the company of comparative strangers within a focus group. I had also anticipated, through my knowledge and experience of the nature of survivorship (which I checked and confirmed with the clinical database) that it was unlikely that sufficient numbers of surviving patients recovering at the same time would be available for simultaneous participation. Furthermore, locating a suitable space in which to conduct a focus group would have been challenging within a hospital environment, as it would have needed to be near to a clinical area to enable less mobile patients to attend, additionally those who were not ambulant could not have been included in the study. Being pragmatic, it was clear that a focus group would not provide an appropriate methodology for the interviewing.

As a consequence of rejecting a positivist approach I found myself drawn towards a constructivist / interactionist qualitative position. The ontological position that I opted for was one that was firmly aligned within the established constructivist / interactionist framework. Denzin and Lincoln (2008) offered an over-arching definition of qualitative research whereby the researcher conducts a series of interactive, inquisitive, interpretive actions within a social setting in order to make sense of the world, as it happened, within its conventional, naturalistic setting. The interactionist qualitative researcher reflects upon and accepts the non-hierarchical, equivalence and multiple realities or truths that exist amongst their informants, the readers of the research and the researcher's own interpretations (Creswell, 2007). Moreover, Denzin (1969) detailed

the symbolic interactionist perspective on its interpretation of the complexity of ordinary human behaviours as one that recognises that people consciously and sub-consciously interact with one another, in a manner that is directed by their sense of self, which leads to the development of social and behavioural structures. This ontological position resonated strongly with my personal philosophical stance and was synonymous with the epistemological lens that I had envisaged using, as stated by Creswell (2007), being one that brings the researcher into close proximity with the research participants.

With regards to establishing my analytical approach I had not planned to test a specific hypothesis of recovery and I was not able to verify existing theoretical constructs (as none were evident from the literature), I therefore resolved to adopt a grounded approach to data interpretation in order to develop a theory, or at least contribute new knowledge and insights as to how patients experience their recovery following cardiac arrest. This appeared to provide the most appropriate methodological structure from which to derive a patient-centred theoretical account of recovery experiences following survival from cardiac arrest.

The seminal work of Glaser and Strauss (1967) that detailed the process of grounded theory was derived from the simple premise that theory is discovered / generated from the data and that the derivation of the theory is reliant upon a series of rigorously conducted processes. The constant comparison method of analysing the data as it arises so as to re-inform, mould and direct the subsequent interviews is fundamental to the process (Glaser and Strauss, 1967). As outlined by Strauss (1987), grounded theory provides a structured, systematic but flexible approach that seeks to deeply explore the richness of the data and generate the theory held within through the intensity of the deductive and inductive analytical processes.

Whilst the use of grounded theory in qualitative research within the healthcare setting is widespread (Mills, Bonner and Francis, 2006) an array of different interpretive approaches have evolved, all of which are generally seated within one of the two divergent methodological positions that were adopted by the originators. Glaser has continued to defend the traditional purist grounded theory approach whereas Strauss has diverged towards what some describe as an evolved position (Heath and Cowley, 2004). Amongst others, Charmaz (1990) provided a further methodological

(constructivist) position for grounded theory where she talked about it being used to explain or, rather, construct the social reality being researched and this model and its associated language held further appeal with regard to its use in this study.

The continuing evolution and ontological / epistemological flexibility offered by the grounded theory method is part of the appeal of using this approach, and despite the methodological variability adopted by scholars of grounded theory, a set of core principles that characterise grounded theory have been identified (McCann and Clarke, 2003a). The seven characteristics are presented in table 4. below.

**Table 4. Characteristics of grounded theory (McCann and Clarke, 2003a)**

- Theoretical sensitivity – sensitivity and insights into the likely nature of the data being collected
- Theoretical sampling – informed by the emergent data, the researcher adjusts the focus of their lens to develop further insights into the emerging theory
- Constant comparison analysis – analytical thinking and the development of theoretical categories is explicitly undertaken *during* data collection
- Coding and categorising data – honing down the key emergent themes that inform and generate the theory, conducted on a number of levels and integral to constant comparative analysis
- Theoretical memos – research notes made during each stage of the analysis to assist in the conceptualisation of the emergent theory
- Literature as a source of data – used to support the validity of undertaking the research and contributes to the theoretical sensitivity
- Integration of theory – interweaving of the emergent theory with the existing literature, also can inform the theoretical sampling

Whilst it is important to acknowledge the evident divergence and complex debate that surrounds the conduct of grounded theory research I have opted to follow Glaser's recommendation (Glaser, 1998, as cited in Heath and Cowley, 2004), that is, to just get on with doing the research whilst retaining all of the methodological processes that are considered to characterise the grounded theory approach (McCann and Clarke, 2003a).

The generic grounded theory construct described by McCann and Clarke (2003a) sits comfortably within my declared ontological and epistemological position of symbolic interactionism / constructivism alluded to previously in this chapter. Subsequently I used this to frame the specific grounded approach that was applied throughout the analytical phase of this research. The next section of the chapter details the process of data generation via in-depth interviewing.

### **3.1.1 In-depth interviewing**

It has been estimated that interviews have been used as a data-gathering tool in 90% of social science studies (Holstein and Gubrium, 1995). One-to-one, in-depth interviewing has an established position as a critical and fundamental tool for the acquisition of data within the sphere of qualitative research within health and social care (Bray, 2008). Lawton (2003) suggested that qualitative methodologies and in-depth interviewing have led the way in providing an important and previously unheard voice for patients and have influenced their positioning to being placed at the centre of researchers attention. Nevertheless, it was evident from the literature review discussed in the previous chapter that the patient's voice is conspicuous by its absence within the medically framed survival literature.

When considering her work that involved interviewing women, Oakley (1981) challenged the objective, positivist paradigm that was dominant within sociological research at that time when she regarded that traditional approach to interviewing as a sterile, one-directional method that attempted to extract data without feeling, social interaction or consequence. Oakley, citing publications that admonished the social skills of interviewers, rejected this premise and embraced an array of human behaviours that she regarded as integral to promoting the quality of interview data. Not only did Oakley (1981) recognise the importance of human sociability factors that enhanced the rapport between the interviewer and the participant, she made the crucial point in acknowledging that the creation of an open, transparent and trusting demeanour in the interview, with a flattened hierarchy is likely to yield deeper, richer data. This important realisation was echoed by Johnson (2001), who described in-depth interviewing as a social form that involved a particular type of interaction between people, based on a developing intimacy between the interviewer and the interviewee. He went on to define

an in-depth interview as usually being conducted one-to-one, with face-to-face interaction and of relatively long-duration. In a post-modernist context, Fontana (2001) stated that with a breakdown in the former patriarchal relationships, the roles between the interviewer and the researched have become more ambiguous and previously unheralded opinions have become important, consequently interviewing is now seen as an interactive, dynamic process shared between the researcher and the researched (Bryman and Cassell, 2006).

In keeping with my methodological rationale outlined in section above, I had settled upon an unstructured, grounded approach to conduct the interviews. This was akin to the epistemological stance taken by Strauss (1987), being one of an acknowledged active, participatory approach taken by the interviewer to facilitate and encourage the development of new and perhaps unpredictable themes and discussion items that are consequential to the interview without conflicting with the core questions previously identified for the purposes of the in-depth inquiry, a strategy previously described by Bolam, Gleeson and Murphy (2003). Furthermore, having taken a symbolic interactionist / constructivist position it was important to adopt a methodologically approach that incorporated open, unstructured interviews which placed the patient at the centre of the inquiry. In the interests of methodological rigour and as a reflexive researcher it was also important that the opinions, views and biases of me as the researcher would be kept to a minimum whilst intending to be transparent in the acknowledgement of my participation and influence as a the researcher in the derivation of the data.

In the context of unearthing truths about the world, some argue that qualitative research, by necessity, requires a reflexive approach in order to explain the constructed nature of the interview and the uniqueness of the relationship that develops during the interview between the researcher and their subject (Power, 2004). In support of this approach Jootun, McGhee and Marland (2009) suggested that such a reflexive strategy is highly appropriate. Furthermore, Kezar (2003) cited the importance of reflexivity, within the context of conducting qualitative research, where the interviewer considers and acknowledges their own contribution and influence upon the entire research process, critically, the acquisition of the data. Kezar (2003) also linked reflexivity and the awareness of the researchers part in the process, whereby the balance of power and



the direction of the interview is shared between the interviewer and their subject, as first described by Oakley (1981).

A further important consideration is to regard the interaction between the researcher and the researched, which was highlighted by Richards and Emslie (2000) who argued that in addition to gender, age and ethnicity, the professional background of the researcher is important to the nature of the data obtained during the interviews. Richards and Emslie (2000) found that the status of the researcher is perceived differently to the extent that it may significantly influence the responses of their interview subjects. Mindful of this evidence, and given that all of the interviews took place in a clinical setting, I opted to wear my usual work clothing (formal shirt and a suit) along with my NHS identification card and name badge, but I remained aware of the visual significance of how my appearance may underpin and / or influence the perceptions that potential recruits may formulate when regarding my (dual) role as a researcher and a clinician. However, I believe that it would have been more explicit had I worn a uniform.

I considered that it was important to attempt to overcome any sense (for the participants) that they were in a traditionally passive Parsonian sick role (Parsons, 1951). I attempted to minimise this effect through open, transparent and explanatory dialogue with each of the participants so as to firmly establish that their contribution was fundamental to the quality of the research. I also ensured that, to the best of my ability, each and every participant understood my role as a researcher and how that interfaced with my dual role as a clinical nurse. I was confident that my professional and personal life experiences enabled me to engender an appropriately respectful and convivial relationship with each participant and that this provided a solid platform upon which I conducted the interviews.

When considering the researcher participant encounter I also viewed this engagement as a nurse patient encounter and I experienced my own internal difficulties with being in a potentially conflicting dual role. Given the acuity of illness present amongst the occupants of the clinical areas where the interviews were being conducted there was a genuine potential for a medical emergency to arise (with the participant or other patients in the vicinity of the interview space) in an instant. Accordingly, I had cause to consider that I might be required to switch into an active clinical role at a

moments notice. As an experienced expert leader in resuscitation and critical care I was cognisant of the fact that not only was I was recognisable by colleagues and medical staff and would be expected to respond to any emergency that arose, I was also under the professional, ethical and regulatory auspices of the medical gaze (Nursing Midwifery Council, 2008). It is interesting to note this situation is not covered in the guidance offered by the Royal College of Nursing (2011) or in the Research Governance Framework for Health and Social Care (Department of Health, 2005), a point that I will return to in the discussion chapter.

Creswell (2007) also identified that whilst being open to external influences, the qualitative researcher will bring their own opinions, views, experiences and philosophical positioning to their interpretive framework, furthermore the researcher will be influenced in their decisions by the ontological, epistemological and methodological perspectives that they hold. Some consider that a reflexive approach is necessary in order to explain both the *constructed* nature of the interview and the uniqueness of the relationship that develops between the researcher and their subject (Power, 2004). In recognition of this and with particular reference to the nature of the intended subjects, caution is advised when interviewing patients who are critically ill.

Morse (2001) noted that the nature and severity of the illness may render the (ideal) sample of patients as unreliable informants as their normal biographical competence may be suspended. Paradoxically, it has been evidenced that interviewing such patients can be a welcome distraction for them once recovery and rehabilitation has commenced, even amongst those recovering from serious illness or injury. They often have questions to ask about what happened to them and may require an explanation as to the circumstances that led them to their current situation and it may be and it can be reassuringly therapeutic to the patient (Morse, 2001).

The patient accounts published on the Healthtalk web resource (previously Healthtalkonline) are entirely constructed from in-depth qualitative interviews and reflect individual patient's experiences of healthcare. This resource and has provided invaluable insights into patient's experiences of healthcare and has added a new level of accessible knowledge to the medical fraternity and beyond. Healthtalk is well respected in the medical world and was fully supported by the Department of Health

(Healthtalkonline, 2008) and continues to expand. Furthermore, it is evident that qualitative methodology has become increasingly and more widely accommodated as an acceptable and valid methodology, the National Institute for Health Research (NIHR) research specification document (NIHR, 2009) selection process specifically requests evidence of qualitative methodologies, including in-depth interviewing.

I had envisaged that each of the interviews would be loosely framed by a fluid interview schedule (appendix 1) that I developed from a theoretically informed position that arose as a consequence of interactions and responses during a previous research study with patients recovering from cardiac arrest. This interview schedule was an *aide memoir* designed to ensure that potentially important areas were not inadvertently overlooked.

Accordingly, I concluded that the use of the one-to-one, in-depth interview represented the most appropriate methodological model to successfully address the research questions within the planned study. My previous 30-year history of talking to patients and my recent experiences of interviewing patients was also very helpful. Furthermore, the chosen approach would provide the best possible circumstances to yield high quality data, provided that sufficient preparation was made in constructing a psychologically safe environment that would be conducive to disclosure of their genuine thoughts and feelings regarding their experiences of recovery from cardiac arrest. The next sections of this chapter detail the research setting, the sampling methodology, the ethical issues and recruitment to the study.

### **3.2 The research setting**

The research was conducted at my place of work, which is a large National Health Service Trust composed of five hospitals that is situated within west London. The Trust provides a wide range of conventional clinical services to the local population, but it also offers a range of regional specialities and the most notable is the location of one of London's eight designated heart attack centres within one of its hospitals. Also of contextual relevance to this study is the accommodation within the Trust of the west London renal centre, a supra-regional neuroscience service and its status as a major trauma centre, all of which provided a source of participants. Additionally the Trust is

associated with a long established and respected medical school, it is also an integral component of an Academic Health Science Centre and is globally positioned as a centre of excellence in biomedical research.

As I had wanted to understand something of the experiences of patients recovering from cardiac arrest, the fieldwork was planned to be conducted with the informants (hospitalised patients) in their *natural habitat*, that being the clinical setting, preferably at their bedside, but certainly within the hospital ward. The initial approaches to each of the potential participant patients were all conducted within the clinical setting, across a range of wards that included the general intensive care unit (ICU), the cardiac high dependency (HDU), the coronary care unit (CCU) and the cardiology ward the cardiothoracic ward and a rehabilitation ward for elderly patients.

### **3.3 The study population – sampling**

The present study was framed upon a grounded approach that incorporated a form of theoretical sampling, which is regarded as a central tenet of grounded analysis (McCann and Clarke, 2003a), which was recounted by Strauss (1987), who stated that theoretical sampling is a process where the researcher makes a decision as to what data needs to be collected, where from, and why, based upon current analytical output or initially informed through theoretical sensitivity. Charmaz (1990) provided a further purpose of theoretical sampling, whereby she regarded that it not only informs the analytical direction of the data collection (and constant analysis) of the data (whilst situated in the field), it also provides structure to the analysis. These were the methods that I used to determine the nature of my sampling / questioning approach and I had recognised that without having developed any pre-determined theoretical sensitivity I would, as a grounded researcher, have encountered a conceptual impasse as a researcher needs a starting point from which to establish the initial inquiry.

My sampling was initially informed through theoretical sensitivity, which was gleaned during a number of semi-structured interviews that I had conducted during a previous research study (Parnia, Spearpoint, de Vos et al, 2014). During these interviews I became sensitised to an issue raised by participants in that many of them were not aware that they had actually had a cardiac arrest and had learned that they

had done so as a direct consequence of the consent process. This realisation prompted me to consider and question how informed patients had been during their recovery. This discovery was fundamentally influential to the development of the research questions in this study, furthermore it also theoretically informed the interview schedule, a similar experience to that outlined by Orona (1990) in her work on temporal identity loss.

Glaser and Strauss (1987) could have argued that my sampling method was akin to a selective or purposive sample, as I declared in my research protocol submitted to the research ethics committee that I planned to interview up to 30 patients that met my inclusion / exclusion criteria, however Draucker and colleagues (2007) offered a detailed critique of contemporary approaches to grounded theory sampling methods that detailed a hybrid model of selective / theoretical sampling. Their model identified an evolving, changing sample that commenced with a small, theoretically informed purposive sample, which as the research progressed became increasingly more theoretical, as a consequence of the constant comparative method. This was the sampling model that I had applied to the current study and my prospective recruitment strategy was designed to be efficient, utilising the most reliable information sources (patient databases) and communication methods (e-mail, telephone, face-to-face contact), which will be described in the forthcoming sections of this chapter.

As anticipated, my strategic approach became more meaningfully informed once I had conducted the first few interviews as the primitive themes and coding categories were conceptualised, a situation that had been identified by Glaser and Strauss (1967). Regardless of the source of theoretical sensitivity, sampling was at all times directed towards patients recovering from cardiac arrest and theoretical sampling/questioning was conducted rigorously during the analytical coding.

The inclusion criteria were comparatively easy to construct, but because of the potentially devastating sequelae associated with cardiac arrest survival, it was felt necessary to determine explicit exclusion criteria so as to provide as clear as possible delineation between those participants who could be approached for inclusion in the study and those would not be suitable, which was particularly useful when I made initial contact with the respective wards where the patients were located. Table 5. Below details the inclusion and exclusion criteria.

**Table 5. Inclusion / Exclusion Criteria following recovery from cardiac arrest**

Patients who regained consciousness  
Patients who are able to communicate effectively.  
Patients who are able to understand or speak English.  
Patients who are able to provide informed consent.  
Patients are 18 years of age or older.

Patients who have not regained consciousness  
Patients who are not able to communicate effectively.  
Patients who are unable to understand or speak English.  
Patients who are unable to provide informed consent.  
Patients below 18 years of age.

The inclusion criteria were derived in order to facilitate reliable data capture through the in-depth interview approach, accordingly it was felt necessary to limit the criteria to exclude those patients who were considered unable to communicate effectively through speech. Whilst it was recognised that this would potentially limit the sample and exclude a voice that would otherwise be unheard, the time constraints and the considerable difficulties associated with using a non-verbal approach to undertaking a detailed, complex interview, subject to theoretical sampling justified the exclusion criteria. A similar opinion was reached with regard to participants' abilities to understand and speak fluently in English. Kapborg and Bertero (2002) utilised interpreters during qualitative interviews and identified significant interpretive complexities that undermined the validity of the data. Temple and Young (2004) acknowledged the missing voice of the deaf and / or non-English speaking patients whilst understanding the not insignificant difficulties associated with trying to overcome the communication medium and language problems. In addition to the reliability of data interpretation, there were a number of implications surrounding the involvement of interpreters in the interviewing process within a clinical research environment, specifically their availability at short-notice and their availability for purposes of transcription, accompanied by the associated costs.

The initial plan was to conduct in-depth qualitative interviews with up to 30 surviving patients, or at least sufficient to reach a point of data saturation, a position that is reached when the frequency of novel data declines almost to a situation where little or

no new data emerges (Creswell, 2007), whereas Glaser and Strauss (1967) determined that sampling in grounded methodology is continued until theoretical saturation is reached and hence it is difficult to pre-determine how many interviews may be necessary. However, a recent detailed discussion amongst recognised expertise in the field indicated that there are many factors that should be considered when contemplating the optimal sample size, which should include the ontological and epistemological stance taken by the researcher and the researcher should be sufficiently rigorous in deciding that a sufficient sample size is achieved in the context of their inquiry (Baker and Edwards, 2012).

In the development of the study protocol I prospectively considered that the first two to three interviews would be directionally important to the continuing refinement the nature of the inquiry through my phrasing of the questioning and deeper probing of the theoretically informed areas (through constant comparison between each of the interviews), but they were also considered as useful pilot interviews in helping to determine the appropriateness of the participant information sheet, the consent form and the outline interview schedule (appendix 1) as measures of good ethical practice (Royal College of Nursing, 2011), but this situation did not arise for the participants.

### **3.4 Ethical Approval**

At the commencement of the ethical approval process, the study was registered on the Integrated Research Application System (IRAS) (Health Research Authority, 2013) on the 18<sup>th</sup> January 2010. Meticulously accurate completion of the four key documentary components was conducted over a period of two years. During this time a number of version upgrades to the IRAS software took place, this merited occasional refinement, most intensely during the latter period, in the preparation of the final submission. All information pertinent to completion of the ethical application was completed for submission in January 2012; this included the participant information sheet (appendix 2), the study consent form (appendix 3), the study protocol and the sponsor insurance documents.

One of the key upgrades to the IRAS process was the addition of the proportionate review service in September 2011 (National Patient Safety Agency,

2010a), which was accompanied by supportive documentation in the form of the 'No Material Ethical Issues Tool' (NMEIT) (National Patient Safety Agency, 2010b) and a 'proportionate review summary for researchers' information sheet (National Patient Safety Agency, 2010a). After consulting the NMEIT tool and the supportive information sheet it appeared that the research proposal met the criteria for a proportionate review. This was confirmed following e-mail communication and a brief telephone interview between myself as the chief investigator and a nominated representative of the National Research Ethics Committee in late October 2011. The final submission for ethical approval for the study was conducted on 19<sup>th</sup> January 2012, being submitted, as directed, to the Bristol Research Ethics Committee (12/LO/0202) through the IRAS web portal.

The application was reviewed by the proportionate review sub-committee on 1<sup>st</sup> February 2012 who subsequently tabled a single inquiry and requested information via e-mail as to what was planned if a patient was to "make an allegation/complaint of inappropriate care by staff during the interview or disclose something of an illegal nature during the interview" (National Research Ethics Service Chair, personal communication, 2012). After being invited by the Research Ethics Committee (REC) co-ordinator to submit a response by e-mail and following discussion with the supervisory team a comprehensive response was forwarded on the 14<sup>th</sup> February 2012, which was accepted by the REC and ethical approval for the study was confirmed in writing on 29<sup>th</sup> February 2012 (appendix 4). In accordance with statutory policy and guidance (Imperial College, 2010) an application was then made to the Joint Research Office for NHS Trust approval for the study to proceed across all of the NHS Trust's hospital sites, which was confirmed in writing on 16<sup>th</sup> March 2013. From this point the patient recruitment process actively commenced in accordance with the research protocol as described in detail in the next section this chapter.

### **3.5 Recruitment**

Interrogation of the Trust's resuscitation audit database had indicated that the target number of thirty recruits to the study should be readily achievable within twelve months of commencement of the study, hence it was predicted that the data collection process would take between six and twelve months, depending on the contact



availability of potential recruits, their suitability for inclusion into the study and most importantly, their successful recruitment as research participants.

Prior to my nurse consultant position, I was, as the senior resuscitation officer, leading the day-to-day work of the resuscitation service in the host NHS trust and during this period I had established a clinical audit of cardiac arrest. Continuous auditing of cardiac arrest had been recommended for educational, quality assurance and outcome reporting purposes (Royal College of Physicians, 1987). Continuous data capture of all cardiac arrest calls commenced in April 1997, which was facilitated through a database that I had designed and written using Microsoft Access '97™. The software enabled input of a range of key clinical interventions and their respective timings that was compatible with the Utstein template metrics (Cummins, et al 1991, 1997). The database provided a confidential and secure storage system that enabled retrieval of detailed clinical records of each and every cardiac arrest event that had occurred in the Trust's hospitals. Contemporaneous data entry was conducted by all members of the resuscitation service, all of whom were trained and accurate and proficient in data entry skills.

The primary aim of this surveillance system was to provide the resuscitation service, the resuscitation committee and the associated clinical governance systems with detailed, meaningful output. This process audited resuscitation procedures, clinical compliance with published treatment guidelines, frequency of events across departments, services and hospitals, and most importantly patient-centred outcomes. It was from this database that potential research participants were initially identified and each patient was cross-referenced with the main electronic patient record system. This system enabled validation of each of the patient's demographic information and the tracking of the placement and movement of patients as their recovery journey progressed, up to the point of discharge from the hospital.

Active recruitment of potential study research participants commenced on the 16<sup>th</sup> March 2012, which was conducted in full accordance with the then current research governance guidelines (Department of Health, 2005). A spreadsheet was designed and written to record and store basic details for each of the potential recruits, which was located on my secure personal drive within an NHS server. Table 6. (below) depicts the

data fields used to record the necessary information sufficient for the purpose of tracking the progress of each potential study recruit during their recovery journey to the point of hospital discharge. The spreadsheet was also used to record brief but important functional research issues, such as ‘patient unable to speak fluent English’. Time related recordings were made of visits patients, including the initial approach, the provision of the participant information sheet, the suitability for inclusion in the study (meeting the inclusion / exclusion criteria), setting mutually agreed appointments for obtaining informed consent and the conduct of the interview. A *post-hoc* colour-coded system was used to differentiate those patients who had agreed to participate and were subsequently interviewed from those who were not interviewed.

<b>Table 6. Data points – patient tracking spreadsheet</b>	
<b>Field Name</b>	
1.	Unique identification code for each recruit
2.	Date of cardiac arrest
3.	Event location (ward or unit)
4.	Sex
5.	Age
6.	Date aware of cardiac arrest
7.	Comments (open text)
8.	Current location of patient (ward or unit)
9.	Last status check (date)
10.	Date of first approach
11.	Consent obtained (date)
12.	Interview conducted (date)
13.	Transcription started (date)

First contact with a prospective recruit usually followed identification of the surviving patient’s placement within the hospital. The ward or unit was then visited in person and after providing the necessary proof of identity (as required) and an explanation of the reason for the contact with the patient, the resident staff were asked about the patient’s current health situation and recovery status. If the patient was conscious, staff present at the time (nursing and / or medical staff) were invited to provide their professional opinion as to whether they thought that the patient was sufficiently lucid to undergo an in-depth interview that may last up to one hour. Whilst

the information provided was not always accurate, this initial discussion about the potential recruit provided useful insights into the patient's situation and their behavioural demeanour, which was helpful in the preparation for the face-to-face meeting. As stated earlier in this section, by necessity the sampling strategy adopted was a (theoretically informed) purposive sample that was influenced by the structural methodology detailed by Charmaz (2006), the expert opinion discussed by Baker and Edwards (2012) and later in the process by the work of Daucker, Martsof, Ross and Rusk (2012).

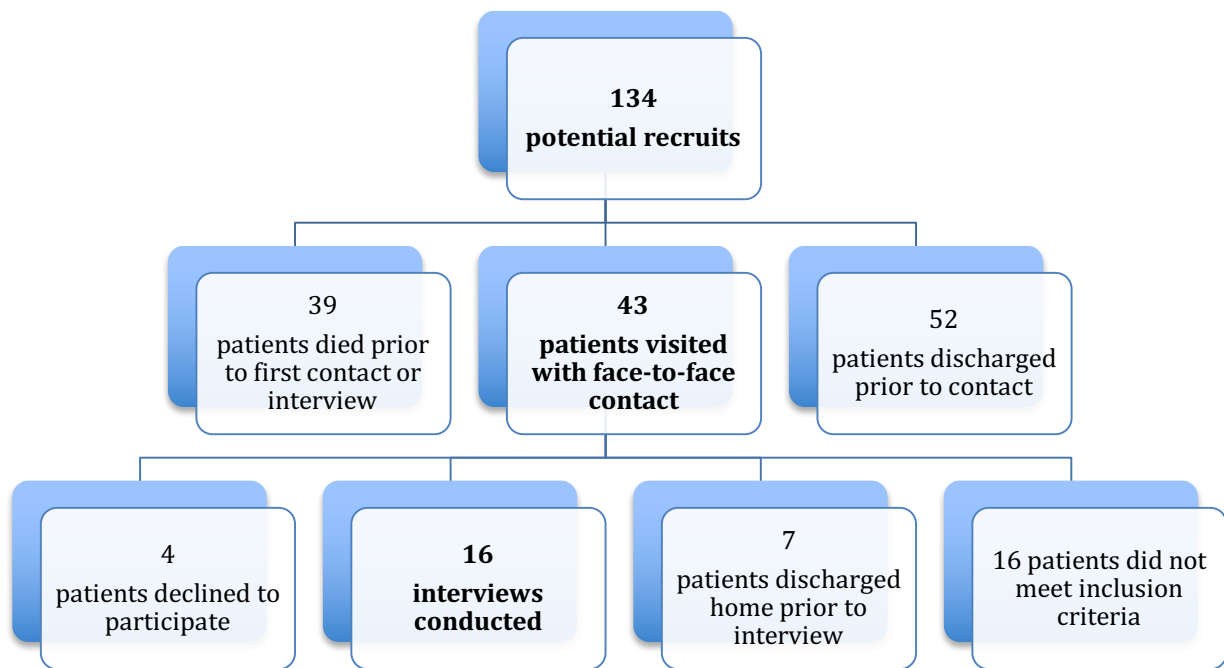
Once the exact location (bed space) was ascertained, the patient (if present) was approached. The strategy used was one of an open, friendly introduction using a frame of words that resembled the following; *"Hello my name is Ken, I am a consultant nurse, I work in critical care and resuscitation, I am conducting some research and wondered if I may talk to you about your recovery?"* This opening dialogue with the patient provided the necessary opportunity to explain and discuss of the purpose of the research. The decision to proceed towards recruitment to the study was formulated during these initial, exploratory conversations and where it was unquestionable that the person met the inclusion criteria, active recruitment was conducted. These preliminary conversations were also vital in establishing the initial rapport with the patient and contributed to the development of a position of reciprocity and trust between the researcher and the participant, considered to be positively influential to the quality of data (Corbin and Morse, 2003).

During this part of my visit, the potential participant was provided with their own copy of the participant information sheet (appendix 2) and encouraged to read through the document thoroughly, or alternatively ask a relative or friend (advocate) to read it with them and (at their discretion) discuss their potential participation in the research. In the context of obtaining full informed consent prior to recruitment to the study it has been recommended to verbally support the information contained within the participant information sheet (appendix 2) (Royal College of Nursing, 2011), accordingly additional explanatory conversational dialogue was provided to the patient's satisfaction. At the culmination of the initial recruitment conversations I re-iterated to the potential recruit the importance of reading through the material and left the clinical area, whilst letting them know that I would return (where possible, at a specific time and day) to conduct the consent process and proceed to record the interview, ensuring that this would be

conducted at a time that was mutually convenient. I was confident that I provided potential participants with sufficient time in which to accustomise themselves with the purpose of the research and the value of their participation. I was also confident that I conducted myself in an ethically sound, professionally credible manner as it is important that patients see the researcher as someone who can be regarded as a professional, transparent confidant (Corbin and Morse, 2003).

In the lead up to and during the acquisition of legitimate consent to participate in the study, it is ethically important to be absolutely clear that the patient explicitly understands all aspects of the nature of the proposed research (Department of Health, 2005). This included verbally checking their knowledge and understanding of all of the aspects covered on the consent form and the research governance measures that were in place to safeguard their vulnerability. This ensured that their participation or non-participation neither positively nor negatively affected their on-going care and treatment. I also endeavoured to ensure that each participant was free from any undue pressures or coercion to participate and that they were at liberty to withdraw from the research project at any point.

The potential risks and benefits consequential to participation in the study were outlined, as were the data protection issues regarding the recording, anonymisation, transcription and subsequent storage of the interview. Finally, they were informed that the study being undertaken was for purposes of a doctoral dissertation and that at some point the results were likely to be published in learned medical journals and / or presented at conferences and seminars. The participant information sheet contained information as to how the participant could obtain a summary of the findings of the research. Furthermore, each potential participant was positively encouraged to ask questions at any point in the process and if I was unable to answer their questions, they were informed that further expertise was available and this information was also contained within the participation information sheet. Due diligence was afforded to these matters and the consent materials had received ethical approval, in addition to this, they were fully compliant with the informed consent guidelines that were current at that time (National Patient Safety Agency, 2007). Figure 1. below illustrates the numerical capture and flow of the recruitment process, including how potential participants were lost to the study.



**Figure 1. Schematic diagram – participant recruitment**

The missed recruitment opportunities identified in figure 1, were consequential to the logistical challenges of accessing potential participants whilst being actively engaged in clinical, educational and managerial activities that were inherent within my job role. Although the sample size was smaller than planned and data saturation may not have been reached, it was felt that in the interests of completing this research study and submitting the dissertation within the allotted time frame, sampling was concluded after 12 months of active recruitment. At the completion of data collection on the 8<sup>th</sup> March, 2013 a total of sixteen patients had been interviewed. Unfortunately one interview was completely lost due a technical failure with the recording device during the electronic capture of the interview. This problem was discovered the day after the interview and a limited quantity of field notes were made from memory, however these limited recollections were not considered sufficiently reliable for analytical purposes and were discarded from the analysis.

### **3.5.1 Participant characteristics**

According to the personal patient medical records, all sixteen of the patients in this study had their cardiac arrest as a direct consequence of heart disease. Twelve of the

sixteen patients had been admitted directly to the hospital as emergency cases that required immediate therapeutic medical intervention by the proficiency or expertise of the medical teams working in the speciality of cardiology. Nine of those twelve patients had coronary artery occlusion that had caused myocardial infarction, the other three had heart rhythm problems, one of which had a very slow beat, the other two had experienced a very fast and irregular heartbeat - these two individuals also required the medical attention of the cardiology specialists. Of the remaining four patients, three had voluntarily attended the hospital for an elective surgical procedures, three to undergo coronary artery bypass, the other for a surgical correction to her a dysfunctional heart valve, the third patient had voluntarily attended hospital for investigations into his on-going kidney function, which had revealed to the doctors that he had severe coronary artery disease that required emergency surgery. Table 7. below details the participant's basic demographic data, including the date and location of their cardiac arrest. Pseudonyms were used to project the identity of participants and details of their employment status were also withheld in the interest of confidentiality.

<b>Table 7. Participant demographics</b>				
<b>Name</b>	<b>Sex</b>	<b>Age</b>	<b>Reason for admission</b>	<b>Event Location</b>
<b>Janet</b>	Female	73	Heart valve surgery	In hospital
<b>Wilfred</b>	Male	81	Myocardial infarction	In hospital
<b>Laura</b>	Female	77	Atrial fibrillation	In hospital
<b>Graham</b>	Male	62	Myocardial infarction	Out of hospital
<b>Jose</b>	Male	44	Myocardial infarction	In hospital
<b>Peter</b>	Male	79	Complete heart block	In hospital
<b>Alice</b>	Female	92	Myocardial infarction	In hospital
<b>Gloria</b>	Female	79	Coronary artery surgery	In hospital
<b>Francis</b>	Male	81	Myocardial infarction	In hospital
<b>Gordon</b>	Male	71	Coronary artery surgery	In hospital
<b>Eddie</b>	Male	54	Coronary artery surgery	In hospital
<b>Stephen</b>	Male	65	Myocardial infarction	In hospital
<b>David</b>	Male	59	Myocardial infarction	Out of hospital
<b>Sanjay</b>	Male	49	Ventricular arrhythmia	Out of hospital
<b>Philip</b>	Male	67	Myocardial infarction	Out of hospital
<b>Mike</b>	Male	71	Myocardial infarction	Out of hospital

### **3.6 Fieldwork - conducting the interviews**

In order to ensure that organisational arrangements for the interview were convenient for the participants, I had found it necessary to make several visits to each of them and each of those visits had to be accommodated within the boundaries of my

job role. The visits provided participants with sufficient time for them to read through the participant information sheet and gain an effective understanding of the research and their role as participants, which in turn ensured that the consent process was functionally and ethically robust. Once the arrangements for the interview were finalised the practical preparation for the interview was conducted, which ordinarily involved the manipulation of the environment, for example, helping the participant to choose where they would prefer to sit for the interview (on their bed or a chair), placement of drinks, tissues and their mobile telephone.

I had one printed copy of the interview schedule and I took it with me to each of the interviews, but it was deliberately kept in a folder out of sight until I reached a point where I felt it necessary to refer to it (if at all) and in anticipation of doing so I explained to the participant at the beginning of the interview that I might, towards the end of the interview, refer to the said schedule. It was envisaged that each interview would take between 45 and 60 minutes, depending on the responses and the fatigue of participants, however there were no plans to prematurely discontinue the interview. Finally, the MP3 recording device was readied, which utilised a small microphone that was clipped to the patient's clothing and the face-to-face, in-depth interview was conducted with each participant. Table 8. below provides the precise location details for each of the participant interviews.

<b>Table 8. Interview location of participants</b>					
<b>Name</b>	<b>Sex</b>	<b>Age</b>	<b>Interview Date</b>	<b>Interview location</b>	
<b>Janet</b>	Female	73	19/04/2012	4 bed bay in ward	Bedside chair
<b>Wilfred</b>	Male	81	20/04/2012	4 bed bay in ward	Bedside chair
<b>Laura</b>	Female	77	16/07/2012	4 bed bay in ward	Bedside chair
<b>Graham</b>	Male	62	15/08/2012	Single side-room	Bedside chair
<b>Jose</b>	Male	44	15/08/2012	4 bed bay in ward	Patient's day room
<b>Peter</b>	Male	79	15/08/2012	4 bed bay in ward	In bed
<b>Alice</b>	Female	92	30/08/2012	Single side-room	Bedside chair
<b>Gloria</b>	Female	79	20/09/2012	Single side-room	Bedside chair
<b>Francis</b>	Male	81	12/10/2012	4 bed bay in ward	Bedside chair
<b>Gordon</b>	Male	71	26/10/2012	4 bed bay in ward	In bed
<b>Eddie</b>	Male	54	26/10/2012	6 bed bay in ward	Bedside chair
<b>Stephen</b>	Male	65	19/11/2012	4 bed bay in ward	Patient's day room
<b>David</b>	Male	59	03/12/2012	Single side-room	Bedside chair
<b>Sanjay</b>	Male	49	18/12/2012	4 bed bay in ward	In bed
<b>Philip</b>	Male	67	08/03/2012	4 bed bay in ward	Bedside chair
<b>Mike</b>	Male	71	08/03/2012	4 bed bay in ward	Bedside chair

Whilst the conduct of each interview presented its own intricacies and there were a number of challenges that arose but repeated interruptions were common. Almost all of the interruptions were attributable to clinical matters, but some of the interruptions were avoidable and trivial. The next section of this chapter details the technical elements of data management.

### **3.7 Data management**

Each interview was digitally recorded using an MP3 player, downloaded to an encrypted portable drive, which was accessed for each transcription prior to storage in a locked drawer in a secure office. Trust policy required storage of the interview files for 10 years and ethical approval was acquired with regards to storage of the data on appropriately secure computer systems, which included personally issued NHS computers.

Each interview was transcribed verbatim using inexpensive, open source transcription software (F4, dr. dresing & pehl GmbH), which provided a simple interactive platform that enabled control of the playback speed of the recording, which could be varied and paused. However, the most useful function was being able to type simultaneously into an integral word-processor whilst listening to the interview dialogue. Data accuracy was further strengthened through an additional function that enabled a user-defined replay period of the recording ranging from 1 – 6 seconds when recommencing transcription following each pause in the playback taken to type that is necessary when transcribing. This software made the transcription process significantly more efficient than conventional physical manipulation of recording devices whilst writing using word-processing software. Following transcription, each of the interview transcripts were saved and converted into Microsoft Word 2007/2010™ documents and subsequently exported into a computerised qualitative data analysis software (CAQDAS) package (QSR NVIVO™ version 9) for further analysis, which is detailed in the next section of this chapter.



### 3.8 Analysis

The earlier sections of this chapter detailed the ontological and epistemological interpretative position that I adopted and applied to the analytical process. This section of the chapter recalls the method that I applied in the undertaking and application of a grounded analysis of the data collected as detailed in section 3.1 in this chapter. This section specifically addresses three of the core characteristics of grounded analysis (McCann and Clarke, 2003a), commencing with my first, tentative steps into the analytical thinking, which took place during the interviews and the transcription processes. This then led to the use of the constant comparison method to develop the theoretical categories and inform the data sampling within the later interviews. I then cover how I coded and categorised the data and honed down the emergent themes that went onto eventually inform and generate the theory, which was conducted on a number of levels that was integral to constant comparison process. Finally, I elucidate the work I undertook towards developing the theoretical memos in the form of conceptual notes that I made during the conceptualisation of the emergent theory.

Analysis of qualitative data has been described as a process that involves '*breaking down the data into bits*' and then '*beating the bits together*' (Dey, 1993, page 30). Without analysis we would have nothing but our own impressions and opinions and whilst our views have their place, the purpose of analysis is to interpret, explain, understand and perhaps predict, but fundamentally analysis provides us with a fresh view of our data and through analytical rigour we can understand the interconnections, concepts and theories that are central to the research question(s) and the hypothetical framework.

Whilst Sandelowski (1995) suggested that the researcher begins to contextualise and get a feel for the data when they are proofing the transcripts against the audio recording, for me the analytical process actually commenced during the interviewing process, particularly after the first two or three, when more theoretical sampling occurs (Glaser and Strauss, 1967). In the accepted tradition of grounded theory (Charmaz, 1996), my inductive analytical interaction with the data occurred at the earliest opportunity, during the activity of data acquisition, whilst I was interacting in a research context with the participants. I was explicitly aware that I formulated views and opinions

from the data as it arose, which continued throughout all of the interviews. I was also conscious of my developing skills as an analytical listener and of becoming accustomed to accepting one's preliminary analytical thoughts. However, as identified by Charmaz (1996) caution is required not to place any undue emphasis upon initial, rudimentary thoughts and I was merely expectant and enthusiastic to be in a position of having generated some real data from the participants and the beginning the process of inductive thinking.

Another step in the analytical process that I found helpful towards both the inductive elements of analysis was to listen back to the interview on the train journey on the way home, usually on the day that I acquired the recording. Listening back to each of the interviews provided an additional opportunity for focussed interaction with the data and helped to frame the rudimentary concepts that developed from the patient's narratives of their recovery experiences (Pope, Ziebland and Mays, 2000). Furthermore, it also provided a platform for a critical review of my interview technique, the tone of my voice, the language I used, the generation of an analytical lens and how I framed the questions. Pragmatically, I felt that it was useful preparation for the transcription.

Transcription of the interviews was both time consuming and arduous, but it provided important time during which further initial analytical contemplation was possible. I found that the process of listening attentively, through headphones as I typed the transcripts brought me closer to the data and many inductive primitive themes began to emerge. As an example of inductive analysis and the use of the constant comparative method, my first thoughts about coherence came to mind during the transcription of the third interview. This was to prove very useful in informing my questioning / theoretical sampling in later interviews. Upon completion of the transcription of each of the interviews the files were saved as Word™ documents prior to being exported to the CAQDAS software package in preparation for the initial line-by-line coding and subsequent analysis.

Despite the challenge of learning to use computer software as a tool to conduct the formal analysis (Creswell, 2007), I opted to use a CAQDAS package as this offered efficient, reliable and structured functionality in the manipulation of data and the generation of a theory. Furthermore, when contemplating the multi-layered complexity

of the analytical process, I was intimidated by the cognitive challenge of being able to manage the multi-dimensional complexity of the data. Whilst it may have been possible to use readily accessible software that I was very familiar with, such as a word-processor, spreadsheet or database software (I have some skills in programming in visual basic computer language), this presented an analytical risk that I wasn't prepared to accept. Seale (2001) supported the rigour that is associated with the use of CAQDAS applications in context of their use in qualitative research and in particular the rigour obtained from using analytical models such as the constant comparative method described by Glaser and Strauss (1967). Accordingly, the CAQDAS software (NVivo version 9™) was utilised heavily for almost all of the coding, all of the constant comparison work, and most of thematic analysis and memo writing, within this work, pen and paper and word processors were also used.

The use of the CAQDAS package provided a very straightforward platform for the initial line-by-line (multiple) and subsequent coding of the data and as the number of interviews increased, it provided an intuitive system that facilitated the constant comparative model (Glaser and Strauss, 1967). I was able to readily compare incidents across the interviews within the categories (nodes) that had been induced from the data (in accordance with the grounded methodology). The categories / themes were subject to constant refinement within the analytical continuum and placed in new categories as the themes began to emerge after further analytical scrutiny. The package used provided easy retrieval of data alongside sophisticated filtering and powerful manipulation functions during the analytical phase that would have otherwise been impossible to contemplate, a position commented upon in the medical literature (Murray et al, 2009). Figure 2. below provides a snapshot example of the resultant coding, which was taken after completion of the coding process.

Name	Sources	References	Created On	Created By	Modified On	Modified By
communication	17	223	07/06/2012 19:51	KGS	14/02/2014 20:04	KGS
insider role	14	174	01/09/2013 20:36	KGS	08/11/2013 18:14	KGS
cardiac arrest experiences	16	165	07/06/2012 17:51	KGS	14/02/2014 20:04	KGS
medical care - doctors	14	101	07/06/2012 19:55	KGS	04/02/2014 19:22	KGS
Nursing care	16	96	07/06/2012 20:00	KGS	14/02/2014 20:04	KGS
Discharge home	17	93	07/06/2012 20:27	KGS	08/02/2014 16:19	KGS
Self	2	55	07/06/2012 20:01	KGS	08/11/2013 18:14	KGS
Physiotherapy	12	47	07/06/2012 20:29	KGS	27/01/2014 21:03	KGS
General Care	10	44	04/11/2013 16:40	KGS	08/02/2014 16:19	KGS
CPR training	14	40	01/09/2013 22:41	KGS	03/01/2014 13:02	KGS
End of Life	13	38	07/06/2012 21:30	KGS	14/02/2014 20:04	KGS
safety	8	33	01/09/2013 21:26	KGS	08/11/2013 18:14	KGS
interruption	10	29	01/09/2013 22:33	KGS	08/11/2013 18:14	KGS
Occupational Therapy	4	27	07/06/2012 20:19	KGS	27/01/2014 21:03	KGS
Pre-hospital	6	23	15/10/2013 11:08	KGS	08/11/2013 18:14	KGS
Privacy	3	11	07/06/2012 20:37	KGS	27/01/2014 21:03	KGS
Consent	4	8	01/09/2013 19:59	KGS	08/11/2013 18:14	KGS
Post event debriefing	2	6	01/09/2013 22:45	KGS	08/11/2013 18:14	KGS

**Figure 2. Screenshot of the coding results**

### 3.8.1 Coding the data

The constant comparative method of grounded theory (Glaser and Strauss 1967) is a term used to describe the integral, systematic analytical method that is involved in the process of coding data into categories, developing and refining (delimiting) the categories to the point of developing the theory. The approach to coding is conventionally conducted in stages; an initial, open-coding stage followed by selected categorical coding, where large quantities of data can be processed to facilitate the forming of knowledge (Charmaz, 2001). Having listened back to each of the interviews and transcribed each one of them, I felt analytically close to the data. The initial line-by-line coding commenced following transcription of the interview, once the text file had been exported into the CAQDAS software. Charmaz (2001) supported the use of line-by-line coding from the perspective that it ensures that the researcher gets close to the data and is then more likely to really understand what the respondent is trying to say and how the respective codes relate to the key data. The line-by-line coding was conducted inductively as I meticulously scrutinised the words of the research participants, where appropriate, coding each line into a series of preliminary categories.

Further coding of the interview transcripts commenced with the comparison of each of the notable incidents that arose within the data against those already recorded / documented. The CAQDAS package that I used presented an intuitive interface that made this first stage of coding particularly easy as it enabled me to line-by-line code whilst being able to visualise all the previously determined codes in a separate window within the software. This checklist was very helpful in the process of maximising the categorical opportunities (multiple line-by-line coding) advocated by Glaser and Strauss (1967). Nevertheless, I was trepidacious when coding the earlier interviews in that I had a blank canvas, with nothing to code against or compare to. It was only when I commenced the coding of the second and subsequent interviews that I started to get a more formative sense of the themes, at this stage I was now beginning to develop awareness of the emergent hypothesis.

With regards to my preliminary thoughts about the data and the emerging themes, which had been often arrived at during the various stages of data management, many of my initial thoughts dissipated during the initial coding, although a number of the preliminary themes persisted and metamorphosed through the categorisation and constant comparison method. For example, the development of a *sense of coherence* had been theoretically informed as a potential framework for this study through the published literature and was an early category to emerge from the data acquired from the interviews with the research participants. Silverman (2005) argued that the development of a theory provides a framework for us to critically understand the information that we are gathering and a position from which we can organise the new knowledge. Throughout the coding process, I recall being struck by the feeling of excitement alongside a sense of purpose and meaning that working with the data had brought to me.

Whilst I had intended to utilise the coding strategies outlined by Charmaz (2001), I found myself taking a slightly different approach when actually faced with the task in that I noticed that at times my coding focus was influenced by the strength of purpose that a number of key categories began to demonstrate. Strauss (1987) identified an intermediate coding stage between the initial open-coding stage and the selective coding stage, which he described as axial coding. The line-by-line coding process enabled the development of the substantive categories and as the process was

undertaken, the transcribed narrative of the participants was coded to all appropriate categories. As I worked through the coding of the interviews (which was conducted chronologically) a small number of new categories emerged, which required re-examination of previously coded interviews for potential sources of pertinent information that may have been otherwise lost to the analysis, this process of cyclical coding has alluded to by McCann and Clarke (2003a). It was during this process that I understood and recognised the importance of what the data was saying, in terms of the *in vivo* codes that reflected the language and meaning being conveyed by the participants during the interviews (Strauss, 1987). I found that the *in vivo* codes provided very powerful imagery and readily conveyed very useful, informative, emotional and psychological content with regard to the recovery experiences of the participants, which are reported within the forthcoming findings chapters. Strauss (1987, page 33) had also classified another coding type, in the form of what he labelled as '*socially constructed codes*', which he saw as those categories that the researcher formulated as a consequence of both their '*scholarly knowledge*' and their '*knowledge of the field under study*' (Strauss, 1987, page 34). This approach appears close to the constructivist position described by Charmaz (2001).

The categorisation of the data is a critical and fundamental element in the analytical process (Dey, 1993) and McCann and Clarke (2003b) recalled the process of axial coding (theoretical coding) first postulated by Strauss (1987) where previously coded data are intensely inductively and deductively reconstructed and conceptualised in the direction of the emerging theory. According to Strauss (1987), this process provides a preparatory platform for the final stage of selective coding and the systematic determination of the final core categories, which are themselves fundamental to the final theoretical position. Charmaz (1996) termed this part of the grounded process as focussed coding and whilst prominent grounded theorists have described distinct phases in the derivation of the final core categories through the grounded process (Glaser and Strauss, 1967, Strauss, 1987, Charmaz, 1996), I preferred to think of the processes as an analytical continuum that progressively refined and re-informed the categories that emerged from the data through the coding procedure and the constant comparative analysis.

The initial coding resulted in the development of 69 initial codes, which through axial / focussed coding, and then selective coding, were re-constructed into four main categories which culminated in the findings discussed in the following three chapters. The writing of memo's during the focussed coding stage and then later during selective coding stage provided an extremely useful contribution to my analytical reasoning. Memo writing was recommended in the original grounded concept (Glaser and Strauss, 1967) and was developed further by Charmaz (1990), who viewed memo's as an integral, critical tool that provides an opportunity for thinking space within which the researcher can analyse, formulate, conceptualise and refine the categorical data. Several of my coding memos were written within the CAQDAS software, however, I constructed many more of them freehand on note paper and with a word processor, often when provided with opportunistic thinking moments. On occasions I even used the note application on my smart phone to record conceptual thoughts about the data, which was particularly useful. The final section of this chapter considers the question of methodological rigour and trustworthiness.

### **3.9 Analytical rigour and trustworthiness**

The question of analytical rigour in qualitative research is a seemingly perennial problem that continues to attract criticism, particularly from those who subscribe to the objectivist, positivist ontological position associated with quantitative research (Rolfe, 2006). In framing their support for qualitative methods as being the most suitable approach to social theory, Glaser and Strauss (1967) challenged the historical limitations of methodological rigour offered by qualitative research and held the view that both quantitative and qualitative research are both valid research methods when conducted appropriately and rigorously. More recently Charmaz (1990) argued that the grounded theory method, being one that is constructed from of a number of systematic processes, almost by default, promotes and engenders rigorous qualitative research. In a later paper, Charmaz (1996) steadfastly defended the rigour of the grounded method by recounting that in addition to the systematic processes, grounded researchers remain in close contact with large quantities of their data whilst conducting the inductive analytical approach. Furthermore, Charmaz (1996) indicated that through its widespread use, across a range of professional academic research settings (e.g.

medical sociology, education and nursing) grounded theory methodology has been afforded significant validity as a reliable and robust method of qualitative research.

Gioia, Corley and Hamilton (2013) have very recently provided an account of their own experiences of establishing rigour with regards to inductive qualitative research, which in some ways echoed the opinion of Charmaz (1996). Entangled in an attempt to defend their qualitative submission to a group of reviewers generally accustomed to quantitative studies, Gioia, Corley and Hamilton (2013) presented a robust defence of the grounded theory approach that included an explicit demonstration of the direct relationship between the data from the informants and the interpretation of the researcher, furthermore, within the article they presented a series of steps that declared each of the grounded processes transparently, through a more dynamic structural approach to the data.

Sandelowski (1993) argued that the term rigour is in itself an unfairly harsh term that places qualitative research at a distinct disadvantage in that it represents a distraction from the richness, depth and value of the output that it produces. From her naturalistic / interpretive perspective, Sandelowski (1993) argued that it is a mistake for qualitative researchers to accommodate conventional approaches to reliability, such as persistent and consistent responses from subjects.

Tina Koch (1994) supported the view that the trustworthiness of qualitative inquiry is dependent upon credibility, transferability and dependability. She suggested that it is important that researchers are very much aware of their role as a researcher, which can be strengthened by maintaining a detailed field journal throughout the research process. Koch also supports the view that rigour could be gained by asking the subjects themselves to critique the research, a position argued strongly against by Sandelowski (1993), who considers that there are different theoretical and ethical interests and different stories to tell, put simply, there is a conflict of interests which could potentially undermine the value of the project. Koch (1994) suggested that any reader can provide validity to a research project, if for example, they can, from their own independent experiences, corroborate the findings when they match those that they themselves have experienced; an account of the context of the research and a description of the setting are likely to help the reader to have a fuller appreciation of the situation.



Sandelowski (1993) opened up the debate around the scientific context of truth and value and suggested that there are no hard and fast rules with which we can use to ascribe validity in a dynamic set of circumstances within an ever-changing social world. She suggested that validity is historically and culturally positioned and it is a matter of interpretation rather than a fixed set of rules. It is evident that this may prove to be a difficult concept for the traditional quantitative researcher to accommodate, for example Runciman (1993) acknowledged and accepted the scientific applicability and the value that a qualitative approach can have, but he only did so in the knowledge that established methods were used to test reliability and validity. For some this may represent a post-positivist position that may be at odds with the qualitative paradigm (Barusch, Gringeri and George, 2011).

Koch (1994) considered that the dependability and consistency of data is best challenged through audit of the researchers decision trail; if the researcher has left a decision trail around their choices of methodology, analysis and theoretical frameworks and that they are sufficiently detailed for the reader to follow then the work is likely to be considered to be acceptable, sufficiently rigorous and trustworthy. Accordingly, this chapter contains a detailed, succinct description of the methodology used in order to demonstrate sufficient rigour in this research. Furthermore, in the context of being a reflexive researcher I believe that I have declared, understood and accommodated my bias as researcher, acknowledging and challenging my own presumptions (Jootun, McGhee and Marland, 2009). This enabled me to be confidently placed in being open and transparent about my chosen methodological approach, which sat comfortably with where my ontological and epistemological views were situated.

The following three chapters detail the findings pertinent to the three key categories that emerged from the data having been subjected to a methodologically rigorous, grounded process.

## **Chapter 4 Findings**

### **4.0 Introduction**

As identified in the introduction of this dissertation, the main research question, supported by the methodological approaches detailed in chapters two and three, was primarily aimed at developing a deeper understanding of what cardiac arrest patients experienced during their recovery in hospital. A central element to the inquiry was to gain insights into how patients viewed their recovery and how they would approach their immediate future in the knowledge that they had survived a significant life-threat in the form of a cardiac arrest. It is perhaps worthwhile recounting that the methodological intention was to conduct the interviews at a time that was as close (as was practicable) to the point at which the patient regained functional consciousness.

Analysis of the data provided a myriad of complex, over-lapping and inter-twined themes that represented a direct and genuine reflection of the patient's voice, drawn from the unique insights of the recovery experiences of the study cohort. For purposes of clarity and understanding, the findings chapters were organised into three important, over-arching recovery themes. The arrangement of the three findings chapter was grounded in the patient's experiences and the apparent phased, contemporaneous nature of their recovery journey.

The first was the existential phase and the search for coherence, which then this led to the second phase of recovery, the development of recovery milestones. The third and final chapter reflected the patients' experiences of how the clinical gaze interacted, interweaved and affected the quality of their recovery journey, within and beyond the hospital panopticon. A striking feature was that all of the interviewees clearly demonstrated an experiential rationale as to how they accommodated and adapted to the remarkable circumstances within their lives. To a greater or lesser extent, they were all able to develop a coping strategy that relied upon an array of resources, upon which to shape their altered future, thus providing a new, better informed knowledge of how people recover from cardiac arrest and critical illness.

This first findings chapter focuses on the initial period of patients' recovery experiences, from when they first emerged from unconsciousness. Having survived cardiac arrest, they provided detailed, critical insights into how, through a search for coherence, they came to terms with this significant life-threat and the impact that this had upon on their immediate future when discharged from hospital. The second findings chapter then considers how patients, having acquired a level of coherence, were able to develop a strategic approach through the identification of recovery milestones, which provided a structural framework that further promoted their recovery. The third and final findings chapter takes account of the paradox between the patient's views of their recovery and their perceptions of how their recovery was approached by the medical gaze.

#### **4.1 The search for coherence**

Each of the participants had spent time under the highly concentrated gaze of advanced cardiac life support, a strongly regulated, team-orientated surveillance system used during their cardiac arrest. Following restoration of the patient's heart beat the intensity of the medical gaze eased slightly, but nevertheless persisted into the immediate post-resuscitation care and recovery period. For the nine patients who were able to breathe independently and / or had not sustained any significant brain injury there was a requirement for close monitoring and observation within a coronary care unit (CCU), whereas the remaining six patients were placed under the attention of the closest surveillance system available, that is, within the intensive care unit (ICU).

The analysis of the interview transcripts revealed that following cardiac arrest and a period of unconsciousness many, if not all of the patients demonstrated significant anxieties towards re-establishing their individual, cohesive, cognitive thought processes and a strong desire to re-gain their sense of self as a whole person. For some who had spent time in the ICU, the lost time that lapsed during the period of unconsciousness was difficult to quantify and they appeared, from those recollections, to feel extremely vulnerable, disorientated and uncertain as to the circumstances of the here and now. However, the patients remained able to skilfully articulate their thoughts and feelings, ably describing, when aware, the coping strategies that they used, all of which contributed to their determination to return to health and full recovery.

The first section of this chapter takes account of a range of patients experiences following their emergence from a period of unconsciousness resulting from cardiac arrest and how they dealt with the life-threat that this represented. The second section takes the theme of coherence a step further and looks at how patients received professional care that supported their recovery through a search for coherence and return to a healthy state. The final section of the chapter considers how the patients search for coherence influenced their longer-term survival prospects and what they were feeling about returning home to their normal lives, if indeed they were.

#### **4.1.1 Emerging from unconsciousness and coping with chaos**

All patients in the study expressed what appeared to be existential thoughts when recounting their initial feelings as they struggled to regain a sense of self when returning to consciousness from the chaos of cardiac arrest. Many displayed additional anxieties in that they were actively seeking knowledge and information as to what had happened to them during the short, but significant period of their lives that had been lost to unconsciousness. This apparent desire to know what had happened to them could be termed a search for coherence or in other words an attempt to make sense of their situation and their circumstances. Their anticipated life-world trajectory had been unexpectedly and almost fatally disrupted. Some patients were going about their normal daily business ordinarily when the cardiac arrest event occurred, others were already under the medical gaze in the context of undergoing medical or surgical interventions designed to restore their health and well being when their heart stopped beating effectively.

Laura was a seventy-seven year old retired professional who had been to see her general practitioner (GP) as she had been feeling unwell due to a long-standing heart condition resulting in an abnormally fast and irregular heart rhythm. Her condition was such that it merited an immediate referral to the specialist cardiology department at the hospital, where she underwent emergency treatment. She had made her own way to the hospital and had not prepared for a prolonged hospital stay. She had expected to be discharged home later that evening or the next day, however a complication arose during the procedure, which led to her suffering a cardiac arrest.

She regained consciousness on the ICU in a different hospital to that which she had originally been admitted, approximately three days later. The characteristics contained in a section of dialogue from Laura's recollections of when she first regained consciousness demonstrated a level of existential disbelief at what had apparently happened to her, at a point where she had not as yet acquired sufficient knowledge of her situation. The presence of a close friend at her bedside at the moment of her re-awakening provided a recognisable and tangible signpost to her normal life and it is easy to see how this became an important constituent in her search for coherence and helped her to re-engage with her reality. The second and third quotes in the series indicate that underneath the surface lay an intricate and personal struggle to come to terms with the events surrounding her situation and represents her first experience of recovery.

*[...] So I went to St Anne's, went in, I think I took my clothes off, buggered if I can remember what happened afterwards...'cos the next thing I wake up and erm...my friend was there and erm...she said I'd been on life support for three...three days!  
[...]*

*[...] Well, nobody came and actually told me...erm, I don't know...erm...Sally told me what had...what had gone on [...]*

*[...] I was fine...I was fine...and then I just woke up in...in a bed, you know...thinking 'where the hell am I'? [...]*

Having been admitted as a day case for a straightforward procedure, Laura had indicated that it was deeply shocking for her to discover that she had been unconscious for three days. Upon her re-awakening she recalled being told by her closest friend that in addition to the three days of intensive care she had also suffered a cardiac arrest. This was a particularly distressing discovery because she had entered the hospital virtually off the street. Whilst expressing a level of gratitude to her friend for the kindness of intent, the orientation that Laura received from her friend had not been solicited and during the interview she explicitly stated that at this stage of her recovery she did not want to know any more of the detail of her time within the ICU. This was, in

her view, fundamental to her on-going psychological recovery, which was framed by wanting to put the ICU experience behind her and look forward positively.

The determined manner in which Laura addressed her situation and circumstances suggests the presence of a confident woman with a previously acquired, perhaps inherent, ability to begin the process of making sense of this period of intense biographical chaos. This is in stark contrast to a more persistent existentialist position of disbelief and 'why me' demeanour demonstrated by Stephen in the following section.

Stephen experienced severe chest pain at home and following diagnosis of myocardial infarction by the attendant paramedics he was transported to the nearest heart attack centre and whilst undergoing the procedure of primary angioplasty he had a cardiac arrest. His response to being asked to contemplate his cardiac arrest resulted in one of disbelief, a situation that he had never imagined possible.

*Stephen: My heart stopped, yeah*

*KS: and what do you think of that...that happening to you?*

*Stephen: disbelief...total and utter, like...just disbelief...I just thought...*

*KS: and tell me why that...it's hard to*

*Stephen: (coughs)*

*KS: (inaudible) that...to believe it?*

*Stephen: Erm...I think because...why...just...never expected it to be me...*

At this early point in his recovery Stephen was struggling coming to terms with the temporal elements of his disturbed life-world and had not yet, or was unable to rationalise his thinking beyond an existential framework. Throughout the interview Stephen expressed thoughts of disbelief, in the following example he was struggling to

reconcile his current health situation against lifestyle decisions he had taken and the effort he had made when he was much younger.

*[...] you know, erm...I suppose, because I've well I...I've had a sort of reasonable healthy lifestyle, play...play a reasonable amount of sport..(coughs)...when I was a kid. When I was six...sixteen I used to weigh seventeen stone...and did a conscious thing of losing weight when I was in my thirties...and maintained pretty much an eleven stone weight ever since...be...being more aware of what I eat all the time, you know [...]*

In the following two extracts from his interview, Stephen further explained that he was both scared and shocked by his situation. The extent of his existential disbelief (with regard to his circumstances) had reached a point where his search for coherence had taken him towards a position of denial, reflected through a search for confirming evidence that he had actually had a heart attack and a cardiac arrest. This position presented a three-way paradox. To start with he was scared and shocked, then moments later he found his situation unreal.

*[...] and it's scary, but I was still just a bit err...bomb-blasted by it, just the...the whole thing, I just thought this is not real, this is...this is surreal. In fact I still find the thing a little bit surreal [...]*

Finally he was surprised that he was asymptomatic and carried no obvious residual deficits of his heart attack or cardiac arrest.

*[...] the weird thing about is, I don't feel any different now than I did a week ago, in fact a month ago...I don't feel any...I don't feel tiredness, I don't feel how I sort of...think...after a heart attack [...]*

The lack of tangible deficits following heart attack and cardiac arrest was spoken about by another patient, but in a very different context. Jose was a forty-four year old man who experienced a myocardial infarction late one Sunday evening at home whilst watching television, after arriving in the cardiac catheter laboratory Jose suffered a brief cardiac arrest whilst undergoing the invasive treatment that unblocked his coronary

arteries. This was how he described his thoughts, which contain elements of guilt about his situation and his on-going recovery, just two days after the heart attack and cardiac arrest:

*[...] it's like I have taken vacations for one week, or at the most, but usually it's, like I go back to work immediately and erm...I don't know...it's kind of very strange to be here to know that I should be in the office, but I cannot be there and err...and that I'm going to be taking this...resting...doing...I don't know, maybe going to a museum for a couple of hours and then go back home? Something that I never do [...]*

Eddie, a fifty-four year old man who had progressively developed unstable angina, was recovering from elective coronary artery bypass surgery when he suffered a series of cardiac arrests. The first occurred late in the evening of the day before he had been due to be discharged home. Up to that point he had experienced an otherwise unremarkable recovery and he had expected to return home and re-establish his normal life. Below is his account of his immediate recovery following his second cardiac arrest.

*Eddie: ...and I came round then and I recognise where I was at that time, because I had been here for a few days anyway, so I was very familiar that I was in the ICU department and I was familiar with the people looking at me and dealing with me and I understood that after what had happened the previous night that I'd certainly had another arrest.*

*KS: and how did that...where did that...what did that do to your thinking?*

*Eddie: Erm...terrified me...erm...absolutely terrified me...so I was thinking...I think I was laying there and everybody was talking amongst themselves, not at me...erm...talking amongst themselves, and it was clear to me that nobody knew the answer, they were all saying 'should we try this, should we try that' and I was just laying there on the bed literally terrified [...]*



In this example, Eddie's recollections reveal a rather complex and insightful perspective of his immediate recovery experiences. In the first section of dialogue where Eddie re-awakens and finds himself in the intensive care unit, surrounded by staff that he knew, he is provided, through his recognition of the environment and the familiarity with the attendant staff, some elements of comfort and safety. However, we can see from the second section of dialogue that these overtly recognisable bio-semiotic markers that are usually associated with care, protection and well being (a combination of the technical healthcare environment and the behavioural demeanour of the healthcare personnel) hold a paradoxical dual role in that they also acted for him as signifiers that he had deteriorated and he concluded that he had suffered a second cardiac arrest. Furthermore, in the second section of dialogue, Eddie talked of being terrified by having had a second cardiac arrest and his fears appeared to have been underpinned by the behaviour of the assembled group of healthcare professionals who seemed to Eddie to be openly demonstrating a collective uncertainty (perhaps inadvertently) as to what to do to safeguard him in this crisis situation. Consequently, his perception was that the expertise of the medical gaze was being seriously challenged by his deterioration, the realisation of which appeared to have thrown his coping strategy into temporary disarray, indicated by his thoughts of personal terror.

As the interview progressed Eddie indicated that once the discussions amongst the attending healthcare professionals had concluded, elements of the medical and nursing staff present became mindful of his anxieties and took time to communicate with him. He recalled that their attempts to comfort him, whilst being limited from his perspective, still went some way towards reassuring him. He recounted the following.

*KS: and if you were to go through that again, but not wi...not wishing you to of course, would that kind of thing, when you are coming out of it, people talking to you was...would it be helpful?*

*Eddie: Yes, I think so because you fff...I felt so absolutely isolated, that you know, to have any reassuring voice or friendly voice, you know, soothing you was of benefit...erm...I think I would have preferred somebody that could have said 'right, we're going to do this and you will be alright now', but that wasn't going to happen and I was sufficiently alert enough to know what had happened to me and realise*

*my God, this is my second heart attack in two days, where I am going, because, again if I just elaborate slightly you know, I've got...my family have got a history of heart problems...*

In this section of dialogue, the patient was demonstrably isolated and frightened by the circumstances of his life-threatening crisis. During this acute phase of recovery he had no immediate access to people he would normally turn to in such circumstances - his wife, his family or close friends and he was reliant upon receiving human comfort from people that he barely knew and who barely knew him. Eddie clearly stated that he would have preferred more direct information and confident re-assurances from the medical fraternity, which indicated that this was of great necessity to his developing coping strategies.

Gordon, a seventy-one year-old man, had undergone emergency coronary artery bypass surgery and had been originally admitted for investigations into his kidney disease when severe coronary artery disease was discovered. His cardiac arrest occurred post-operatively, whilst he was recovering in the cardiac intensive care unit. It is notable that during his resuscitation it was necessary to re-open his original surgical incision and he received internal cardiac massage. The following succession of extracts from the interview indicates that whilst the patient did not understand the meaning of the word resuscitation, he became sufficiently worried in knowing his heart had stopped and he appears to have gathered all of his issues into a single, overarching, general worry.

*KS: In the knowledge that your heart has stopped a couple of times, have you got any long-term thoughts on that...about that...or what...*

*Gordon: No, I mean I only knew about it afterwards when my wife told me...err...I still don't know when they say 'resuscitation' what it really means, whether they had to an artificial machine to be...err in place of the heart, I don't know, you see.*

*Gordon: so it must have been fairly critical [...]*

*[...] Gordon: It has...it happened twice*

*KS: yeah*

*Gordon: yeah...but I mean in a sense all these things worry me as to the after effects...you know, I'm a bit worried about...a vessel bursting later on or whatever [...]*

It became clear during the interview that the difficulties he encountered whilst recovering from the surgery and the cardiac arrest were framed by his recurrent and irreconcilable hallucinatory experiences, rather than the immediate life-threat of cardiac arrest. He spoke frequently of his extensive experiences of a series of very vivid dreams that at the time he was unable to differentiate from reality. Throughout the interview Gordon conveyed a very intense desire to understand and reconcile these disturbing experiences and even looked to me to provide some coherence for him. Here, in two separate sentences, he talks about the hallucinations.

*[...] Well, it's so real, I like to know what the truth is, put it that way...you know, whether the...whether it was a hallucination or whether something really went on in my mind, you know [...]*

*[...] but I don't know whether it is true story or fantasy or whatever and the fact that err...it was turned into some sort of a story, because if that is true it's phenomenal because everything went...that went on happened...in my mind...I was there on that train and basically everything that was in the book tied up with what I thought happened to me [...]*

Gordon had great difficulty in coming to terms with his hallucinatory experiences and constantly sought solace in his attempts to understand the phenomena. In doing so he appears to have relied almost entirely upon his wife and children in his search for coherence, perhaps because the healthcare professionals were an integral, embedded constituents of the hallucinations, which he had not as yet been completely reconciled.

This section of the chapter has focussed on the patients' experiences of the immediate phase of recovery and their search for coherence, when they first emerged from unconsciousness. In the next section of this chapter, this theme is taken forwards

by attempting to understand the contribution that the care delivered by a multi-professional healthcare team met the coherence needs of the patients as they continued their recovery from their condition and the cardiac arrest.

#### **4.1.2 Facilitating coherence**

The provision of compassionate care, one that is actively and positively supportive of the patient's (potential) ability and (inherent) determination to survive, that was evident amongst all of the participants, will foster their desire (when present) to understand the context of what has happened to them and why it happened. This may then provide the patient with an additional cognitive and psychological safety net that helps them to begin to regain control of their self and move positively towards a healthier, more independent status.

Graham was a sixty-two year old man who in the past year had been recovering from extensive surgery for oesophageal cancer. He suffered a heart attack and subsequent cardiac arrest at home early one morning whilst working at his computer. After receiving prompt and effective cardiopulmonary resuscitation from his son he was admitted to the heart attack centre for primary coronary intervention. Graham recounted two experiences from his recovery that identify the importance of how a caring approach is perceived as beneficial in terms of understanding what had happened to him, the first that was direct, unambiguous provision of information, the second was simple, subtle caring human interaction. Both were significant to him, as demonstrated by his recognition of the differential between good care and the ordinary.

*Graham: I...I don't remember anything...I just remember waking up in here and being told what happened...*

*KS: and what were you told?*

*Graham: basically that I'd had a heart attack...*

*KS: and it...did...did you get told that you'd had a cardiac arrest?*

*Graham: err...yeah I think so...as it was the same thing...Well I...I think I was told that but I wouldn't say...I've been out of it for like, a few days.*

*KS: yeah*

*Graham: and all I know is I have had a stent put in...I've got marks here so...and there so [...]*

*[...] there's a few nurses here, very good...some they do their job, efficient, that's it...but they're not interested in the small talk, it's a case of, they're in, do what they've got to do and go...some of them come in, chat to you, tell you what they are doing...what each...what each thing they're putting in you, no problem [...]*

Within these two sections of dialogue, one can see how the patient was beginning to make sense of what had happened to him through the combination of the information provided that was aligned with the visible evidence trail that confirmed the medical instrumentation of his body. His fleeting recognition of a period of reduced awareness lead him to a more complete understanding and acceptance of a truth as to what had happened to him. The provision of information delivered with a caring demeanour appeared to have helped to create a structural and contextual platform that enabled him to make sense of his situation. This, and other caring interventions may have provided the necessary stability for recovery progress and underlines the necessity for healthcare professionals to provide an explanation of events to the patient that is as close as is possible to the truth.

Mike was a seventy-one year old who had been admitted to hospital for investigations into persistent chest pain. Following a radiological examination of his heart (coronary angiography) he was given the all clear and was discharged home. Whilst being accompanied to his car by his daughter he had a cardiac arrest in the hospital car park. Mike's account of his immediate recovery and return to consciousness indicated how the simple matter of the caring touch coupled with a few well-placed, reassuring words were felt and appreciated by a vulnerable patient recovering from a life-threatening crisis;

*“At about half-past three a crash call was called in and I had died, so they brought me back to life again, thank God...erm...spoke to...to the nurses that were there...this morning actually...and err...you know, they were holding my hand and they said ‘you had a very close call, but you look very healthy now’...and I’ve come to the conclusion that I have learned more about how...how...the effects that you can take on a person’s life is unbelievable...you think you’re healthy when you come in here, you walk around outdoors...at home, you know...I’m a man that worked in buildings all my life and all of a sudden you’ve got everything wrong with you and you haven’t realised half these things...you...you know”*

This patient recalled his waking up from the cardiac arrest in a cold sweat, with a large number of people gathered around him. He remembered the pain in his chest, which was tempered by his knowledge that the staff present had done what they had to do to “*get him back*”. He attributed the pain in his chest to the chest compressions received during his resuscitation. From this point on he regarded his hospital care as thorough and felt that he owed his life to those involved in his resuscitation.

Within this framework it is easy to see how this patient was positively affected by the simple, caring interventions that supported his resilience and his move towards health and recovery. He had been well informed with regard to the advantages and disadvantages of receiving the necessary emergency medical treatment and was able to understand the physical effects as well as the psychological impact. Furthermore, he was able to contextualize and validate what he had been told against his actual experiences. Despite a significant life-threatening oversight that occurred during the early part of his admission, he did not appear to apportion any blame towards the medical gaze for its apparent failure. Interestingly, this patient reached a saturation point where he stated that he no longer wished to receive further, more intricate details about his medical condition or previously conducted life-saving procedures. Perhaps this signified that he was approaching cognitive overload, in that a limit had been reached as to the level of information that he was able to understand and / or cope with?

David collapsed in cardiac arrest suddenly as he was walking up a long set of steps at an underground station whilst on his way to work and in doing so he sustained a serious head injury. He spent two days in the neurological intensive care unit before being transferred to another hospital for specialist investigations and treatment for the heart problem (myocardial infarction) that was the primary cause of his collapse. During the course of his interview he demonstrated a calm acceptance of his situation to the extent that he felt that he had no long-term residual functional deficits.

*[...] I mean that's the...the amazing thing about it that I seemed to have got through unscathed, but they have found these err...problems with my arteries [...]*

*KS: Do you...do you...how have you found erm...information being given to you from the medical people?*

*David: Well, its the same kind of information erm...they've obviously got their information from the same source and you know, they've stressed 'hang on, look', you know, you had a bad accident, you know, you've got to be careful, you've got to take it easy, you got to do what we tell you to do, there's no ignoring erm...machines like this, erm...unplugging them and using the bathroom and yeah, I mean, I see their point, but, you know...I'm kind of used to working with machines...*

*KS: mmm*

*David: So I feel as though I'm slightly invincible (laughs) [...]*

David appears to have successfully come to terms with having survived two potentially catastrophic medical conditions. From the manner in which he spoke during the interview, he intimated that he held a pragmatic appreciation of his circumstances that aligned with the information provided to him from the medical gaze, accordingly he had a very limited requirement to search for coherence. In this respect, David was different to the other participants in the research, having survived these events and his recovery was framed from an apparently more coherent, confident position, typified by his phrase “I feel as though I am slightly invincible”.

The final section of the chapter is focussed on how patients viewed their longer-term recovery as they looked towards being discharged from hospital. How did they contemplate their recovery progress and their return to normal health status and an increasingly independent life, remote from the medical gaze?

## **4.2 Coherence, coping and the future**

An aspect of recovery included in the research question was to gain knowledge of how patients might harbour fears and anxieties about their future, in the knowledge that their heart had stopped and been re-started. This section of the chapter recounts the patient's expressions about their worries fears and anxieties that were pertinent to their specific set of circumstances and how they looked towards returning to normal life. Having overcome the existential crisis and acquired a degree of coherence, this phase of recovery heralded a period where patients had (generally) begun to develop their recovery milestones and think more about returning home and contemplate their longer-term future. They also appeared to recognise that they might need additional support and help to that provided by their family friends and social networks, including input from the medical gaze. For others, they faced an uncertain future that was too difficult to consider. This final section of the chapter reports these findings.

Graham is a sixty-two year old man recovering from an acute myocardial infarction and oesophageal cancer that we met in the previous section of this chapter. The transcript below reflects his initial thoughts about his cardiac arrest and his overview of the longer-term.

*KS: How do you feel about it now, have...have now, in the knowledge that you've had a heart attack and you've had a cardiac arrest?*

*Graham: Not happy about it...I mean...it makes you wonder what's going to happen in the future doesn't it...*

*KS: what are you thinking about, in terms of your future?*



*Graham: well, I wonder what...I'm sixty-two...I mean will it happen again...that's what worries me, I mean, next time, am I going to be so lucky?*

Graham appears concerned and regards to his future as uncertain, a view that he verbalised without any overt emotion. It is interesting to note that he referred to his current survival status as being “lucky”, being that, by good fortune his son, who had been trained in cardiopulmonary resuscitation and had performed it on Graham, had opted to stay overnight with his parents, rather than return to his own house the evening before. Alternatively, like other participants in this study, he may not have had an informed understanding of why and how he survived and expressing this as ‘lucky’ this may have represented the only way in which Graham could rationalise his survival and comparative well being. Moreover, this apparent throw away comment was not followed up with any serious contemplation of his own mortality. Graham went on to say this about leaving hospital.

*KS: have you got any worries at all about what happens now?*

*Graham: Err....no, not really....I mean I'd just like....I really want to get home...*

Peter’s views about his discharge home and his longer-term future were framed entirely differently to Graham. Peter was a seventy-nine year-old retired council worker who had been admitted to hospital after being found collapsed at home by his son. His cardiac arrest took place within the hospital several days into his admission. Peter’s collapse was secondary to having developed a very slow heart rhythm (complete heart block), which was eventually treated by having a pacemaker inserted into his heart sometime after the cardiac arrest and after the interview had been conducted. During the interview Peter spoke very candidly about having had to perform cardiopulmonary resuscitation on his wife, which he had found it necessary to do on two occasions. His wife’s second cardiac arrest resulted in her death. In order to more fully appreciate Peter’s perspective about his future and his discharge from hospital, it is helpful to read two passages from the transcript where Peter was able to articulate his recognition of the traumatic consequences that he experience after having conducted cardiopulmonary resuscitation on his wife. Not only did Peter associate the procedure of cardiopulmonary resuscitation with the death of his wife, it was also integral to his grief.

Fortunately, it was evident from the following two sections of his interview that Peter had recognised this and had actively sought appropriate help.

*[...] but my wife more or less traumatised me, especially the second time, and I'll tell you now, honestly, I wake up in the night and I hear her calling and...and I jump up thinking she's still there and I'm actually covered in sweat [...]*

*[...] and I've been traumatised ever since...I can be out in the street and I go to do my shopping and I...I'm walking along normally and suddenly I get a flashback of what happened to her. Now, I've tried to get counselling and my son's been again last week to the GP, to get me a councillor, so I can talk it through [...]*

As can be seen from the extract below, Peter's re-living of the stressful and traumatic circumstances surrounding his wife's death, through flashbacks and the night sweats, have provided him with a very real and disturbing confrontation with his own mortality. At the time of the interview, when confronted by his imminent future, Peter was unable to make a judgement on his longer-term future or for that matter a full and meaningful recovery.

*KS: yeah...so what, if I said to you what do you think is going to happen to you now...from now, what do you...what would your answer be?*

*Peter: I don't know (laughs)...I really don't (laughs)*

*KS: and, you know, you...you*

*Peter: I hope to get better but I really don't know, I can't say for sure what would happen to me...I live in an uncertain world at this particular moment...*

*KS: yeah...are you frightened at all?*

*Peter: yeah, I am a bit frightened, I'll be honest about that...because I've never been like this before, so it does frighten me and I've seen the effects of it and that frightens me even more...I'd be a liar if I said I wasn't frightened, yeah I am frightened.*

Peter's fears for his own future are tangible in the above extract from the interview, but he also demonstrated a determination to positively move forwards towards a satisfactory recovery, even though he might not know what that might be.

Whilst appearing pragmatic about their recovery, neither Graham nor Peter indicated any form of confidence when asked to consider their longer-term future. There was a deliberate vagueness, perhaps fear, in what they have said, although Peter appeared more determined within his uncertainty and was persistent in taking important steps to overcome his on-going psychological difficulties.

By way of a contrast, Jose presented a different set of recovery challenges, as he was clearly surprised to find himself feeling well enough to seriously contemplate returning to work. His view was that he had recovered quickly and had done so without incurring any obvious deficits, which did not fit well with his expectations of recovery from such a serious life-threatening illness. He went on to express surprise at how normal he felt, but retained a modicum of reticence, as he did not directly question the wisdom and the warnings that had been proffered by the medical gaze. Instead he took a more subtle, cautious approach towards the apparent risk to him as he almost certainly expected there to be some residual effects from having had a heart attack and a cardiac arrest, which he had no tangible sense of at the time of the interview.

*Jose: But I don't feel anything. I feel nothing, and maybe that's a problem...because I've been told that what I've had was very...important or very dangerous or whatever...*

*KS: It was life threatening*

*Jose: yes, and err...it was not at the moment, but for the next month, or month and a half it's very important to take it easy, to, not err...do many things...to rest a lot and err...I don't feel like I have to [...]*

For him there were no overt signs of danger and minimal biographical disruption, accordingly he felt good enough to return to his normal life, which could be easily accommodated through a series of minor adaptations to his current lifestyle. Interestingly, he was less clear about his longer-term on-going recovery.

*Jose: now...I don't know what I am going to do in the next two-weeks...*

*KS: but for the intervening period?*

*Jose: I...I have no idea, I just have to go home and take it easy...that's all I know...*

*KS: yeah*

*Jose: but what is taking it easy? I'm not quite sure? (laughs)*

And later in the interview...

*[...] I...and I don't know how long that's...the GP is going to tell me it's going to be for one more week, or two more weeks, or three...I have no idea...so that's why I don't have that long range of what I'm going to do, because I don't know how long I'm [...]*

These confused feelings about his recovery at this time were based upon a paucity of appropriate information and guidance offered by the medical gaze. He was unclear as to where to place limitations around his physical activity for the coming few weeks and months. This left him searching for coherence regarding his on-going recovery, which resulted in his anticipation of receiving some degree of expert guidance upon his commencement of the cardiac rehabilitation programme he had volunteered to participate in.

Stephen was interviewed during the day before he was discharged home and just two days after his cardiac arrest. Hours from leaving hospital he has retained sufficient doubt in his mind that he may still be prone to sudden collapse and was still carrying significant concerns as to his vulnerability when contemplating his discharge home. This is not dissimilar to the position that both Jose and Peter alluded to earlier, in that due to inadequate preparation for discharge he appears to have little confidence in being able to conduct his normal activities of daily living once he returns home and he appears bereft as to what to do.

*[...] well I've got something that I have to be aware of, you know...will I be OK? What if I go off walking? 'Cos I certainly don't want to, you know, end up clutching my chest and dropping down erm...dead in the middle of a park, that...because it's...you think...well I have a problem that I never thought I'd have...so it...it's, suddenly a reality and you, well I feel err...err...what's the word...erm...I'm trying to think of the word, I know the word that I'm searching for...err...nervous about...about the condition...aware of it...nervous [...]*

This position of vulnerability when preparing for the return home was not universally held amongst all patients. Janet, a seventy-three year old woman had been admitted to hospital for a surgical procedure designed to help her very badly diseased heart valve (trans-catheter aortic valve implantation). This is a procedure that carries considerably less risk than conventional open-heart surgery and is reserved for patients who may otherwise be not fit for surgery. Janet was interviewed the day before she was discharged home.

*KS: home...what...have you got any thoughts about what...what's going to happen when you do get home?*

*Janet: erm...*

*KS: and about your ongoing care?*

*Janet: I don't know...I don't err...I...I keep saying to the erm...doctor...what's his name, Suntire, Santire or something...the...the ward boss...erm...the house is the still the same sized house, err...and it can be just as crowded, crowded with a...do I want care? Do I have erm...carers that want you to get ready for bed at eight o'clock at night? No we don't need that thank you very much...err...(laughs)...err...if they are anything about carers that other people I know have had, I don't want them within twenty yards of the place...erm...I don't...we...we managed perfectly well for the munch (unintelligible word?)...shall we say...I mean things could change, obviously, I mean...we didn't know all, know that all this was going to happen, I'm not living in that much of a cloud cuckoo land...*

*KS: mmm...*

*Janet: but, erm...in the meantime we do not want carers, 'meals on wheels', 'things on wheels' ...err...or people complaining 'cos we've got too many ornaments...*

Janet was desperate to return home, fiercely independent and strongly rejected any suggestion that she would need any of the general home support services provided to her. Her view was that she would return home to as normal a life as possible, with the good support of her husband, as articulated in the following passage. Janet did not appear to be searching for any form of coherence, she had come into hospital for a procedure, undergone that procedure and was now more than ready for returning to her home comforts and her privacy.

*[...] The longer I sit here looking out of the window...erm...I would much rather be at home tripping over my husband and err, arguing with him rather than sitting here indefinitely...being a total waste of space...there are things I could be doing...I...I am I would be at home...erm...and erm...just leave us alone to get on with it, you know [...]*

Francis, an eighty-one year-old amputee who had survived a number of cardiac arrests was also very much looking forward to returning home, he did however harbour a significant worry as can be seen in the following abstracts.

*Francis: I'm going home tomorrow and I maybe I'll succeed, if not I'll go the day after...erm...I've got no worries on that...*

*KS: You're not worried about that...are you looking forward to it?*

*Francis: Who wouldn't be, you know...your own bed, your own telly, err...*

*KS: Is there any erm...thing that you would like help with when you leave hospital?*

*Francis: Of course...of course. I mean...*

*KS: What would that be?*

*Francis: Well, my main worry is that Karen is my partner of thirty-two years and err...two-years ago was diagnosed with breast cancer, err...so I don't want to put any more worry or pressure...*

As he looked forward to enjoying the everyday pleasantries of being back in his own home, Francis' concerns were primarily aimed at the burdens that his discharge home may have on his partner, whom he considered to be at least as vulnerable as himself.

It is abundantly clear from the patients' accounts of their recovery, that they had unique, individual perspectives as to how they have contemplated their lives and sought coherence in the wake surviving cardiac arrest and the consequences of their hospitalisation. They described a multitude of complex experiences whilst recovering from their condition and their cardiac arrest and many expressed feelings of disbelief, terror, isolation, shock and disorientation whereas others felt invincible, unscathed and ready to return to work.

To a greater or lesser extent, each one of them possessed, at some stage in their recovery journey, a requirement for comfort, attention, information and clarity about what had happened (or might happen) to them. Their ability to assimilate the information

(or lack of it) that they received was influential upon their resilience to adversity and the quality of their recovery.

The next chapter reports the findings that emerged from their experiential perspective as to how, through the development of a sense of coherence, they were able (or not) to move forward from a coping position to one of a positive influence contribute to their own recovery trajectory.



## Chapter 5 Recovery milestones

### 5.0 Introduction

Thematic analysis produced a number of themes that were centred upon the worries, fears and anxieties that arose when patients contemplated their return home and how their continuing recovery from a significant life-threat might affect their existing lifestyle (if at all). These elements, supported by their developing sense of coherence, provided further understanding of how patients recovering from cardiac arrest viewed their longer-term and on-going recovery.

The secondary thematic coding analysis and the constant comparative method (Glaser and Strauss, 1967, Charmaz, 2000) revealed that there appeared to be two distinct phases of recovery. The first was the more immediate, almost entirely existential, in-hospital phase of recovery, centred on the patients' search for coherence that was evidenced in the previous chapter. The second phase appeared as a more pragmatic, strategic phase, often in partnership with the clinical gaze, where patients determined their own recovery milestones. Patients used these recovery milestones to develop, plot, evaluate and signify their recovery journey. Alongside their emerging realisation and appreciation of their situation and circumstances, the milestones helped them to progress through their hospital admission towards their discharge from hospital and return to functional, stable and health status. It is noteworthy that this recovery theme was inspired by a form of words used by a particular patient (Philip) who talked of reaching his recovery milestones.

This chapter commences with the presentation of the analytical findings that were consequential to how the patients identified individual progress markers and how these milestones provided coherent support towards their preparation for discharge from hospital. The second section considered their plans for work and section three covered their perceived re-engagement with normality and their ordinary personal lives. Alongside the search for coherence, the recovery milestones provided additional support to their increasing confidence and diminished their feelings of vulnerability. Many patients indicated that their personal recovery milestones were integral to their recovery as they enabled them to manipulate their situation favourably and position

themselves strategically within the healthcare system, in order to optimize the circumstances of their return home. There was an extensive and diverse range of experiential, conceptual and psychological factors that brought influence upon the views that patients expressed with regards to the critical steps along the recovery pathway.

These different factors are illuminated in the following sub-sections, the first of which is mobility. In the context of this study, all of the patients had been independently mobile prior to this hospital admission, however they all expressed concerns regarding the restoration of their functional ability to move and mobilise as they had done previous to their current illness.

### **5.1 Regaining Independent Mobility**

Many patients expressed concern regarding their mobility, for Laura this began with her awareness of the apparent necessity of her enforced restriction, of being confined to bed. Laura was a seventy-seven year old woman whose cardiac arrest occurred during an interventional procedure to slow her rapid and irregular heart beat. Upon awakening from sedation in the intensive care unit, Laura found the circumstances of her initial recovery genuinely shocking.

*So the shock of suddenly not being you, of being in bed and not being able to walk, you know, it...is really...it's amazing, I mean it really knocks you back.*

Laura was a keen cyclist and had previously seen herself as fit and well and had neither expected nor experienced this type of situation before. Regaining her mobility was a significant recovery milestone that featured frequently in the interview and as she moved closer to being discharged home it became increasingly more important to her. As can be seen below, Laura described an example of the challenge that her immobility had presented her with during her rehabilitation. Additionally, her interaction with the physiotherapist is indicative of her on-going struggle to regain control of her activity.

*Laura: and she wanted me...the day before I came here...she wanted me to go down...stairs...and practice getting in and out of a bath...now I couldn't lift my leg up...that far up...you know.*

*KS: mmm*

*Laura: ...and I said I couldn't do it...and she kept saying 'well you'll have to come and try'...and I just ignored her...you know.*

She was anxious to improve her lower body strength and walk normally prior to going home and saw this as necessary to regain and re-establish her independence. Later in the interview Laura indicated considerable determination to ensure that she received appropriate input from what she perceived to be quite a difficult physiotherapy team.

*KS: What's your worry about going home tomorrow, what are your worries?*

*Laura: well, first of all there are two flights of stairs, there's a lift and two flights of stairs and then when I'm up there (clears throat) you know, I'm not strong enough yet...I mean I'm...I...today I did stairs for the first time. No, tomorrow and this evening I will sneak along and do the stairs myself.*

Laura had felt unduly pressurised into going home prematurely, furthermore the decision to discharge her from hospital care had apparently been taken without consultation or explanation, at a point in her recovery, that was in her view, too early. As someone who lived alone she was worried about her general strength, mobility and ability to manage the stairs at home. Despite taking every opportunity to exercise and build up her strength during her hospital stay, she didn't feel confident enough to go home. Feeling vulnerable and discarded, she successfully remonstrated with the physiotherapy team and received further input to support her, once she was back home.

*Laura: well, the...the...when the physio came, when...you know...when I made a fuss...the physio came and she's found err...something else where...who will come and do physio at home with me. That's OK, that's fair enough you know...*

*KS: mmm*

*Laura: All I want to do is get better...you know*

Laura had identified that regaining her independent mobility was a significant recovery milestone, she also recognised that the decisions regarding her discharge from hospital had initially been outside of her immediate control. Her own determination ensured that she was at least adequately prepared to return home and she clearly stated her ultimate recovery milestone when she said, *"all I want to do is get better"*.

Janet, a seventy-three year old woman had undergone surgery to the aortic valve in her heart. She had endured a prolonged hospital recovery (thirty-six days) and was interviewed the day before her discharge from hospital to home. Her husband of fifty-three years was her main carer. The principal reason for the delay in getting home was, from her perspective, due to her limited mobility. Janet's immobility was significantly influenced by her medical condition, both in terms of lower limb dysmorphia and her breathlessness. The following extract from her interview typifies her view of her recovery period.

*I was unable to rely on anybody...and there was nothing I could do for myself...I was stuck in this rotten bed, erm....*

Very slowly Janet began to make important progress with her mobility, to the extent that she was able to mobilize herself.

*[...] but I mean, I...every morning I wake up in that bed...I'm...my first few steps are quite shaky...which is annoying me [...]*

As can be seen from the short quote below, Janet was also dismissive of the contribution to rehabilitation that is made by occupational therapists.

*[...] they come and they go...you know...I see no purpose for therapists anyway [...]*

Despite her hitherto undisclosed rationale' for her disregard towards the physiotherapists who were attempting to help her, she was eventually able to grudgingly recognise that the team had provided some form of useful contribution towards her ambulatory recovery.

*I was taken for a walk the other day erm, which was fine, I managed the stairs, very quickly and quite well, err, far bigger stairs than we've got at home [...]*

Wilfred, a largely independent eighty-one year old man had his cardiac arrest in the emergency department. During his recovery he identified mobility concerns and recognised that he may need help, at least whilst in the hospital.

*Wilfred: And all of a sudden its hit me that it is something that I might have to consider that fact that I...I'm going to have to need a little bit of help to...*

*KS: right...*

*Wilfred: ...to get around, I...I...I...let them lead me around earlier on...to the toilet and that, you know.*

Wilfred went on to speak about his mobility plans, his aim being that of getting back to the situation he was in prior to his current illness, but he approached the situation pragmatically and accepted the necessary adjustments, taking things more carefully.

*Wilfred: ...no I think...I think...I think what's...what's going to happen from now on is I'm...I'm going to try and do some of the things I normally do...*

*KS: yeah...*

*WW: but in a slower pace [...]*

It can be seen in the next extract from the interview that Wilfred considered that, at this point in his recovery, assistance with walking in the form of a walking stick appeared to be the only help with mobility that Wilfred expected to need once he returned home.

*Wilfred: I...I...I don't...err...erm...I...I...do not think at...at the present time that I will actually need any other real help for moving around because I...I can walk around fairly eve...fairly well*

*KS: Yeah...*

*Wilfred: ...with a walking stick and that and erm [...]*

For Francis, an amputee, mobility had played an important part in his progress and he had anticipated that his release from hospital would be entirely dependant on his ability to demonstrate independent mobility, which was to him, a recovery milestone determined by the healthcare system, rather than by him.

*Francis: They're mumbling about the weekend...so...*

*KS: Right. It's Friday today...*

*Francis: Yeah...so if I show them I can jump in and out of bed a few more times...erm...*

For Francis, this was the extent to which his suitability for discharge home had been assessed and in his desire to get home he intended to conform to the request.

Jose, the forty-four year old recovering from his myocardial infarction had slightly different mobility related milestones. He was fully independently mobile and entirely able to undertake normal functional activities of daily living, but he was wary about over-doing things and was unsure as to how delicate his body might be and was grateful for the support of a family member.

*Jose: I also have a cousin who has been living here in London for many years and err...ah...he is the one who is going to pick me up today and take me home...*

*KS: right...*

*Jose: and help me buy some things from the supermarket...*

*KS: yeah...yeah*

*Jose: because that was one thing I was thinking...OK if I cannot carry heavy things so how am I going to go to the supermarket, to the store and then get some milk or something to take home? And then...erm well, I think it...everything's working out...*

In the absence of forthcoming rehabilitation advice from the medical professionals providing his on-going recovery care, Jose harboured concerns about his physical limitations following his heart attack and had taken the necessary steps to organise a basic shopping trip with his cousin. Without guidance or advice, Jose felt compelled to impose arbitrary limits on his own exertions.

Gordon was in a similar position in that when questioned about his return to normality he didn't appear to have any real idea as to whether to expect his physical recovery to be complete. It was also interesting to note that Gordon framed an element of his recovery in a physical context.

*KS: [...] what do you expect will happen now...you talked earlier you hoped to recover 'back to normal' but what...what's your actual feeling...where you might be?*

*Gordon: well, to tell you the truth I...I don't know much about how physically strong one can get after this sort of operation [...]*

Sanjay, a forty-nine year old man, who had collapsed in cardiac arrest at the beginning of his yoga class, provided an example of how enforced restrictions on mobility impedes the ability for patients to perform ordinary mundane bodily functions, for Sanjay this was a dignity issue, a measure of his independence and a cross-reference to alternative approaches to patient-centred care.

*[...] I wanted to go to the bathroom and err...and so they unplugged me, I went to the bathroom and came back, plugged me back in erm...when I was in the other hospital they wouldn't let me do that, they wanted to bring me a bad...bedpan here and I'm sorry but its very difficult to OK erm...and urine bottle as well erm...I remember doing a urine bottle last night [...]*

Unlike the other patients in the study, Graham and Philip had both experienced recovery from major surgery and openly discussed their previous experiences of hospital care. Graham had undergone surgery to his oesophagus in the previous year and Philip had undergone an aortic aneurysm repair two years previously. They both used their previous experiences as a benchmark against which they measured their current recovery progress. Graham had viewed the hospital phase of recovery for his current admission as being good. At the time of the interview, his improving mobility situation had provided him with a suitable yardstick against which he measured his recovery progress and he stated that he had been “*up and about*” earlier and more comfortably than both he and his family had expected. Furthermore, mobility appeared to have been considered by the medical gaze as a confirmatory milestone with regards to his readiness and suitability for being discharged home, with Graham appearing to be fully compliant.

*[...] but they are gonna review...he said he can't see...the doctor said he can't see any reason why I can't go home. They've asked me if I've got...what stairs I've got and mine are quite steep, but then I put up handrails both sides, because my mother-in-law used to come round a lot and she needed to hold both handrails to get up and down stairs [...]*

Philip considered that he has successfully recovered from major surgery and as he discussed his anxieties in the extract below, he clearly recognised how his previous recovery experiences provided insights and helped him to form reasonable expectations as to how having some of the veins stripped from his legs to provide the grafts to his coronary arteries might affect his mobility through pain.

*Philip: [...] I started to move...look at these legs they're going to be painful 'cos it's had a vein stripped out of it...*

*KS: uhum*

*Philip: and this is going to be discomforting, but because I've had the triple A, I've got some experience of...*



KS: yeah

*Philip : get...having got through that process...*

Unlike the other participants in this study who had experienced a myocardial infarction, Philip had been aware that he had coronary heart disease as it had been brought to light following a car accident and his collapse at a major railway station didn't appear to have come to him as a complete surprise. He had been fortunate to have the event witnessed by a passing doctor who provided cardiopulmonary resuscitation prior to the arrival of the ambulance staff, which he only briefly mentioned during the interview.

*[...] six years ago I had a car accident, this was diagnosed soon afterwards, I knew all the way along I had a heart issue...but I thought I'm just gonna keep going [...]*

Philip's previous hospital experiences appear to have provided him with a level of self-determination regarding his recovery. During the interview at his bedside, Philip talked about his recovery progress and in doing so he suggested that he had been helped by having set himself a number of recovery targets to measure progress whilst in the hospital and looked forwards to pleasurable, but therapeutic activities during his immediate post-discharge recovery period.

*[...] because I feel that I am recovering...so my end goal, get out of here, get back on the golf course, walk the dog and all the other bits OK, so it's part of the process that you know, I've set my own...goals and err...at the moment I feel better today and every time another tube comes out and something else gets not used anymore and I'm off the oxygen now so those sort of things...for me mentally, that's a progressive thing for improvement so...*

Philip was the only patient that clearly and transparently verbalised the overt psychological benefit that he gained from using small but important recovery milestones, however as patients recovering from a life threatening situation and remaining within the hospital system, most, if not all of them appeared determined to reach the major recovery landmark of being considered fit enough to return home. The next section of

this chapter considers how patients viewed their progress towards their impending release from the safety net of the hospital environment.

## 5.2 Leaving Hospital

Whilst undertaking the analytical coding it became abundantly clear that the milestone that carried the most significance for patients during the in-hospital phase of recovery was that of leaving hospital. Whilst most displayed a positive, almost desperate desire to return home, others conveyed a mixed picture of positive expectancy whilst harbouring anxieties and fears when faced with the reality of imminently leaving the hospital. A few were contemplating the homeward journey reluctantly and one appeared completely indifferent to the prospect.

Mike, a seventy-one year old who had collapsed in cardiac arrest in the hospital car park after being discharged home, stated brightly that he had no worries or fears about returning home because he considered that he was now ready to return home. He had made that judgment and was able to articulate why this was important to him, but his judgment was not made in the context of a return to health, but because of his need for good quality rest and sleep away from the considerable distractions that accompany modern in hospital care.

*KS: mmm, have you got any worries about going home?*

*Mike: no worries at all*

*KS: are you looking forward to it?*

*Mike: I am, I...I would go now if I could (laughs)*

*KS: and what...why...tell me why...why you're looking forward to getting home*

*Mike: because you can't err...these places...you cannot really rest, you can't sleep, you know, there's something...your...your brain goes to mush all the time. You listen to other people moaning and groaning and...and just when you're settling down, somebody comes along and 'hello, excuse me, Michael' and they want to give you this, I want you to take this...I want to...you know*

However, in the interests of ensuring his timely departure from the hospital, Mike indicated that he intended to be fully compliant with the recommendations and guidance offered to him by the medical gaze.

*"All I've got to do is follow the rule book properly and do what I'm told".*

When directly questioned, Graham was absolutely clear and very positive about his imminent discharge.

*KS: It's erm...what would...what's...what are your biggest worries about going home?*

*Graham: none*

*KS: haven't got any?*

*Graham: No...just want to be there...*

Even when questioned further about how he had planned to occupy his time, Graham has already formulated his approach, where he anticipated that he would receive advice and guidance from the doctors as to how best assist his on-going recovery.

*KS: Have you got any ideas about what you're going to do with yourself?*

*Graham: well yeah, I mean, take it easy for a while but...*

*KS: Has anyone told you that or is that something..?*

*Graham: No, I think that is something the doctor will tell me before I go, I mean he...he's not going to say anything now...but he will obviously tell me tomorrow...that yes I can go home err...I think he said that there, that you know, they'll obviously let me know what the situation would be...*

Janet, who was recovering from aortic valve surgery, had a different perspective had indicated some frustrations with still being in hospital more thirty-five days after her surgical procedure and cardiac arrest. She was anxious to return home and in the following extract from the interview transcription, Janet made a further reference to her mobility.

*[...] every morning I wake up in that bed...I'm...my first few steps are quite shaky...which is annoying me.*

Janet's dry, sarcastic tone seemed to purvey a covert sense of bitterness and regret about her situation and her decision to agree to undergo the procedure, which in itself raises a number of other questions. She appeared very keen to avoid any form of medical surveillance, which is a separate recovery theme, visited in detail in chapter six. Janet had retained significant concerns regarding her mobility and when contemplating her suitability for discharge she was clear about her needs. Sensing the pressure from the healthcare team, she was adamant that everything should be in place before her imminent departure from the hospital.

*[...] and the nurses started trying to get hold of somebody during the day to see if they could...push things forward, but I can't go home until there's a complete care package.*

However, Janet did occasionally express positive views about her future and one that was particularly interesting occurred when she went to reveal a more longer-term recovery milestone. She hoped that she would at some point during a period of convalescence, be able to spend some quality time with her husband, at their caravan.

*[...] erm...I've lost most of this year...we've got a caravan down on the south coast...I would dearly love to get down there...even for a few days.*

Some patients were more reticent and apprehensive than others, depending on their own specific set of circumstances and their expectations of their continuing recovery. Alice was a ninety-two year old lady who had suffered a myocardial infarction followed by a cardiac arrest that had occurred during coronary angiography in the cardiac catheter laboratory. Her recovery was medically uneventful and during her interview she displayed a rather *laissez-faire* demeanour and appeared indifferent towards her recovery progress. Alice lives in a warden controlled flat within an elderly persons community and has a cleaner that visits her daily, she did however maintain that she was functionally independent. Alice was a participant that used very few words to convey her experiences and gave very little away. Nevertheless, it was clear that she was not particularly looking forward to going home, but not unduly worried or anxious and summed up her impending discharge when she said she will "*just go and cope*".

Eddie was able to readily express his particular concerns regarding his rather eventful recovery from two cardiac arrests, which had followed the coronary artery bypass graft surgery he had undergone. He wanted to be absolutely certain that he was in the best possible condition prior to leaving the hospital and he had almost reached that point at the time of the interview. Eddie was discharged home three days after the interview had been conducted.

*KS: Have you got any particular concerns, worries, anxieties about...going back home?*

*Eddie: Erm...yes that's why, at the moment, I am in no tearing rush to get out of the hospital until I assured that I'm a hundred per cent, because I still have this fear in the back of my mind, I still don't feel a hundred per cent well at the moment, a couple of days after the episode and I'm putting that down to the concoction of drugs and that were pumped into me...erm...but...but I do feel confident and happy now that the problem appears to have been identified, rectified and erm...one can only go forward, so yeah.*

David, who had his cardiac arrest at an underground station and sustained a minor brain injury as a consequence of falling as he collapsed, took a very broad, pragmatic and almost matter-of-fact line towards his recovery progress.

*KS: What do you expect to happen to you in the next few days and weeks?*

*David: Well I expect to have a bit of surgery, heart surgery erm...I expect to recover, I expect to go back to work erm...I...I expect erm...a bit of a slow pace leading up to Christmas and perhaps after Christmas maybe it will pick up a bit faster?*

David was very much looking forward to getting home, largely it would seem, to enjoy a more restful, comfortable sleep, a point that had also been made earlier by Mike.

*KS: see how it goes? And what's erm...what are your thoughts about going home?*

*DJ: I'd love to go home, simply because I just can't sleep at night here...it really is just...I don't know what it is about the place, and I'm...I'd like to go home and have a good nights sleep and I was hoping that was going to happen like tomorrow, but that's not going to happen.*

Gordon had other worries about his return home and these were centred around the situation with his wife and the impact that their decisions about her discontinuing work status were likely to have on their financial status.

*KS: how do you...have...what worries have you got about, if any, about going home?*

*Gordon: I haven't got any worries at all...*

*KS: none at all?*

*Gordon: None at all...oh, I've got a slight worry about how I'm am going to finance all this...*

*KS: how you are going to?*

*GD: Finance all this, because...*

*KS: Finance it?*

*GD: Finance in a sense that...my wife has just given up her job...*

*KS: mmm*

*GD: so, we've got to think about doing something else to fill the gap, you know...*

There were only two patients that directly referred to the negative impact that their recovery from illness might have upon their financial situation, the other was Graham who referred to an on-going situation that pre-dated his current illness and had been receiving telephone calls from his bank during the acute phase of his recovery.

### **5.3 Returning to their normal lives**

A return to a level of independence and the re-establishment of a modicum of control over their own lives was of significant appeal to many and the majority of patients had very much looked forward to returning to the comfort of their own homes and enjoying the simple pleasures of life. Alongside this, they had developed expectations that they would be able to re-establish the routine order of their private lives. Additionally, this section includes details of a diverse range of challenges and situations that patients had anticipated as they looked forward to settling back into the normal flow of life.

Peter, who was seventy-nine years of age, had a very positive view of his return home, but it was a situation that posed an altogether different prospect to others in the study as he lived alone within an elderly community. In the following extracts from his interview he highlighted a number of his fears and apprehensions.

*Peter: You see the frightening thing to me though, if I hadn't seen my wife...is having seen my wife*

*KS: mmm*

*Peter: It frightens me at what position I'm in...*

*KS: yeah...'cos you'll be a...alone at home...yeah*

*Peter: even with a pacemaker, I know a pacemaker helps a lot.*

Peter's experiences of having seen his wife collapse and having had to conduct cardiopulmonary resuscitation on her had remained etched on his mind and had clearly determined the direction of his thoughts and perceptions about how he was going to be when he eventually returned home. The interview with Peter had been conducted twelve days after his cardiac arrest, but prior to his pacemaker being fitted and a considerable time before his discharge home. Despite the psychological obstacles, Peter went on to indicate that he had considered his situation and had been actively planning his own care strategy in readiness for his departure from hospital, whenever that was going to be.

*KS: [...] so you don't really have a clue about when you might go home and how you, have you got any things...who's going to help you when you're at home?*

*Peter: My son, he might either come to my house or he might take me to his house or flat...I live in a ground-floor flat, but he...he doesn't, but he has a lift outside, he'll look after me [...] What I...what I find amazing is like, that when I've come in here, this is the first time in my life I've been in hospital and err...people say to me 'who looks after you?' (laughs) I say, 'I look after myself' I shop, I wash, I cook, I go out, go to football, do what I want to do, nobody has to look after me, until I had this illness!*

Peter was demonstrably independent and in his eyes, more than able to manage the mundane elements of his own life as well as the more pleasurable activities. He was



astonished that his care providers viewed him differently. He fully intended to return to the same level of independence that he enjoyed prior to his current illness, but he had realised that it may not be fully achievable.

*KS: yeah...so what if I said to you what do you think is going to happen to you now...from now, what do you...what would your answer be?*

*Peter: I don't know (laughs)...I really don't (laughs)*

*KS: and, you know, you...you*

*Peter: I hope to get better but I really don't know, I can't say for sure what would happen to me...*

When asked to contemplate his return home Wilfred viewed this milestone positively and being clear in his approach he had retained a determination to maintain his independence and appeared to have an insightful understanding of the necessity for him to moderate his physical activity, a decision that he himself had taken.

*KS: [...] Do you think that having this heart problem is going to affect how you...how you are when you go home?*

*Wilfred: I...I don't think so now because...I might have done so but because I'm eighty, gone...gone eighty years old...*

*KS: mmm*

*Wilfred: and I've real...and I am actually now realising exactly what it is that has happened and I...I also realise that I must put it upon myself to slow myself down...*

*KS: mmm*

*WW: and not go dashing around for others all the time as I...as I...as I've been doing for the last few years...*

By way of a contrast, Stephen did not view his leaving the hospital as a particularly positive measure of his recovery progress as he readily stated that he viewed the prospect with considerable caution. The extract below was taken from a lengthy discussion about leaving the hospital and settling back into independent life with his wife.

*KS: It doesn't seem to be erm...doesn't seem to be something that you are looking forward to...*

*Stephen: Err...I'm...I'm looking at...now...at the future...with a little bit of err...err...trepidation [...]*

Stephen, who was recovering from a myocardial infarction, went on to reveal that he had harboured a number of significant worries regarding the first few weeks back at home, which he had proved keen and able to articulate. Firstly, he perceived there to be a loss of overt control over his life. Secondly, he spoke of a missing element that was difficult to describe, which had brought fear and vulnerability into his thinking. Thirdly, he was perhaps struggling to come to terms with having to face the reality of his own mortality, which was exemplified by his thinking that he might suffer another heart attack and / or cardiac arrest.

*KS: have...have...have you got any particular worries about going home...about the immediacy...and, you know, the first few weeks?*

*Stephen: err...any worries...err...from a health point of view or from...a mind point of view?*

*KS: any, just from your perspective...*

*Stephen: Just feeling not err...as intact as...as w...as I felt I was...*

KS: *mmm*

*Stephen: I've always been a kind of person, I mean I was a [...], so I've always been totally in control of everything and erm...err...never, ever delegated, now I feel just as if I'm incomplete, you know, in a certain way. As though, well I've got something that I have to be aware of, you know...will I be OK, what if I go off walking, 'cos I certainly don't want to, you know, end up clutching my chest and dropping down erm...dead in the middle of a park, that...because its...you think...well I have a problem that I never thought I'd have...so it...it's, suddenly a reality and you, well I feel err...err...what's the word...erm...I'm trying to think of the word, I know the word that I'm searching for...err...nervous about...about the condition...aware of it...nervous [...]*

The source of Stephen's anxieties didn't seem to be seated in his leaving of the perceived safety of the hospital. Rather, his depiction of collapsing in a comparatively remote place suggested that he had been more concerned with finding himself away from the immediacy of emergency care, being isolated and dying alone.

#### **5.4 Returning to work**

Five patients (Sanjay, Eddie, David, Graham and Jose) had been in full time paid employment prior to their current illness and this section details the thoughts of those within this group who presented their return to work as a significant recovery milestone. The anxieties conveyed about returning to work were placed on a number of levels, by all four of the study participants who were of conventional working age.

In the transcription below Jose expressed a clear desire to not only return to work, but felt as though he could do so almost immediately, feeling as he did, in good health both physically and mentally. He did however express caution in this regard, recognising that for someone recovering from a heart attack such a move would be viewed as unconventional and unlikely to be permitted by those overseeing his medical care and advising his employers.

*KS: Do you feel able to go to work?*

*Jose: Yes, I mean...I...I...right now I think I could go and have a shower and go to my office to-die...today...I feel...like that [...]*

*Jose: I know I am...I am not allowed and I shouldn't do it (laughs)...I know that...*

*KS: mmm*

*Jose: Err...that's maybe the most difficult part because I feel well [...]*

When considering his return home, Jose continued to appear slightly frustrated with the lack of forthcoming information from the healthcare team, which had limited his preparations for his impending discharge from hospital, a point which Jose had repeatedly identified, being that it was also covered in the first section of this chapter.

Graham, who was self-employed, was similarly pragmatic and took a seemingly sensible position about restarting work.

*KS: Do you...is that what...what...what...I'm interested in why you're keen to go home, is it so that you can just get back to being normal?*

*Graham: Yeah, I mean, I don't anticipate doing much work because my work is quite heavy...*

*KS: Are you...do you do the physical work or are you on the managerial side...*

*Graham: No, I...I just work for myself. I've got a workshop in the garden.*

Despite being repeatedly contacted by clients whilst he was recovering in hospital, Graham had been largely compliant with his wife's request that he should refrain from any type of work during this time. She had eventually found it necessary to confiscate her husband's mobile telephone.

*Graham: One bloke who...who's waiting for some work off me, rang up at nine o'clock Sunday night and it wasn't only just to see how I was it was to see...*

*KS: yeah*

*Graham: well...how he was going to get some work and my wife said 'you're not having the phone in there 'cos your not going to talk to anybody', 'you're stressed enough as it is'*

David framed his recovery around two key milestones, the first being a return to work and second being a return home in time for Christmas. During the interview it had become clear that David had enjoyed his job and he took an ambitious view towards an early return to work, but his recovery progress, at the time of the interview, had indicated to him that he might have been looking at this from an idealistic perspective.

*KS: Have you got a view about when you might go back to work?*

*David: Well, no I haven't, erm...I was thinking next week, but I don't think that's going to happen [...]*

David went on to consider whether his illness had affected his ability to perform his conventional work role and in doing so had raised the question of on-going biographical disruption, which will be discussed in chapter 7.

*David: I do wonder what's going to happen at work as well, 'cos I'm going to be behaving slightly differently...*

*KS: are you, why do you say that?*

*David: Well I won't be racing around like before, you know, I'd get a queue of students and it'll be a case of dealing with them as quickly as possible and quite often I'd do the job for them just to get them out the way and you know...*

*KS: mmm*

*David: and I do wonder, whether, you know, I probably won't be capable of doing that.*

*KS: why do you think that?*

*David: well, I...I'm going to be a lot slower I think.*

The above transcription was taken from a later point in the interview and here David demonstrated his awareness of the potential reduction in his functional delivery of his job role. Whilst he might have been thinking about his job security, he did not verbalise any concerns that his job may be under threat at any point in the interview.

The issue of work was of concern for Sanjay who was the remaining participant amongst the study cohort who commented on returning to work. Sanjay's heart had stopped during a yoga class and during the previous year he had required a pacemaker to be inserted. Sanjay had found it necessary to conduct organisational work whilst recuperating in his hospital bed. In the interview he had been careful to justify his decision to conduct this work. As the owner of his business he felt that he had needed to ensure that everything was under control, which had enabled him to take a step back to concentrate on achieving a full medical recovery.

*Sanjay: It is niggling in the back, because if I didn't have those things I could just say 'right, I'm gonna stay here until I get hundred per cent better, everything's fine, nothing to worry about, OK?'. What I can do is work from here and fix all those problems so I don't have to worry about anything, so maybe tomorrow, day after tomorrow, get my wife to bring some stuff I need to do, I quickly do it and that's it with that and I'm fine...err...its something that I nee...I need to do, that no-one else can do...I'm not worried about err...the business because I've got staff that are looking after it so...I'm...I'm not...I'm not that...and It's not...it's not, it's a slow time of the year, so it's not like undue pressure on my staff...OK, so, I'm quite capable of staying here till...till...till I get better [...]*

During the course of the interview Sanjay demonstrated a determination to fully recover, he appeared to be well informed and cognisant of his situation. He also alluded to his responsibilities towards his extended family, which under-pinned his strategic approach to that recovery.

The complexities of the individual patient recovery journeys that have thus far been revealed through scholarly inquiry indicated that healthcare professionals have found it challenging to adopt a genuinely patient-centred holistic approach to care. Healthcare professionals appeared oblivious to the individual physiological needs of the patient that might have been helpful in assisting them (and their families and friends). By providing more effective support and better quality information, the search for coherence is likely to be enhanced, which may also help patients to determine realistic, positive and encouraging milestones along the tortuous route of recovery.

The third and final findings chapter will consider how the influence of the medical gaze, viewed through a Foucauldian lens that saw the hospital as failed panopticon, affected the recovery experiences of the patients.

## **Chapter 6 Illness and recovery – encounters with the medical gaze**

### **6.0 Introduction**

According to the documented records made through the mechanisms of the medical gaze, all fifteen of the patients in this study had their cardiac arrest as a consequence of heart disease. Twelve of the fifteen patients had been admitted directly to the hospital as emergency cases that required immediate therapeutic medical intervention by the proficiency or expertise of the medical specialists working in cardiology. Ten of those patients had coronary artery occlusion that caused myocardial infarction, the other two had heart beat regulation problems, one of which had a very slow beat, whereas the other experienced a very fast and irregular heartbeat - these two individuals also required the medical attention of the cardiology specialists. Of the remaining three patients, two had voluntarily attended the hospital for an elective surgical procedures, one to undergo coronary artery bypass grafting to his heart, the other for a surgical correction to a dysfunctional heart valve, the third patient had voluntarily attended hospital for investigations into his kidney function, which unveiled that he had severe coronary artery disease that required emergency surgery.

All of the patients required the close surveillance of the clinical gaze, either in the coronary care unit (CCU) or in the intensive care unit (ICU). As their recovery progressed they required progressively less intense surveillance, but it was still considered necessary by the gaze to place the recovering patients into hospital spaces where they could be attended to by specialist healthcare professionals with a level of proficiency and expertise specific to cardiac recovery. It has been generally accepted that, with the exception of emergency departments and acute admission areas, ward areas have become increasingly more specialised and as such there are no longer general ward areas. Consequently all patients were managed within specially constructed hospital spaces where they could recover in a situation of improved safety.

Each of the patients in the study group had an illness that emanated from a disease and clinicians conducted physical examinations, tests and therapeutic interventions upon and within their bodies and all of the medical activity took place within designated spaces in the hospital. Therefore, in terms of surveillance, the



patients underwent their interventional treatment and the consequential recovery period situated under a clinical gaze that had a strong resemblance to the conventional Foucauldian construct of a panopticon.

The findings obtained regarding the recovery experiences of patients was reported in chapters four and five and as discussed in the literature review it is important to recall and recognise that the healthcare panopticon is purposefully designed and constructed to optimise the recovery of patients, albeit within socio-economic and political constraints.

Utilising the lens of the panoptic gaze, this chapter will consider three important aspects that emerged from the thematic analysis of the interview transcripts. The first section considers the experiences of the patients' encounters with the technical and environmental construct of the clinical gaze, including their perceptions, interactions and the receipt of interventional care (covering the medical and nursing work upon or within their bodies) during the hospital phase of their medical treatment and recovery.

Being discharged home was the most prominent recovery milestone portrayed by patients in chapter five and acted as a major signifier for a move away from their illness state and a return to a more healthy state. Looking through the lens of the extended panopticon of modern surveillance medicine, the second section of this chapter reports the patients' thoughts, feelings and expectations in advance of their imminent departure from the hospital and the transition into community-based care and beyond.

Finally, as a major influence on the patients return to a position of relative health (and possibly, better health) this chapter will conclude with a detailed account of patients' experiences of the medico-social interactions that took place between themselves and the main agents of the clinical gaze – the doctors, nurses and other members of the hospital staff, and how their recovery was influenced by these interactions. One of the primary research questions posed in the research was centred upon how patients discovered that they had had a cardiac arrest and what they understood this to mean. An important finding that emerged that was strongly evident from exploring this theme with participants was centred around the medical construction of the consultation between the patient and their doctors, particularly the ward round.

## 6.1 Patient's experiences of the structure and work of the clinical panopticon

Stephen portrayed an interesting account of how he came under the clinical gaze after he began to experience chest pain at home and eventually found it necessary to call for an ambulance. Stephen was attended by paramedics, who are, with the exception of helicopter emergency medical systems, staff with the highest level of clinical skills, knowledge and experience available to the gaze. They were able to conduct the necessary emergency medical interventions upon Stephen's body to diagnose, treat and safeguard him until they handed him over to the expertise of the medical gaze at the hospital. Stephen had been taken to a specialist heart attack centre, where considerable expertise in the work of the heart is conducted.

*I just thought...oh, it'll go off...go away and then early hours of the morning you think, oh GP's not there yet, you know...I never thought about 999 'cos I didn't think it was an emergency, but err...obviously it was...and err...err...so 999 was called and then the ambulance arrived, they gave me an ECG and err...I was told 'you are actually having a heart attack', he said, 'so, I'm going to inject you with morphine'.*

Unlike Stephen, Gordon was significantly more experienced in the behavioural workings of the clinical gaze and did not appear to be intimidated or distressed at how he came to be placed in his current situation. His chronic renal failure had brought him under the close attention of the gaze for a prolonged period and as Gordon readily articulated, he had recently been admitted to the hospital panopticon for assessment regarding a kidney transplant.

*[...] Well I have been having a problem with my kidneys for about five or six years erm...which seemed to be all under control, but in the last six months my creatinine level went up from about four hundred to six or seven hundred and err...my kidneys couldn't be sustained in this, at such a high level and then they were look...looking at option for a kidney transplant and erm...that took some time, about two months for them to come up with an...that I need a kidney transplant. What happened was then the erm...the...the kidney specialists suggested that I had a heart...whatever they do to make sure everything else is ok with my heart*

*and to his surprise and everybody's surprise I had four blocked arteries for the...that was the start of my cardio-thoracic experience erm...I came in on the second of err...October...err...unfortunately they err...I was ill, about three days...postponed, they couldn't do the operation, but err...I think it was the ninth of October, they did the operation and erm...I went into...it wasn't a straight-forward operation, I had two cardiac arrests erm...and the problem was that...err according to the....the angiogram didn't actually show that there was some deviation in the arrangement of my arteries, err...its unusual [...]*

It is clear from the interview transcript that whilst Gordon was very well informed about his on-going health difficulties, he had been keen to demonstrate that he was sufficiently familiar with the functional operation and the language of the clinical gaze, which he used to his advantage during his recovery period.

The apparent failure of Sanjay's pacemaker that had been implanted in his chest just less than a year prior to his cardiac arrest led him to question the safety of the gaze, a situation that was central to his sense of coherence. One of the most advanced technological surveillance systems available to the medical gaze, one that has to be functionally operational continuously appeared to have failed. Sanjay had indicated that the specialist doctors had themselves been puzzled about the failure and had contacted additional, external expertise to investigate and advise them. These people being the commercial agents of the medical gaze who manufactured cardiac pacemakers.

*[...] I remember the gentleman as well, who...who works for the company for the pacemaker and he came to figure out why...why it didn't fire in when it should have done OK, and they did some test and apparently everything seems normal, but they haven't told me anything, but from what I gather it seems to be normal, so there's nothing they can suggest on that [...]*

Janet, a seventy-three year old lady recovering from aortic valve surgery displayed significant insights into the concept of the clinical gaze within the hospital setting in that she clearly appreciated the therapeutic input when the unanticipated life-threatening problems arose. Following her surgery, she had required cardiopulmonary resuscitation and subsequently, the insertion into her body of a permanent pacemaker to help

regulate and stimulate her heartbeat, if and when it slowed down to dangerous levels. Janet appeared to have understood and valued the provision of these additional, unplanned medical interventions that she had not explicitly consented to undergo, which she clearly acknowledged during her interview.

*[...] and the pacemaker, which I didn't know I was going to have, erm, and I do erm, obviously I didn't have any choice in the matter, err, it is very nice that they brought me back from the brink. But err, I do appreciate it, and don't think for one minute that I am not grateful, because I am.*

Janet also painted a very vivid picture of her experiences in the CCU, where she had been placed in the immediate recovery period following her cardiac arrest. Her account articulated her awareness of being under intense surveillance, as she described a brilliantly constructed, well-organised, mini-panopticon that featured both the technical and the clinical elements of the gaze. Whilst it is possible that she had experienced something akin to hallucinations, she had not alluded to such experiences at this point in the interview.

*Janet: yes, the coronary care unit...well, there was a lot of helicopters going overboard...and I kept thinking I was in an airport err...and the nurses would going in and sit down at the far end...erm...playing with their computers...or whatever it was they were doing...and they looked just like the screens on a control unit...and I...I kept thinking that they were running the flights from there...you know...erm...that was one...and I...I don't know how accurate this is...but people would come to the doorway...in...in that bit there...with pieces of paper in their hand...and they'd stop and they'd pause and they would stand and look at these pieces of paper...and then, they'd walk off again...it was very choreographed...*

*KS: uhuh...*

*Janet: and I (laughs)...and I got the distinct impression...that they were filming...that they were...they might have been, I mean...they might have been doing some technical filming, I don't know...but everybody...they all kept stopping...all in blue...they...they...they were all in blue...and err...they'd pause,*

*then they'd move off again...and erm...it...it...it was really quite balletic...err...so how near I was to that one I don't know...but it...it really did seem like secret filming...and it was the same distance, same members of staff...erm...that are about now...so...but I mean there were lots of silly things [...]*

The detail appeared to Janet to indicate the surveillance element of the work of the gaze and suggested that she had experienced a very tangible encounter with the medical gaze. She was able to make sense of the complex bio-semiotic construction of healthcare that played out in front of her through two metaphors, one of an airport control centre and the other as a choreographed film set. Perhaps her words “*lots of silly things*” were used to recognise behaviours she was unable to comprehend or contextualise? Janet’s account contained no particularly positive or negative elements. This suggested that this was for her a neutral experience, however during the interview Janet made a number of further statements that were pertinent to both her care and the quality of communication between her and the gaze. These comments convey a number of negative experiences and are detailed later.

Francis was recovering from a myocardial infarction and had his cardiac arrest under the intense gaze of the coronary care unit. Even though he was talking from his bed space in a standard ward area that is tasked with helping patients recover following their operation, he appeared acutely aware of the level surveillance he was under and that it was aimed at controlling his apparent deviance from the expected recovery pathway.

*[...] err...and they are tracking me down this very minute I expect, sniffer dogs probably all at the ready (laughs). Yeah.*

In a later section from his interview, in discussing his operation, Francis inadvertently provided a direct reference to the spatial placement for the conduct of the surgical intervention that is the specialist work upon his body and included the elevated social status of the physician in his comments, all of which closely matched the post-modernist Foucauldian premise of the medical gaze.

*[...] I have tremendous support from all the people who have worked on my body...err...the chap that tried to err...open up the arteries down the leg, is a very well known err...London surgeon, vascular surgeon [...]*

Eddie, who had been admitted for elective surgery to bypass his diseased coronary arteries, was another patient who demonstrated awareness of the gaze. In the passage below he recollected his thoughts and feelings about his second cardiac arrest. His words suggested that he had insight into technical abilities of the electronic monitoring systems that are routinely placed in a high-dependency clinical area and belief in the efficacy of the hospital panopticon. Eddie was certain that the surveillance equipment was sufficiently refined that it would have been able to pinpoint the exact moment that his cardiac arrest occurred.

*[...] the one single memory I will say, I can't recall the times, I'm sure there are factual recordings of the times but...err...if the last attack was about three-thirty-ish, I believe...and I went through until about nine o'clock before I saw a particular doctor here, anaesthetist, senior doctor...erm...and in that time I was conscious all the time and awake and the thoughts I had in my head were one of absolute desperation [...]*

Whilst being fearful of having further cardiac arrests, Eddie indicated his confidence in the ability of the clinical gaze to safeguard him and he appeared comforted by the specific circumstances of hospital where he was recovering. In the construction of an intense safety surveillance system, the gaze had organised specialist hospital space, populated by a highly regarded body of clinical expertise to conduct the necessary regulatory work of healthcare.

*[...] I was in a high-dependency unit in the middle of a top hospital and heaven forbid if something else happened again then I was in the right place [...]*

Eddie identified that his familiarity with the clinical space positively influenced his perception of the safety of the environment and that the recognition and rapport he had established with many of the clinical actors who were positioned within the safe spaces of the gaze provided him with comfort and security.

*[...] and I came round then and I recognise where I was at that time, because I had been here for a few days anyway, so I was very familiar that I was in the ICU department and I was familiar with the people looking at me and dealing with me [...]*

However, In Eddie's account of his recovery, his apparent unrelenting faith in the security and reliability of the clinical gaze began to diminish as the interview progressed. He started to question the gaze as he realised that the efficacy of the panopticon contained flaws.

*[...] in the sense that the first attack was on Monday and the medical team looking after me were completely puzzled as to what had happened, it didn't make sense, you know, everything had gone extremely well for three or four days following the op and for me to suddenly deteriorate and have an attack like that...obviously there was a fundamental problem there somewhere [...]*

Janet was able to provide an almost perfect summary of the critical constituents of the hospital gaze and what she saw as the benefits to herself and other patients. Whilst doing so she was appreciative of both the exceptional and mundane components and she was even able to acknowledge the important part that research plays within the gaze.

*[...] You, you've got the...all the facilities and the research and the brilliant things going on, people who are really sick an all...erm, and that of course is a marvelous thing. Ah, then you the...ah...more mundane sort of problems where people come in and go pacemaker, or, are only in for a day or, day or three...you know...erm they'll go out again...and the nursing though is brilliant [...]*

The next section of this chapter takes into account the patients views of their forthcoming discharge from the hospital gaze and their main recovery goal – the return home and a return to normal life, away from the intrusion of the clinical gaze.

### 6.1.1 Panopticons without walls

In chapter five, there were patients who were keen to escape the attention of the clinical gaze and were not unduly perturbed when considering their return home to the embrace of the gaze of their host community. There were others who clearly expressed anxieties and fears about their potential vulnerability consequential to their disease and a perceived risk of having a further cardiac arrest.

There was one patient who portrayed an almost complete belief in the safety of the extended clinical gaze. Sanjay was interviewed the day after his cardiac arrest and during his interview his general demeanour and emotional status indicated that he was overwhelmed to have survived the event. Unsurprisingly he was positive about the medical work that had been conducted on his body from the moment that which he collapsed at his yoga class, right up to the present point within the interview. Even though the gaze was investigating a potential technological failure with his pacemaker, he clearly placed considerable faith in the work of the medical gaze and its availability to him at his point of need.

*[...] well look, I...I have to trust the doctors because they...they know...they know what's happening to me better than anyone else and erm...you have...you have...you have to...I think you have to have some sort of trust...that level of trust and you have to...I understand that they...they...they're here for you, but having said that I can still do what I want once it's in there, couple of months, three months, I can go back to normal [...]*

It was interesting to note the nature of the language that both Eddie and Janet had used when they were thinking about leaving the hospital. Janet, who expressed a very negative view towards the interference elements of the gaze, verbalised that she had felt like the 'Prisoner of Zenda' at times during her hospital stay, whereas Eddie, despite having demonstrated a largely positive view of the hospital gaze, also referred to a captivity status about his admission to hospital.



*[...] after, I believe it was three-days, the staff here were sufficiently impressed or pleased with my progress that they were talking about releasing me within a day or two, and that I actually achieved...they agreed to release me on the...I forgive the dates...erm...Sunday...Sunday's date?*

With regards to his readiness to leave the hospital and determine his own recovery pathway, Frances depicts a regulatory conflict between his intentions and those of the clinical gaze. Here Frances appears to reject the gaze and assert himself as a more effective agent in the regulation of his recovery and the important decisions about when he is ready to leave the hospital.

*Frances: and I don't see what the hell it's got to do with them, as to whether it takes me three weeks to get there or whether it takes me two months - I will get there.*

*KS: You are determined about that are you?*

*Frances: Yeah, yeah.*

*KS: Do you consider saying to folks, you know, the interventional folks...I need to do this in my own time?*

*Frances: Do I?*

*KS: Do you...does it ever occur to you to say to them...*

*Frances: yeah, but you offend them.*

*KS: Well, do you?*

*Frances: Well, I know...I couldn't care less...I'm afraid.*

Whilst demonstrating her disquiet with the manner in which her discharge planning had been handled, Janet took a similar contradictory position to that of the gaze when

discussing her impending discharge from the hospital. She seemed to be mindful of the continuing overt regulatory presence of the clinical gaze, a gaze that did not appear to her involve her at any point in the decision making process.

*[...] and for them to then say that I can't go home...erm, and if I do so I will have to remain in my bedroom, which is, is about the size of this room, until they approve the house to their satisfaction. Ah, either that or I stay here indefinitely...until they all got together and had a bit of a conflagration [...]*

Janet continued to elaborate on her position and displayed some distress at having been kept out of the picture, appearing powerless in the discussions as different elements of the hospital gaze attempted to determine what was best for Janet, whereas she had considerable belief in the abilities of her husband to provide the necessary support. During this part of the interview Janet appeared desperate to escape from the clutches of the hospital gaze, but as is seen in the second quotation from a few minutes later in the interview, she was also anxious about being visited in her home by agents of the gaze.

*Janet: you know...erm, I was sitting here crying my eyes out this morning...having changed it all again.*

*KS: right...*

*Janet: ...ah...and the nurses started trying to get hold of somebody during the day to see if they could...push things forward, but I can't go home until there's a complete care package for (inaudible)*

*KS: mmm*

*Janet: ...that care package, is fifty-three...has been married to me for fifty-three years, he knows to cook...*

*[...] but err...I am sorry I've got to get back to this...got people banging on the door and wanting to come in...see how old your carpets are...I mean...I...I feel it's a total intrusion [...]*

Stephen was less confident in his ability to regulate his own health seeking behaviours and was more comfortable with the expertise offered by the medical gaze. He had expressed anxieties about collapsing again, particularly in comparatively remote locations, such as a park (see chapter 4, section 4.2, page 91). His concerns were about being out of the surveillance range of the clinical gaze. However, Stephen was not entirely happy with the extended gaze and was puzzled at the insistence of the long arm of the hospital gaze that he attended a particular cardiac rehabilitation programme associated with the hospital where he was recovering, rather than one that was much more convenient for his personal situation.

*[...] So its it...I don't have to walk that far, its much further to walk to King's Heath, but that...that's just purely convenience really, more than anything else erm...and...err...the first...there was a young girl came in with all the leaflets about this action group thing and she said 'I'm from St Jude's' she said 'I'm...you should come to St Jude's this, 'cos this is really good' and she said 'in fact I could sign you up for it now if you agree', and I...I thought well...no, no, 'cos I don't...I don't know mmm...this has just been put on me and I don't know...I haven't taken any...anything into account...*

The hospital gaze appeared to have subtly pressurised Stephen into their particular rehabilitation programme, but as he indicated, the agents of the gaze did not give him sufficient time to think about the information that he had been provided. However, it did seem likely that he would comply with the request of the gaze and attend the cardiac rehabilitation clinic as directed.

Based upon his brother's experiences of the cardiac rehabilitation programme, Eddie appeared somewhat sceptical about the value of attending when he was being told about the necessity of his forthcoming surgery by his consultant.

*[...] explaining what happens after, setting up, telling me about the programme, giving me lots and lots of information and I've got to say been very helpful, very useful...I would say at the time, I wasn't too interested, I was too upset at having the procedure coming up that I really wasn't of the mind that I wanted to read and take it all in at that time [...]*

*[...] I've got a younger brother that had an almost identical operation eighteen months ago and he had spoken to me about the rehab and he was very cynical of it...erm...however, he did say, you know, the road to recovery is a change of lifestyle, you know, change of diet...change of...excuse me...bit of a change of attitude as well, and he said, by the time you get as far as their clinics they're a bit like, you know, a bit patronising and zumba-like, err...so I'll wait and see, I'll keep an open-mind, but yes I have had offers of help on that and I'll certainly take them up, yeah no problem. The two people that I actually met in the hospital were very helpful [...]*

Eddie's impressions of the extended clinical gaze in the form of the cardiac rehabilitation workshop suggested that the timing of the information about his postoperative recovery was not helpful to him as he contemplated undergoing heart surgery. Despite his brother's views and his misgivings about the information provided, Eddie indicated that he would attend the cardiac rehabilitation programme and comply with the overtures of the gaze.

In the research design, it was intended to explore the concept of a follow up clinic with patients recovering from cardiac arrest, which of course represented another extended arm of the clinical gaze, the following extract of the transcript from interview with Eddie was typical of the responses that patients elucidated.

*KS: to find out what you...what...what patient's views are...and if erm...you've spoken to me today for quite a bit of time...would you like...do you think when you do go home...an you, you know, you start to normalise, do you anticipate that you might want to speak to an expert, someone like me, at some point about what's happened to you?*

*Eddie: no, not really...*

*KS: really?*

*Eddie: No. I'd...rather...I'd rather clearly put it in the past if I felt that I'd made a full recovery.*

Sanjay, who laid his position out very clearly in his response to being questioned about attending a cardiac arrest follow up clinic, echoed Eddie's position almost identically.

*SM: now, because...because when I leave the hospital I'm fine, I wanna forget everything and I wanna go back to my normal life.*

Stephen was able to recognise the potential benefits of the follow-up clinic, but remained non-committal suggesting reluctance in participating in further activities associated with the extended clinical gaze.

*[...] you know, if you are...I think it's good to have follow-up things where people can sort of, 'how you getting on', blah, blah...this, you know and make you think of other things that you may need or how you're coping with it [...]*

By way of a complete contrast, at the time of their interviews, David and Colin both responded with a straight “no” when asked if they had been approached about enrolling onto a cardiac rehabilitation programme. None of the patients who were asked for their opinion as to whether they were likely to attend a post-cardiac arrest support clinic answered with a firm positive.

## **6.2 Communication and the clinical gaze**

Communication has been reported as a common contributor to patient harm, with almost forty-eight thousand events reported in a single year in England and Wales through the portal of the NHS National Reporting and Learning System (2014). For the

participants in this research the experience for them was not different and all of them recalled situations where communication failure occurred during their recovery period.

### **6.2.1. Knowledge of their cardiac arrest**

Another of the specific research questions that had been identified in the initial conceptualisation of the research protocol was to conduct an enquiry to discover if patients had actually been informed by a healthcare professional that their heart had effectively stopped. As a consequence of the methodological approach of using thematic analysis and constant comparison (Charmaz, 2000) a number of additional sub-themes emerged, which were grounded in the data. This had indicated that it would be valuable to understand the patients' experiences of being told about their cardiac arrest through the lens of the medical gaze. Who had informed them that their heart had stopped and which professional group amongst healthcare professionals had informed patients of their cardiac arrest?

Additionally, it was considered valuable to understand how the patients had reacted to knowing that their heart had stopped. What did they understand by the terminology of the medical gaze, were they given appropriate time to absorb and comprehend the situation? Did the occurrence of sudden cardiac arrest bring additional concerns, fears and anxieties, as limiting factors to the progress of their recovery? The third element, which was also part of the original concept, was to explore as to how being in possession of the knowledge that their heart had stopped affected or influenced how they planned to conduct their lives as they recovered.

No particular pattern emerged from the patients' accounts of their experiences when asked as to how they first came to learn that their hearts had temporarily stopped beating (if indeed they had been informed). From the fifteen patient accounts in the study, seven had not been informed of their heart arrest by healthcare professionals. From those seven, four patients reported that they had not been informed at all and had come to be aware of their cardiac arrest through participation in this research (Graham, David, Jose and Alice), two patients were informed by their life partner (Stephen and Gordon) and one learned from a close friend (Laura). Of the remaining eight patients, one was told his heart had stopped by the paramedic in the ambulance on the way to

hospital (Philip), three were informed by nursing staff involved in their immediate post resuscitation care (Wilfred, Eddie and Mike) and four were informed by doctors (Janet, Frances, Sanjay and Peter). Aspects of their experiences and how participants interpreted the information they received is presented in the remainder of this section of the chapter, commencing with those who were not well informed.

Graham's recollection was that he was actually informed that he had suffered a heart attack. He was told when he had just regained consciousness, perhaps at time when he was and was not in full possession of his cognitive faculties.

*Graham: I...I don't remember anything...I just remember waking up in here and being told what happened...*

*KS: and what were you told?*

*Graham: basically that I'd had a heart attack...*

It was clear that at this moment in the interview Graham was not fully cognisant of the fact that he had experienced a cardiac arrest and that his heart had stopped, even though he had previously talked about his wife finding him collapsed and that his son had placed him on the floor and conducted cardio-pulmonary resuscitation. Graham became clear that his heart had stopped as a consequence of the interview.

David, who had also not been explicitly informed of his cardiac arrest prior to the interview demonstrated misconceptions regarding the terms heart attack and cardiac arrest during the interview, which provided further evidence that without clear information and explanation, patients (as lay people) may struggle with the comprehension of the jargon of the gaze.

*KS: [...] we discussed earlier that you've had a cardiac arrest, I'm just interested in asking you a couple of questions about that...what do you understand that means, what's your understanding of the term 'cardiac arrest'?*

*David: well, that there's an obstruction that's erm...that's slowing things up, that's what I understand.*

*KS: OK and you know what it...it...cardiac arrest means that your heart stops...*

*David: yeah*

*KS: stops effectively working.*

*David: well, parts of the heart surely?*

*KS: no, all of it.*

*David: it's all of it is it?*

When directly questioned as to how he learned that his heart had effectively stopped beating, Stephen recounted that whilst he remembered being informed about his heart attack and the subsequent interventional procedures by the attendant clinicians, he thought it was his wife that had told him about his cardiac arrest.

*KS: And who...who told you that your heart had stopped?*

*Stephen: I think err...it was my wife...I think...err...because, as I say, once I got in here and went into the...whatever it was...operating theatre or room with whatever, I was told at the time err...it...it...you realise that you are...are having a heart attack and we're going to inje...in...err...put this stent in (coughs) to alleviate err...the blood clot and erm...but I didn't know anything about actually having gone [...]*

When asked about his thoughts about his heart having stopped a couple of times, Gordon indicated that like Stephen, he had learned this from his wife, but the transcript below indicates that he was not explicitly clear about the meaning of the term 'resuscitation', that is used widely within the clinical gaze and in the consent procedure for this research. It was felt necessary to explain the exact meaning of the word and the associated procedures to Gordon.



*Gordon: No, I mean I only knew about it afterwards when my wife told me...err...I still don't know when they say 'resuscitation' what it really means, whether they had to an artificial machine to be...err in place of the heart, I don't know, you see.*

*KS: oh, no, no, no, no...what I know of your resuscitation is that it was...it was short, both of them were quite short, they have to...they would...the most important thing that you do with resuscitation is chest compression...so they would...would have...healthcare staff would have been pushing on your chest, you may have seen it on the TV. They move your chest about that much and erm...they do that over and over again without stopping, at the same time they would have given you some drugs, like adrenaline...*

*Gordon: yeah*

*KS: and then your heart started again [...]*

As previously indicated in chapter four (section 4.1.1, page 75), Laura had awakened in the intensive care unit and had been told of the seriousness of events by her friend Sally, later in the interview Laura recounted how the medical gaze had communicated with her on the same matters.

*Laura: yeah...yeah, I mean if the doctor had come and explained that to me in the beginning, you know...that would have been good...but you know, nobody said anything.*

*KS: Did you have any thoughts to ask the nurses or the junior doctors what had happened to you?*

*LA: No, not really, no...*

*KS: And did...is that...*

*LA: I didn't actually feel up to it at the time...*

Laura wanted the information on her terms and at her convenience rather than at the behest of the clinical gaze. This was the approach that Philip took when he regained consciousness from his cardiac arrest. At his request, Philip received information that his heart had stopped from a paramedic that had attended him at the railway station where he had collapsed, but hadn't expected the direct bluntness of the language used to tell him.

*KS: [...] when I was...spoke to you yesterday you were already aware...people had told you that your heart had stopped...had...had...were you aware of that?*

*Philip: yeah, I kept...I'd sort of asked at some point and they said yes, more on the guy bluntly said 'you died on the platform at the station', now I don't know the truth of that but I mean I presume [...]*

Wilfred was one of three patients who learned of their collapse through communication from the nursing gaze and recalled his first thoughts when he regained consciousness whilst in the cardiac catheter suite. He remembered that he was distressed and that the staff present had attempted to pacify him, he also recollected that he had been told that he had collapsed, but not that his heart had actually stopped. On responding to the question about his collapse, he remarked.

*[...] Only that erm...that I had err a bad relapse in a way...that erm...and I think I panicked a little bit because they kept saying to me to...to...to calm down [...]*

His recollections had been somewhat vague and when questioned about what he thought about being told his heart had stopped Wilfred said “*Well, I...I only half-believed it*”.

Eddie has also been informed of his collapse by one of the nursing team, he had actually asked one the ward sister's to explain to him what had happened. Eddie's recollections of her description of the event indicated that again, the nursing gaze stopped short of telling him his heart had stopped.

*I asked her 'where was I found' and she said 'you were on your bed', and I said 'did I make a noise' and she said 'actually', she said, 'I was walking past and the guys in your room who were getting ready for the op, it was quiet' and she said 'all of a sudden your breathing changed...and then you stopped breathing and it is all hands to the deck...it was pandemonium'*

Mike had also been vaguely informed of his cardiac arrest by nurses working in the cardiac catheter laboratory, who, by Mike's recall, used the phrase '*you had...you had a very close call*' and had said to him '*but you look very healthy now*'. Mike discovered a little later that he had a cardiac arrest from his daughter.

Sanjay was one of four patients that had been informed of his cardiac arrest by the doctors providing his immediate care, but it didn't appear that this had been done in an entirely clear manner, but he had been able to work out that this is what had happened. As Sanjay had been previously fitted with a permanent pacemaker, he was sufficiently familiar with some of the medical terminology to make sense of this event. However, the medical gaze remained puzzled as to why this had occurred and had already indicated additional technological surveillance in the form of an implantable internal defibrillator might be necessary.

*Sanjay: [...] I've had a doctor come in err...to explain to me what happened and I...from what I make out, I had cardiac arrest but the...they can't understand why the pacemaker didn't jump in and he mentioned putting in another defibrillator just to spark the heart to...to get it going again [...]*

By way of a contrast, Frances was one of only two patients (the other was Janet) who had been overtly informed that their heart had stopped, not only did they tell him, the doctors also told his family. This may have been consequential to him receiving a 'do not attempt resuscitation order' following his last cardiac arrest. Open, inclusive and sensitive discussion with patients (and their families) is a requisite of national and local policy when the medical gaze enters into end of life care decisions with patients, but this was not discussed within the interview.

*KS: How do you know that your heart stopped, who told you?*

*Frances: The doctors*

*KS: The medical people here?*

*Frances: Yeah...yeah*

*KS: OK...and did they tell you...*

*Frances: and of course my...my family...*

Whilst Frances did not indicate at any point in the interview that this was in any way distressing to him or his family, he did express concern that he had survived three such events and posed a question as to the efficacy of the clinical gaze.

*[...] once is all right...three times is probably a bit more than should be expected of them, but err...they seem to have done it all very well [...]*

Janet explicitly recalled her experiences of regaining consciousness following her cardiac arrest and remembered finding it an unpleasant distressing experience, as illustrated by the following two abstracts from her interview.

*[...] I ended up falling out of my chair in the ward, I had to be revived by the doctor and my first memory of that is me screaming...on...on the floor, whilst a bunch of nurses tried to get me up off the floor onto the bed [...]*

*[...] there was a doctor present who...erm performed CPR...and I, I was just absolutely hysterical, I remember that...not at all nice [...]*

When directly questioned about how he felt about having had a cardiac arrest Frances' response was very interesting as he was the only patient to express a view as to what it had actually felt like to die.

*KS: and err...err did you feel anything...anything at all, you know, in the knowledge that your heart stopped, does that make you, what does that make you think about?*

*Frances: Not really, very...if that was it, it was a very pleasant death...painless...unaware of...although I'm glad it's not, glad I'm 'ere.*

The account of how each patient became to be informed of their cardiac arrest and their thoughts, fears and anxieties has provided much to ponder, all of it consequential to the considerable variation in the seemingly *ad hoc* communication strategies employed by the clinical gaze. The next section of the chapter looks more closely at patients' experiences of the two main agents of the clinical gaze involved in their recovery journey, the nurses and the doctors.

## **6.2.2 Experiencing the nursing gaze**

In his interview, David made very poignant, single line comment that seemed to summarise his entire experience of the nursing gaze when he said, "*I pressed the nurse button and again, nurse wasn't terribly pleased*". This was an un-solicited comment that illustrated David's perceptions of the nursing role within the medical gaze that may have acted as a signifier to the lack of patient-centred compassionate care to a vulnerable patient in the acute phase of recovery.

David had also described his unpleasant experiences of being under the intense gaze of the ICU, but his unease was not framed by the direct care or medical interventions conducted upon his body. He had become disturbed by the nature of the interactive behaviour of staff in the ICU.

*KS: What happened at St Anne's?*

*DJ: Oh my goodness it was erm...everything was fine during the day, at nights there were real problems with security and security staff.*

*KS: What sort of problems?*

*DJ: Oh arguments and erm...yeah and daytime staff wanting nighttime staff to finish things off and there was...there was a lot of friction there yeah. So when I was brought here, it was so different, you know, totally different.*

David's experience was not unique. Communication issues appeared as a frequent problem for patients and related to all aspects of care and professional behaviours that were played out in the direct gaze of the patient.

The quotation highlighted below was taken verbatim directly from the transcript of the interview with Janet. Within her five lines of speech Janet identified a potentially serious nursing care quality issue, which raised a serious question about professional nursing behaviour and with it a question as to how effective the regulation of the nursing gaze is conducted. This patient's personal experience of care offered an unintentional window into an otherwise closed experience that would not have been unveiled if it were not for the research inquiry. The lack of caring behaviours exemplified in Janet's account of her experiences represents a serious flaw in the nursing panopticon in that it would appear that the mechanisms of surveillance through the regulatory function of professional codes of conduct have failed, at least momentarily (Freshwater, 2013).

*Janet ...but, I, erm, it just adds to the general misery when you're hanging upside down in a bed, while somebody says 'I can't lift you, what are we gonna do now?' Erm, and that has been a great source of misery to me.*

*KS: Could you, would you be able to expand on that a little, about why, why did you feel, you know, you've used the word 'misery', why was that miserable for you?*

*Janet: Well, they are standing there saying 'Get over', and insisting that you pull yourself up on the bed, I mean I've got this, erm, this is still fairly fresh, this pacemaker [...]*

Janet went further and recalled a similar situation where she again experienced the flawed nursing gaze, this time with a psychological element that had engendered a genuine fear and reticence to call for help at a point where she required a little help her physical positioning.

*Janet: erm...you know...and I was almost afraid to ring the bell for a nurse if I wanted one...you know...cos they would say...'get yourself out of bed', I couldn't get myself out of bed, otherwise I would have gone where I wanted to go...you know...*

*KS: yeah.*

*Janet:...but erm, it sounds petty and I apologised to the nursing staff, but erm...you've got an awful job and, and it's a mucky, horrible job at times.*

Despite the apparent reluctance and inadequacy to provide basic nursing care, Janet ably appreciated the unpleasantness that aspects of body work can bring to agents of the clinical gaze when it becomes necessary. In doing so, Janet reached out to apologetically explain to the gaze that she understood that their work is often dirty and that she felt a level of guilt for being temporarily unable to attend to her own personal hygiene needs.

Francis made a similar assessment to that made by Janet, although he had taken a largely positive view towards the work of the gaze in that it had provided his medical and nursing care safely. Again the unpleasantness of body work was mentioned, but this time it was viewed as a less valuable, hierarchical task, which Francis suggested was conducted less than effectively by those at the lower end of the command chain within nursing.

*[...] Well, the really good are the people that are obviously on top of their work, they know exactly what they think they are going to do and why they are going to do it, they don't mess around and unfortunately that doesn't always apply to the whole menial nasty jobs that have to be done by the lower caste...not very pleasant wiping somebody's bum for them...err, but it's as important I suppose...at the end of the day [...]*

Francis was an articulate man and used open and direct language in the interview and as can be seen he was not wholly complementary about his interactions with the nursing gaze, and earlier in the interview, when considering the variability of his care experiences he remarked that “Some of it is brilliant and some of it is piss poor”. The

variability in care delivery and patient engagement that Francis alluded to was, as a general point, reflective of the experiences that patients endured during their recovery.

Philip talked about the benefit to his recovery that is found from establishing a rapport with nursing staff, as a provision of psychological comfort and safety that would be achievable if there was better rostering of staff. Philip was clearly disappointed that the continuity in his care and the developing rapport with nursing staff had been broken by a system that doesn't seem to understand that these relationships have a positive effect on patients. Establishing a position of trust between patients and nursing staff is likely to bring additional benefits in terms of help in further strengthening of the patient's developing sense of coherence, which may more effectively move them towards a position of independent health.

*Philip: [...] I would have an issue with the frequency of change, I know that...*

*KS: frequency of change?*

*Philip : you...you...well, one builds a rapport perhaps with a couple of nurses, they are on the following night and they're actually on a different ward and you think well, why do that? Why not this, at least build some continuity because when you're in this environment you are looking for comfort, you know, and a familiar face is a comforting face, you know, this was the girl from last night, she was kind to me last night, she'd, you know and so forth and then you find that she's working next door...I find that disappointing*

Developing this point further, Gordon also provided insights into the variability of nursing care, based upon his protracted recovery period, a good part of which was spent lying on his hospital bed. In Gordon's summary of his care he was very able to identify a lack of personal attention to his specific needs. The nursing gaze appeared to be focussed on its own system, its task burdens and the demands of the medical gaze. Whilst there has to be a systematic approach, this is not conducive to the provision of patient-centred compassionate care.



*Gordon: So, there's help. I mean they all do their best here...erm...the care is alright, sometimes the agency workers aren't as good as the normal, regular staff...*

*KS: How do you...how do you make that judgement, in what way are they not as good?*

*Gordon: Well, you get some really rough ones...rough...*

*KS: Rough?*

*Gordon: rough and...*

*KS: How do you know they are rough, in the way they talk or the way they...?*

*Gordon: yeah, I mean...the way they talk, they are unsympathetic, you know...err not friendly and err...they don't like you questioning them, for example...one day if I get six tablets, next day I get eight, ten tablets, I say, you know...they don't like you questioning it err...and they are answering it 'if you are not happy when the doctor came on their rounds you should have told him', I said, 'how can I tell him 'cos I didn't know how many tablets they were going to give me', you see...that's the kind of thing they...they indirectly avoid the question and you know they are avoiding the question so what's the point in carrying on? [...]*

Graham also commented on the variation on nursing care that he had experienced and suggested that there were those who were solely focussed on the work of the gaze, whereas others were able to do so whilst communicating with him more as a person within a recovery framework.

*[...] there's a few nurses here, very good...some they do their job, efficient, that's it...but they're not interested in the small talk, it's a case of, they're in, do what they've got to do and go...some of them come in, chat to you, tell you what they are doing...what each...what each thing they're putting in you, no problem [...]*

Graham spoke at length about his current recovery experiences and compared them to those he had encountered when recovering from his cancer surgery during the previous year.

*Graham: you don't want all these automatons that are just here...*

*KS: yeah*

*Graham: to earn their money, do the job, all right they give a certain amount of care, but they are only here to administer the medicine to look after the person as...to the limit, but without interaction...*

In concluding this section of the chapter, Philip was very able to convey his thoughts and feelings regarding the importance of compassionate nursing care when recovering from life-threatening illness and disease.

*Philip: [...] and I think when you are in this sort of relationship here, you are almost a child again...*

*KS: do you feel vulnerable?*

*Philip: Well, you're vulnerable, oh Christ, I had tears because of what has happened family wise and so forth, at the same time you are on drugs...yeah, you are vulnerable and it can be a bit tearful...*

*KS: uhum*

*Philip: you know, and people reach out for you. I mean certain nurses have reached out, yeah...*

### 6.2.3 The medical gaze, communication and the ward round

The next section contains a representative sample of patient experiences covering a range of communication situations with medical staff. The participants provided a particularly informative and interesting view of the direct interactions and consultations with the medical gaze. The long-established framework and structure of the ward round featured prominently in their dialogue.

David, who had collapsed in cardiac arrest as he was leaving an underground station and following his successful resuscitation he was admitted to an intensive care unit (ICU). In his recollections of his recovery care, he alluded to a specific interventional treatment encounter that for him identified the well-intentioned, but paternalistic demeanour of the clinical gaze.

*David: Yeah, well the problems are erm...two or three-fold...erm...I had a angiogram yesterday and oddly enough err...I was expecting it to be something else, not an angiogram and I thought they were going to remove these tubes from my face, erm...but of course when I got down to the...their department they just made it clear; this is what we're going to do, we're going to put some fluid in your body, we're going to scan your heart to see if there are any problems and...fine, OK err...I was quite excited about it until it started and I could see...at times I could on the screen what they were doing...*

*KS: mmm*

*David: and they were passing needles into my body...*

*KS: yeah*

*David: and I could see these on the screen and it was...it was a bit scary to be honest [...]*

In this example it appeared that David had received inaccurate information regarding the nature of the work of the gaze upon and inside his body, furthermore he

was presented with access to the active instrumentation of his body, perhaps without appropriate consultation, explanation and safeguarding?

As with all participants in the study, Wilfred was asked to comment on his experiences of communicating with the doctors and nurses and he appeared keen to respond positively and that he felt informed, however, in the extract from his interview he very quickly moved onto to describe a situation that he had experienced that morning where there had been an important information miss-match. He was being fasted for a procedure and the nursing staff in the ward at the time did not appear to know this.

*Wilfred: Oh yes...oh yes, because like...like this morning I wasn't sure what was going on, when the doctor come in I said "doctor I understand that I'm on a...on a...fast". He said "oh yes, they should have told you that at (unintelligible word)"...He said "it's not your fault", he said, "They should have told you that last night"...I said "if they had told me", I said then I...would...I would have expected it and would have known what to do...but even...even the nurse that...that...I don't think she realised that at the time, because she came up earlier on to gi...to give me dinner...a couple of hours ago...I said "I'm sorry nurse", I said...I said "I don't think I'm going to eat that", she said "what do you mean Mr Wilson"...I said "I'm on a fast day... yeah...from this morning"..."Oh" she said..."Don't touch it, I'll find out about it" and she went out and she came back and took it straight off me...*

This represented a potential patient safety issue, which appeared to have arisen from a simple communication failure. Fortunately Wilfred had temporarily included himself in the safeguarding activities of the clinical gaze and provided the nursing staff with a timely reminder.

When directly asked about his experiences of communicating with the medical gaze, David was again eloquent in demonstrating his understanding of his position within the structure of the medical gaze and the importance of being compliant with the paternalistic directives of the gaze.

*[...] Well, its the same kind of information erm...they've obviously got their information from the same source and you know, they've stressed 'hang on, look', you know, you had a bad accident, you know, you've got to be careful, you've got to take it easy, you got to do what we tell you to do, there's no ignoring erm...machines like this [...]*

The communication difficulties experienced by patients were common in the participants' experiences of recovery. Eddie recalled a conversation with a member of the medical team who was at that time responsible for his on-going well being. The doctor assured Eddie that if he (Eddie) were to suffer a further cardiac arrest he was certain that successful resuscitation was highly likely. Despite his previous feelings of "absolute desperation", Eddie articulated his faith in the gaze at this point. He had been re-assured that the knowledge and skills of the gaze were infallible and that should the need arise, the work of resuscitation and the use of a defibrillator on his body was bound to be successful and that he would undoubtedly survive the event.

*[...] whereas by nine-ish in the morning speaking to another doctor, he basically reassured me that with the equipment there that ninety-nine point nine percent of the time they were going to bring me back each and every time...erm...so it not as if I was actually going to leave this planet and die [...]*

Eddie had also experienced very positive elements of care in his immediate recovery as is described in the following extract from his interview where he talked about the support he received following a ward round shortly after his second cardiac arrest.

*[...] say there half-a-dozen people there...erm...a couple of them were talking to me constantly I think, especially one particular person, trying to comfort me and keep me sane, if you like [...]*

When directly questioned as to whether there was benefit to him of hearing a comforting voice when coming out of a period of unconsciousness Eddie was very clear in articulating that such an approach had been helpful whilst indicating that he would have favoured confident directives.

*Yes, I think so because you fff...I felt so absolutely isolated, that...you know, to have any reassuring voice or friendly voice, you know, soothing you was of benefit...erm...I think I would have preferred somebody that could have said 'right, we're going to do this and you will be alright now', but wasn't going to happen and I was sufficiently alert enough to know what had happened to me and realise, my God, this is my second heart attack in two days [...]*

During the conduct of the research interviews the perennially difficult issue of end-of life care planning and do not attempt cardio-pulmonary resuscitation (DNACPR) orders arose only once. Interestingly, it was not raised by the one individual (Frances) that had an active DNACPR order recorded in his medical notes, it was raised by Janet. The extract from the transcription below took place in the context of a discussion between Janet and a senior medical doctor regarding her on-going medical treatment.

*[...] but as I say...I forget who it was...one of the very senior doctors I was talking to at the time...and he arrgh...I got a lecture on the subject...err...but there's no point in us going ahead doing this if you're not going to co-operate...and that wasn't what I was saying at all [...]*

This short passage of dialogue contained much that was of concern as it represented a patient's genuine and very real experience of the medical model of communication. In this instance the gaze is paternalistic in its apparent disregard of the patient's right to meaningful, open and transparent dialogue. The agent of the medical gaze appeared to only see the therapeutic task that lies ahead rather than the whole person. The reaction of the doctor here appears as a metaphor for dealing with seemingly non-compliant patients, or individuals who dare to question the superiority of the medical gaze in its functional role of moderating medico-social deviance.

Unfortunately, in Janet's experience this was not the only example of the limited disclosure of information within communications between her and the medical team. This short section of dialogue from Janet's interview brings into play the uncomfortable question of the validity of informed consent and the provision of permission to conduct the invasive work on the body of the patient. It would seem that Janet only partially

consented to have undergone the minimally invasive heart valve surgery, as she was not in possession of the full knowledge of the facts.

*[...] the TAVI's don't last all that long anyway...which was something nobody had told me!*

In the following lengthy extract from Stephen's interview, he talks about his experiences of trying to comprehend the complexity of what has happened to him whilst contemplating what the clinical gaze will do to assist him in the monitoring of his recovery as he moves from the more intense gaze of the in-hospital panopticon towards the comparatively low-level surveillance conducted within the gaze of primary care.

*[...] err...on the first...on the first day...and they say...err...and do you know, 'do you smoke?', 'Yes', 'well you won't be doing that anymore, you're going to be on a lot of tablets'...(coughs) 'probably for the rest of your life' hmm...erm...err...and you hear all this stuff and you...you don't know what to say to them...you...you've got to take it all in, so...whereas normally I would have questions I'd want to fire back...erm...it's always like the next day or later on after they've gone and I think 'why didn't I ask them that', 'why didn't I ask them this'. It...it...it's just too much information all at once...erm...and then you have time to digest it and then you think, 'oh well how's that going to affect that and this, that and the other?'...I assu...assume that something is going to happen later on...once you get back to your GP or when you get called back here in six weeks time...I mean you'll obviously be told what tablets you have erm...but I sort of feel...although, even when you...I suppose at any time...I could ask any of the sisters here and say, well what, you know...what actually caused it to happen? What...so, what's going happen this and it erm...err...this lady's gent...err...this lady's husband over there...she erm...asked...no it wasn't her...it was...on the other bed...asked one of the sisters and she was really nice, she actually spent time listening to everything and answering every single question and adding to whatever she thought was relevant so, from what I've seen, it's...it's very, very good...erm [...]*

In this passage Stephen expressed his anxieties about the quantity of information given to him, which may indicate that the communication work of the medical gaze, in

this instance, appeared to have overwhelmed him. He stated that he did not feel that he had sufficient time to make sense of the things that he had been told and been unable to adequately formulate his necessary questions within the time frame apportioned by the gaze in its consultation with him.

Stephen appreciated the input that the nursing gaze had provided, they were attentive to his psychological needs as they took the time to answer his concerns and provide information about his on-going recovery journey once he had left the relative security of the in-hospital gaze. In the context of contemporary nursing gaze (NHS England, 2012) Stephen may have considered that he received compassionate care.

Eddie, who was recovering from elective coronary artery bypass surgery and two cardiac arrests, was able to articulate his feelings about the consultations that the medical team conducted with him during wards rounds that were undertaken during his post-operative recovery period.

*The language they use and actually doing it, both things...erm...you know the tendency is...from a non-medical person, that err...you have something that is probably the most significant issue of your life medically and you're laying there in the bed and there's three, four, five people discussing you and your case and what's going to happen...a) they are not talking to you, they're talking about you...b) they are talking in terms that don't really make a lot of sense, because you are not a medical person, then they turn round and said 'you're doing very well' and just shuffle off to the next patient. Now, obviously most people, me included, ask them particular questions in plain English, you know...what is my position and to be fair they have generally been happy to do that, I'm not saying that there hasn't been but it's almost been a reluctance to do it unless one asks, which I find disappointing [...]*

At one point in the interview Eddie reflected upon a particularly poignant moment where he registered his displeasure with the demeanour of a particular medical person during an interaction with the medical gaze.



*[...] what I find more difficult is somebody that actually looks into a life and death matter and confirms there is no problem, it's exactly as he'd find and then have rather a flippant attitude at the angiogram, that's what I personally find most disappointing...yeah...it may not be so significant to them, but if it was their body that was on the line I think they might have a different view [...]*

Philip was another participant who had much to say about the critically important interactions between himself and the agents of the gaze during the ward round. Philip had previously experienced a serious encounter with the medical gaze and had undergone a surgical repair to an aneurysm of his abdominal aorta, which may have better prepared him for the challenging interactions with the gaze.

*Philip: when one is dealing with the doctors and the consultants...I don't feel that you can comfortably ask those questions on a one-to-one, to get that feedback. Now it may well be that most people don't give a damn, well maybe I'm just me (laughs)...but I like to know what...and I felt...you get a group...*

*KS: mmm*

*Philip: and one says something and the other one says 'are you're doing well?' and the next one says 'oh, err...no' and compares his notes and said 'we did this to him and that to him' and I've got, some perhaps some very simple, basic questions I want to ask...*

*KS: mmm*

*Philip: and I don't feel I can make that connection with whoever it is that comes round*

Within the structure of the interview, Philip was directly asked how he might prefer the communications of the gaze to be conducted and his answer was succinct.

*I just want one person to say you know [...]. I would have liked to have sat down with the consultant...and said 'right, let's just have a little chat, can we?'*

In wanting to talk directly with his senior doctor, Philip's frustrations were framed by being unable to engage in such a consultation and his experience was in contrast with his relationship with the nurses who provided his post-operative recovery care.

Gordon continues the theme of challenging, ineffective communication, based upon a lack of continuity of care between the medical agents of the gaze (the surgical team) and himself. He raised his perceptual notion that a group of doctors who are strangers to him cannot be knowledgeable about the circumstances of his recovery. Furthermore, Gordon and his wife were demonstrably angry about the paternalistic approach of his surgical team. Firstly, Gordon's account indicated that there were inconsistencies in decision-making between different surgical teams. Secondly, the language that Gordon used suggested that during the ward round the senior surgeon talked over him and the senior surgeon failed to make any attempt to obtain an opinion from Gordon (or his wife) when discussing the need to accelerate his discharge home.

*Gordon: [...] there's a lack of communication here...*

*KS: OK*

*Gordon: Lack...lack of communication in a sense that you've got say, one team of doctors come in the morning, who know nothing about anything about my case...err...and it happens time and time again you see and as I told you earlier the...the top err...erm...I'm not sure what his designation is...erm...but...a Mister...can't remember his name, he came in on Friday and basically he said 'what is he doing here?' he just looked at this, so he said 'he shouldn't be here, he's fit enough to go'...and that was the conclusion on the Friday, so I was going on the Saturday and my wife wasn't too happy about all this, she looked at me and said 'I'm not happy about this, I'm going to make a complaint about this, I want somebody else to see it'...*

A little later in his interview Gordon returned to the theme of his interaction with the senior surgeon and was clearly aware of the contradictory nature of the communication of the medical gaze, nevertheless, he felt re-assured.

*[...] so err...I mean a couple of days ago when the doctors team came here after...this is after Dr Green said I should be out of the premises, he said, whatever we do...he said, you've been an excellent patient and we will make sure that you are completely fit before you leave the place, I mean that is reassuring [...]*

In a clear link between the inconsistencies and the inadequate communication that he had experienced, his strong sense of coherence compelled Gordon to consider how he might best strategically intervene in the work of the gaze, in order to return to a healthy state.

*Gordon: [...] I don't give up, because if I think even the specialist is wrong I will somehow or other circumvent it...*

*KS: mmm*

*Gordon: you know...erm...and go somewhere else and get another opinion and then somebody else will come and tell me, 'yes, we will do this test, this test, well it was only yesterday that I had this test done [...]*

Contrary to others' experiences, both Mike and Wilfred had both experienced very positive and inclusive interactions with the medical gaze during the ward round. Wilfred recognised his own limitations in his understanding of what was happening to him, but he had felt that the medical staff had taken appropriate steps to explain procedures to him. He also remarked elsewhere in the interview that his daughter had been a very helpful advocate in this respect.

*Wilfred: [...] erm...I'm not sure about that...I think...I think...I think they...they are trying to explain things to me, only I'm...unfortunately I'm very, very slow at picking things up, but I believe they know that as well...*

*KS: Right...*

*Wilfred: ...because sometimes they try...they say something for me and I say "err...how do you mean doc...doc?" and he go through a full gram...diagram of it [...]*

Mike talked of his positive experiences of communication with the medical gaze during the ward round, he found the doctors inclusive and patient-centred.

*KS: So you've...you've found that when the doctors have been here, sort of talking, they talk directly to you and they ask you...*

*Mike: straight, look at you...look at you and ask you straight*

*KS: do you feel been involved?*

*Mike: yes*

*KS: right...and the decisions?*

*Mike: it's...it's, to me they're talking, not the four people that's with them...*

The experiences of the patients that were represented in this chapter clearly indicated considerable variability in how the clinical gaze approached the recovery of patients. The detailed personal accounts that were analysed in the study suggested that the recovery process was principally structured around the operational workings of the medical gaze, which demanded a significant level of compliance with that operational framework.

Improvement in the nature of communication between patients and the professional membership of the clinical gaze are necessary to enhance the quality of the recovery process. It would appear highly likely that taking a more inclusive approach that seeks genuine active engagement with patients would improve the planning of bespoke recovery experiences for patients.

Mindfulness and close attention to the psychological aspects of the effects of cardiac arrest coupled with a holistic focus on the well being of patients would appear to add additional value to the recovery experience, especially if that included helping the patient to build the strength of their sense of coherence early in the existential phase of recovery. This would then help them to develop their recovery milestones (as positive assets) which then move them more effectively towards a position of restored or regained health.

Optimisation of the key elements of the clinical gaze – the technological factors, the environmental factors and the professional expertise, developed to an extent where the risk of failure is at an absolute minimum would ensure that patients experience a smooth, person-centred recovery where cardiac arrest becomes a rare occurrence.

During the interview with Gordon a point was reached, about two-thirds of the way through, where Gordon had made a number of intimations (including those contained within this chapter) that suggested that both he and his wife were not at all happy with the stated plans of the medical gaze. Despite the reassurances that had been provided to him by senior agents of the medical gaze that he would remain within the hospital gaze until completely recovered, there were others, equally senior, who had felt it would be appropriate to discharge Gordon from the hospital gaze much earlier and transfer him into the extended gaze of community care, where a district nurse could visit him to provide the intravenous antibiotics that he required for a prolonged period. Both Gordon and his wife had felt this was inappropriate and had been demonstrably angry at such a suggestion.

As the research interview was taking place, four surgeons, dressed in their operating clothing, appeared at Gordon's bedside. The most senior member of the team identified himself to Gordon (but not to me as I hastily paused my recording device) and proceeded to discuss Gordon's medical situation with the other three members of the team, occasionally looking across the bed to acknowledge Gordon's presence as he lay in his bed. Gordon had ample opportunity to raise his concerns about the discharge plan with his medical team, but instead he appeared entirely passive.

During this encounter, I had felt significantly challenged in my role as a researcher as normally I would have acted in accordance with my professional guidance, utilising my knowledge of the patient's previously declared position and intervened in the consultation to present the medical personnel with the patients position, in the best interests of the patient. The reason I chose not to intervene was framed by not been able to discuss this in advance with Gordon.

The situation that had arisen from being in a dual role as a researcher first and a nurse second left me feeling significantly challenged and professionally compromised with regard to my duty of care to the patient. Consequently, the issue of insider research will be discussed more fully in the next section of the dissertation.

## Chapter 7. Discussion

### 7.0 Introduction

This study takes a social constructivist, naturalistic epistemological position to report the recovery experiences of people who were recovering from cardiac arrest. The key findings were detailed in the three preceding chapters and the task of this discussion is to integrate those findings with the existing body of literature discussed and describe the emergent thesis, supported by the theoretical frameworks. The principal research question was to gain an understanding of what patients actually experienced during the in-hospital period of recovery following survival from cardiac arrest. The use of open unstructured interviews enabled the interviewees to reveal their worries, fears and anxieties that were consequential to their personal experience of acute illness.

The literature review revealed a very limited understanding of what patients experienced during their recovery from cardiac arrest. Firstly, whilst noting the exception of the work Bremer, Dahlberg and Sandman (2009) and Prinjha, Field and Rowan (2009), the patient's voice has not been addressed. Secondly, the majority of published literature regarding recovery from cardiac arrest was focussed on outcome measures determined by the positivist, paternalistic demeanour of the medical gaze. Thirdly, with the exception of the work of Parnia and colleagues (2014) the literature reflected a deficit model that only appeared to consider deleterious and debilitating outcomes. Furthermore, the literature was framed by a significant confirmation bias in that the focus of investigative attention was placed upon those patients with a CPC score of 3 or 4 (as a reflection of poor neurological survival) whereas contemporary national data sources indicated that the incidence of serious neurological injury was very low, being 2.5% in survivors from in-hospital cardiac arrest (Nolan et al, 2014) and 6% in survivors from out-of-hospital cardiac arrest (Stromsoe, 2013). This study has reported the recovery experiences of a group of patients, who proportionally represent the majority of patients who recover from cardiac arrest (94 - 97.5%) that have CPC scores of 1 or 2.

A further limitation of the current evidence base was in the timing of the data capture as the majority of the evidence had been acquired from the patient long after they had left hospital. In this study the data was acquired exclusively from patients whilst they were immersed in the experience of recovering from cardiac arrest as in-patients in the hospital. Accordingly, it has provided a unique perspective and considerable insight into the experience of recovery whilst providing a previously unheard voice to the patient.

The thesis contains two major elements that develops and supplements the work of Bremer, Dahlberg and Sandman (2009), Elliott et al. (2011) and Wilder-Schaff et al. (2013). The first element is concerned with three phases of recovery experienced by patients and the second being the interaction, integration and influence that the medical gaze had upon the each of the three phases of the recovery. In order to construct the emergent thesis, it was necessary to go beyond the limitations of the extant survival literature and align the findings with the sense of coherence work of Antonovsky (1996) and the seminal work of Foucault's on the medical gaze (1973) and panopticism (1977).

The three phases of the patient's in-hospital recovery journey were characterised by the emergence of three overlapping stages that began with a period of existential crisis (usually of short duration) that commenced as they first regained consciousness. This seemed to trigger the second stage, which appeared as a search for coherence that persisted throughout the recovery period and enabled the patient to make sense of what had happened to them through information seeking (often provided by those present at the event and / or others well placed to help). This was particularly helpful to them to fill the memory gap that resulted from their period of unconsciousness. However, the search for coherence was not limited to those issues pertaining to unconsciousness, it continued throughout the recovery period as a response to the fluctuating dynamics of the situation that included positive and negative influences upon their anticipated recovery trajectory. This finding concurs with the systematic review conducted by Wilder-Schaff and colleagues (2013) who took a view that psychological disturbances in cardiac arrest survivors persisted throughout the recovery period.

During their search for coherence patients utilised structured coping strategies, which incorporated the third recovery stage, that being the identification of recovery



milestones. This process helped them to move away from the existential crisis, through a coherence phase towards their anticipated and planned recovery state, a return to their normal life. For purposes of clarity and explanation the three over-lapping recovery phases have been delineated in the first three sections of this discussion chapter.

The second element within the thesis was the critical role that was played by the local healthcare system as a medical panopticon and how it observed, interacted and influenced each of the stages of recovery experienced by the patient. The care interface between the patient and the inter-disciplinary, multi-professional healthcare personnel was viewed through the Foucauldian lens of the medical gaze (Foucault, 1973) and that of panopticism (Foucault, 1977). The narrative accounts of the informants in this study indicated their active determination to successfully recover, however those very accounts reflected a significant and important dissonance between the patient and the clinician. In the context of contemporary approaches to healthcare, listening and being attentive to the patient narrative and providing a bespoke, holistic response could be perceived as compassionate, person-centred care, perhaps exemplified by 6 C's campaign, championed the Chief Nurse of England (Department of Health, 2012). The patient experiences recounted in this research suggested that healthcare professionals, as agents of the medical gaze are currently a long way from achieving this.

The latter section of this chapter discusses the challenges that were presented to me as an experienced and senior healthcare professional whilst being placed in an insider role, as a clinician in a research (outsider) role, conducting the research amongst a group of vulnerable patients recovering from cardiac arrest. The chapter also includes a discussion regarding the introduction of the therapeutic interventions, including a novel patient-centred approach, which was considered necessary as a direct consequence of the research findings. Finally, the limitations of the study and its findings are elucidated with a view to how further research might be best directed.

## **7.1 Phase 1 - existential crisis**

The findings indicated that all of the participants in the study experienced feelings of existential vulnerability, disorientation and cognitive panic in the immediate period of recovery following their return to consciousness. Within this very early phase of

recovery patients reported a powerful feeling of disbelief as to what had happened to them alongside a feeling of guilt and a responsibility towards what had happened to them. For a few patients their existential feelings persisted throughout their recovery, others experienced a shorter existential period and for some this vulnerable period fluctuated. These experiences appeared to be influenced by a number of factors that included feeling familiar and secure with the surroundings and the attendant staff of the clinical gaze.

Whilst the existential crisis was clearly challenging and painful for patients, it was likely to be a normal stress response that led them to consider their situation and enabled them to start to make sense of, and place meaning to, what was happening. This period of existential crisis is a typical response amongst patients who experience sudden, unexpected illness that disrupts their routine life (Adamson, 1997). The temporary loss of coherence and the development of an immediate coping strategy can be readily understood and interpreted through the lens of existentialism (Lee and McCormick, 2002). However, the finding regarding an initial phase of existential crisis in this study was incongruous with the accounts of the experiences of participants in the publication by Bremer, Dahlberg and Sandman (2009) as detailed in the literature review.

The findings from this study indicated that as patients became increasingly aware of the gravity of their situation they began to contemplate a variety of consequences that included a potential (or actual) threat to their continuing well being, the unknown possibilities consequential to impact of the illness and even the prospects of death and dying. In such circumstances, an existential crisis would seem to be a natural and understandable reaction (Karlsson et al, 2014). The existential experiences of the study participants resonated with the work of Jensen and Petersson (2003), which examined the illness experiences of patients recovering from their first myocardial infarction.

It would appear from the literature that existential feelings in illness are normal, expected and common. Existential thoughts that occur during a person's period of vulnerability have been identified as part of the biographical disruption associated with illness and the subsequent recovery (Bury, 2001). In their review of sense making processes relating to chronic illness and disability, Lee and McCormick (2002) bridged

the conceptual gap between existentialism and Antonovsky's sense of coherence (1996) in that they postulated that both provide an explanation as to how people cope and make sense of their situation. However, being confident in the grounded analysis conducted in this study, existentialist thoughts appear to be intrinsically linked, integral to and may trigger the search for coherence.

None of the informants appeared concerned by a memory gap such as that alluded to by Bremer, Dahlberg and Sandman (2009). Patients referred to general feelings of disorientation and indicated that they reached their personal point of coherence through the informative accounts of reliable witnesses present at the event (or close to it), which included healthcare professionals, family members and friends. The sense of coherence and the development of generalised resistance resources will be discussed in more detail in the following section.

## **7.2 Phase 2 - the search for coherence**

The search for coherence as described by Antonovsky (1996) and applied in the field of health promotion, provided a suitable theoretical framework through which to understand how patients in this study developed a coping strategy for their recovery from a life-threatening illness. The model is framed by the concept that a sense of coherence is constructed through the utilisation of what Antonovsky (1996) called general resistance resources (GRR's). The concept suggested that a person used their GRR's as positive assets to deal with the current stressors (physical and psychological) in order to move away from an illness state towards one of a healthy state.

Drawing on the accounts of patients' initial coping and resilience indicators (GRR's), the use of Antonovsky's salutogenesis model (1996) provided an applicable, functional theoretical lens through which to comprehend the secondary phase of recovery. As follows, this framework was also used to explain the apparent temporal recovery trajectory, starting from the point where the patient first regained consciousness. It appeared that a patient's very first cognitive awareness triggered an existentialist survival construct, which contributed to, and overlapped with, their developing GRR's. This in turn strengthened the patient's sense of coherence, signifying the secondary phase of their recovery journey. Additionally, the fluctuating,

dynamic nature of their existential thoughts, their generalised resistance resources and their sense of coherence all acted as a barometer for progress towards health (or illness) that persisted for the duration of their recovery period. This stage was recognisable by the patient's increasing confidence in their health status, accompanied by a corresponding decrease in existential concerns.

In considering Antonovsky's model (1996) it is worth recalling that it contained an important element that acknowledged that whilst a person's generalised resistance resources are a positive stress response, their ability to cope was also conditional upon a cascade of internal and external stimuli that are sub-consciously constructed from their personal life experiences and incorporated an array of cognitive, physical, psychological, cultural and / or societal factors. Furthermore, Antonovsky suggested that it is a person's ability to harness and utilise the generalised resistance resources that determines the strength of their sense of coherence that subsequently influences their return to health. In other words, a person that is motivated to cope (meaningfulness), understands the challenge (comprehensibility) and has the resources available (manageability) is one that is more likely to return to health. This personal variability was evident amongst the narrative accounts of participants in this study.

For some patients the early stages of the recovery progress were fragile, unstable and prone to disruption. The psychological recovery curve appeared to be dynamic and responsive to critical events as they arose. It was clearly evident that all of the patients in the study demonstrated the motivation to cope, but (at the time of the interview) some did not appear to have had the ability to understand the challenge or access the resources (internal and external). This situation impeded their ability to develop the necessary resilience to proceed beyond the existential phase, or at least not completely, which may have then limited their progress towards their expected desired recovery outcome. One patient (David) did not manifest any overt signs that they were experiencing an existential crisis in terms of surprise or who am I / where am I? Instead he displayed a rather calm, controlled demeanour that conveyed the resilience that he had expressed in his language. However, in this case the patient still harboured existential thoughts, but they were triggered by his longer-term anxieties that were related to his return to work and an ability to function normally.

Antonovsky's premise was that the strength of a patient's sense of coherence is the key determinant in their move towards better health. It then follows that having full, appropriate knowledge of the nature and severity of illness should be considered (by those patients who wish to be informed) as fundamental to their recovery. For this group of patients this involved their filling in of the life – experience – vacuum that was consequential to such periods of unconsciousness, as described by Bremer, Dahlberg (2009). Later, their sense of coherence helped them to understand and strategically cope with the existential uncertainty that arose as a consequence of the interventions of the medical gaze. In the final recovery phase, their sense of coherence provided further successful coping strategies in the form of personally identified recovery milestones as they prepared to leave the hospital and complete their recovery in the comfort and security of their own homes, which is discussed in the next section.

### **7.3 Phase 3 - developing recovery milestones**

The emergent theme of recovery milestones that was signified by the informants in the findings represented the third phase of recovery. This was most recognisable when the participants contemplated their present situation and linked it to their return home. Being discharged home from hospital was the most important milestone within the recovery construct of this group of patients as it represented a step-wise (but perhaps incomplete) separation from the medical gaze. This was synonymous with the patients regaining some (but not all) of the control of their lives thus achieving a balance between their independent private lives and the necessities of the medical gaze. As this finding was not evident within the extant literature, it is possible then that patient determined recovery milestones have not been considered as reliable markers of recovery and it may be that recovery milestones have been viewed as minor, trivial issues rather than important steps incorporated into a persons generalised resistance resources. Whilst the importance of recovery milestones determined by patients has been recognised in other disciplines within the medical gaze, such as stroke recovery (Glass, et al, 2000) and within the palliative care field (Pinnock, et al, 2011), it has not been done so in significant detail.

Regaining independent mobility and being able to control their own body movements was a common milestone that participants identified as an important early

recovery target. However, this marker was not only framed by the physical act of mobility, it had a number of psychological manifestations. The issue of mobility commenced during the existential crisis and persisted throughout the hospital phase of recovery and for some, influenced their post-discharge anxieties. The identification of mobility as a recovery milestone gave patients purpose, direction and determination during their interactions with the medical gaze. With varying degrees of success, their developing generalised resistance resources provoked them to manipulate the medical gaze to their advantage in achieving their desired goals. It was noticed by a number of patients that the medical gaze had also placed significance against their ability to mobilise, this appeared as a rare, shared goal for both the patient and the medical gaze as a clear signifier of their readiness for discharge from the hospital.

### **7.3.1 Returning home and to normal life**

The ultimate recovery goal that emerged from the data was that of a return home. Whilst most of the participants were strongly positive, others retained concerns, whilst the return home was considered a sign of recovery progress, they harboured reservations and insecurities about leaving the perceived safety of the hospital. The diversity of the responses may have been a reflection of the variation of their respective personal circumstances coupled with their perceptions of their psychological safety, which may have been further determined by their abilities to cope (using their GRR's). Two patients, who had prior experience of recovery from major surgery, were able to benchmark their important recovery milestones during this recovery. They both referred to their previous recovery experiences frequently and argued that this provided them with important and helpful insights as to how things were likely to proceed and they considered that they were better prepared (psychologically) than previously to endure their recovery.

If the medical gaze is genuinely concerned with the provision of holistic, patient centred compassionate care, as would appear evident within contemporary national political (and professional) healthcare policy statements (The Mid Staffordshire NHS Foundation Trust Public Inquiry, 2013; National Advisory Group on the Safety of Patients in England, 2013; Keogh, 2013), then listening to the patient narrative is crucial. The rationale that led patients to view their discharge from hospital as the most

significant recovery landmark contained a range of interesting and informative components that deserve the considered attention of all of those who are responsible for the safe delivery of healthcare. This was not evident from the reported experiences of the participants.

Participants frequently mentioned simple quality of life issues, such as regaining control of their own personal space and being amongst the familiar comforts of home as key recovery milestones. Quality of life is a subject area that is well represented as a reliable and desirable outcome metric within the literature. Within the objectivised world of the medical gaze a range of simple survey instruments have been developed and frequently utilised to measure quality of life (Moulaert, et al, 2009; Elliott, et al, 2011), however none of these measures were derived from a patient's perspective.

Other similar simple but problematic quality of life issues were raised by the informants and these acted as positive motivational drivers for recovery and to return to the privacy of home. Experiences such as the disturbed nature of hospital sleep, the noises of neighbouring patients in the ward or being woken by nurses to take medicines featured prominently in the participants accounts. Some questioned the purpose of remaining in the hospital, seemingly doing very little whilst receiving little or no attention from the medical gaze.

The re-establishment of their independence and regaining control of their own lives was an important recovery milestone that was part of the return home and the return to the routine order of their lives. However, the patients detailed a range of challenges that they needed to overcome for this to happen and some indicated that meticulous planning and preparation would be required for their discharge home. In this regard, the medical gaze appeared to be miss-aligned with the needs of the patient, some patient's felt patronised, poorly understood and significantly under-supported. The net effect of these experiences of the inadequacies of the medical gaze left participants feeling psychologically vulnerable and perhaps not in full control of their situation. This may have been a reflection of under-developed coping mechanisms (GRR's) but in any case the medical gaze considered that they were medically fit and should be discharged from hospital care. In light of this dissertation, this represented another significant failure by the medical gaze to provide patient-centred, holistic care, and this placed a challenging

(retrospective) burden upon my dual role as the outsider conducting the research and an insider that recognised the problem.

### **7.3.2 Recovery and the return to working life**

The medico-sociological preposition that placed illness as a societal deviancy (Parsons, 1951) that requires control and input from the medical gaze (Foucault, 1977) has been discussed in detail in chapter two. Within this construct, the detrimental effects of biographical disruption that illness has had on the working life of people and society as a whole is widely recognised. Five of the participants in this study were of working age and in employment at the time that they experienced their heart problem and subsequent cardiac arrest. Two of those five participants raised the issue of potential or actual financial compromise and one participant identified their financial vulnerability as a concern. However, amongst the remaining individuals, who all expected to return to work, there were a range of expectations, anxieties and concerns regarding when they would return to work and how their job role might be affected. The issues of returning to work and the associated financial challenges are evident within the literature (Arawwawala & Brett, 2009 and Pußwald et al, 2000) as was the provision of appropriate, patient-centred support (Prinjha, Field and Rowan, 2009). Herein lies a paradox in that the medical gaze appeared indifferent to such concerns, at least that was the experience of patients in this study.

The key milestones identified by patients were centred on functional mobility, returning home, independence and returning to work. It appeared that the use of milestones as progress markers provided a useful structural framework for patients as they recovered. It would be reasonable therefore to consider that the development of individualised recovery milestones form a critically important part of their generalised resistance resources that strengthen the sense of coherence and sit within Antonovsky's model of salutogenesis (1996). Having awareness of patient derived recovery milestones and the value they have in promoting a positive recovery is likely to inform healthcare professionals and influence the nature and quality of psychological and physical support provided in the course of their duties. The next section of this chapter discusses this in context with the structure and function of the Foucauldian concept of the medical gaze (1973).



#### **7.4 Clinical space as a panopticon and the medical gaze**

The extensive narratives of the patients' experiences of their interactions with the medical gaze as they recovered from cardiac arrest that have been recounted in this study were interpreted through the post-modernist framework of the Foucauldian lens of panopticism (Foucault, 1977). It could therefore be argued that the modern hospital, when viewed as a panopticon, becomes a purposively constructed building that contains the specific clinical spaces, equipment and expertise that enables the specialised work of the medical gaze to be conducted upon and within the body (and mind) of the patient whilst they are under the medical gaze (Nettleton, 1995; Turner, 1987; Armstrong, 1995). The period of time spent within the hospital ordinarily provides the preparatory time for the clinical intervention(s) to be undertaken and for the immediate recovery of the patient, in other words the hospital panopticon and the medical gaze places the patient under clinical surveillance in a system of intended safety and increasing risk awareness (Scambler, 1997). This model of healthcare fits well with Freidson's post-Foucauldian position of medicine as a socially constructed and highly regulated system (Freidson, 1970) that includes the paternalism of the doctor / patient relationship. However in terms of the extended social function and social value that is pertinent to all areas of healthcare, Freidson's model, like Foucault's, does not appear to fully explain the benefits of providing a panoptic gaze in the context of end-of-life care, other than to regard death as providing an exemption from the obligations of society. Foucault argued that society has developed a pragmatic approach to death that merited medico-legal regulation and therefore it has become a legally regulated pathological process, Nettleton (1995) added the important contribution of religion.

As many of the research participants in the study developed what are medically determined as chronic illness conditions (e.g. ischaemic heart disease) or had implanted devices (e.g. heart pacemaker) that require life-long monitoring, a similar societal risk-benefit paradox arises when it is considered as to how the medical gaze and panopticism have developed in order to address long-term chronic illness. Armstrong (1995) argued that in the context of the successes of 20<sup>th</sup> century medicine, particularly in the immediate period that followed World War II and the founding of the NHS, it became necessary to significantly widen the penetrative focus of the medical gaze to one that is not limited to those affected by the deviancy of illness. Furthermore,

Armstrong (1995) discussed the emergence of health screening, epidemiological surveys and an increase in risk-awareness as a form of normality surveillance that represented a new panoptic model to drive preventative medicine forward in improving the health of the nation. Moreover, the constant monitoring of those people that are in a state where they are hovering between health and illness does not merit the attention of a comparatively expensive hospital based panopticon. This is typical of the situation that is seen in many chronic illness states that are stable and well controlled through medication compliance and self-monitoring, such as diabetes and angina.

A medical gaze of this type, one that is facilitated by a remote, virtual panopticon, has only been possible through continuous technological development that has provided the clinical gaze and its subjects with the necessary tools. An appropriate example of a compliance with the virtual / remote panopticon is provided by those patients who self-regulate their diabetes through the monitoring of their blood sugar levels and the consequential adjustment of their insulin dose. Despite being asked to consider their anxieties and fears about their future, the participants in this study, who were interviewed whilst still being held within the hospital panopticon, did not talk about their longer-term, potential chronic illness state, consequently they did not appear to be aware that this would almost certainly mean that they would remain under the watchful eye of the remotely monitored, extended clinical gaze for the rest of their lives. Persons with permanent and chronically disabling illness may never recover to the extent of being able to provide a net contribution to society and in these cases the medical gaze may be a reluctant participant that becomes exhausted and loses interest.

## **7.5 Knowledge / Power and human factors within the medical gaze**

The patient, who is unwell and unable to fulfil their normal role as a functional contributor to society, is according to Parsons (1951), in a socially deviant role. With the exception of end of life care, the intentional work of the hospital is then ordinarily focussed upon returning the unwell person to their previous functional status at their earliest possible opportunity, according to Foucault (1977) this is the primary function of the medical gaze. In order to achieve this, the person must be sufficiently recovered and restored to a position of health and well being whereby they no longer require the attention of the hospital facing element of the medical gaze, but we have seen that they

may need the prolonged support of an extended medical gaze, and / or other social support from the welfare state.

When considering the experiences of the participants that were reported within the findings in chapter six, it was difficult to detect any evidence that the patients in this study had any sense of an increased level of power within the medical gaze, as indicated in elements of the critical commentary offered by Bologh (1981). Their level of autonomy appeared limited and the informants provided numerous examples within their experiential accounts that strongly resonated with the Foucauldian premise that the basis of the knowledge / power hierarchy between doctors and their patients rested firmly within the medical gaze. As was evident in the findings, there were many examples of poor communication, misinformation and a lack of clarity in the care management, which all featured prominently within the recovery experiences of the study participants. Most significantly, the patient was rarely if ever genuinely involved or consulted for the duration of their recovery.

Open, transparent dialogue and an understanding of trust between a doctor and their patient is fundamental to the doctor / patient relationship of trust and it could be considered to be at its most crucial during the process where consent is required in order to conduct treatment upon the person's body. One of the more interesting and provocative concerns raised by Bologh (1981) was that of un-necessary treatment directly related to a lack of appropriate and effective communication conducted by doctors in their interactions with patients. At this juncture it is important to remember that the issue of consent is enshrined within common law in England. Consent is fundamental to the doctor / patient relationship and recognises that a person (with mental capacity) has the right to self-determination, however, two key legal tests (*Bolam v Friern Hospital Management Committee [1957] 1WLR 582 per McNair J.* and *Bolitho v City and Hackney HA (1993) 13 BMLR 111 (CA)*) ruled that the standards of care provided are a matter of reasonable, logical medical judgement (Kennedy and Grubb, 2000). Accordingly, when a serious patient / doctor conflict arises this ethico-legal precedent clearly places the balance of power / knowledge firmly in the hands of the medical gaze and in a Foucauldian context, this is not surprising. An example of such a premise occurred to Janet who voiced doubts over the reliability of her consent. Janet gave her consent and permitted the medical gaze to perform an operation upon and

within her body in the belief that the surgical procedure was necessary to prevent further deterioration in her condition and improve her health, however having undergone the procedure she encountered a number of complications. In her interview Janet stated that she felt that she had not been provided with appropriately accurate, open and transparent information with regard to the limited long-term benefits of her surgery. Furthermore, following her cardiac arrest Janet also had (by necessity) required a pacemaker to be inserted into her chest, again she commented that she had no idea that this might have been a possibility. Whilst Janet's experiences raise an important question as to the role of the medical gaze and how it appears to view patient autonomy and the right to self-determination, if a negligence claim was made, it would be subjected to the two legal tests identified above that both explicitly indicate that the level of care is determined by the reasoned and logical view of the medical gaze, not the care related expectations of the patient.

Ideally patients enter into the hospital panopticon under a position of informed consent, understanding and acceptance and five (of the sixteen) patients in this study followed the advice of the expertise of the medical gaze and accepted that they needed to go into hospital in order to undergo an invasive procedure or surgical intervention to correct their health problem that was preventing them from fully participating in their conventional functional role in society. Seven of the remaining eleven patients had been admitted to hospital and treated for their sudden life-threatening illness, such as a heart attack or serious abnormal heart rhythms, in this situation consent for treatment was both implied and given under the legal construct of 'best interest' (Kennedy and Grubb, 2000). The four remaining patients in the study group had been treated (medically or invasively) without their consent (as they remained unconscious following their cardiac arrest) and the necessary treatment interventions were conducted by the medical gaze under the auspices of 'best interest'.

Following or preceding their cardiac arrest, nine of the participants in the study had been transported to the hospital via an emergency ambulance, therefore their encounter with a clinical panopticon commenced at the point at which they were attended to by the ambulance paramedics (or emergency medical technicians). In the modern era the paramedical ambulance services have been further supplemented by helicopter air-ambulances, carrying doctors rapidly to the patient and through the

improvement in patient outcomes, this extended gaze is likely to have contributed to a shortening of the period of illness related deviancy (Butler, Anwar and Willett, 2010), thus it is of benefit to society.

In either situation, be it a planned admission or an emergency admission, the balance of the controlling power of authority, generated by the medical panopticon, is placed in the hands of the doctors, nurses and associated healthcare professionals. Moreover, we have seen that this power is supported within and strongly linked with law and the judiciary. Of course, the panopticism of healthcare is conferred through the patient's recognition and consensual compliance with the systematic operational complexities of the medical gaze which aims to provide a physical and psychological safe medical space to its inmates through its continuous observation, monitoring and therapeutic interventions. This situation was exemplified in Gordon's account when, early in his interview, he was able to talk comfortably and confidently, in detail, about his hospital experiences often using the technical language of the gaze. This premise that underpins the validity of their consent to be admitted to hospital, was not raised or questioned by any of the participants, perhaps as a consequence of the severity of their illness or perhaps as a recognition that their longer-term well being is best served through compliance with the perceived expertise of the medical gaze and its cloak of panopticism.

It is noteworthy that patient-facing surveillance featured in the historical development of hospital and ward design as the benefits of such methods in a medical context became increasingly evident. In her book-notes dated from 1860, Florence Nightingale (1860) provided an account of her considerations regarding ward design and effective patient care. Driven by her desire to keep everything clean, regulated and controlled, Nightingale recounted her design strategy, one of open wards with beds arranged in opposing lines that enabled nurses the provision of constant surveillance upon their patient(s). Thus, the panoptic gaze was (inadvertently) inherent within the design of her (Nightingale) wards, which enabled nurses to see all of the patients at the same time, a design that persists to this day, albeit on a smaller scale, within four to six bedded bays in most wards.

All of the participants in this study spent their most vulnerable and unsafe period of their hospital admission under the most intensive surveillance that the watchful eye of the medical gaze can provide. Extensive automated and remote electrical monitoring is conducted in these environments, where a range of vital physiological parameters are constantly monitored by an array of highly technical, expensive medical instruments. Within the ICU there is technology that is able to conduct the functions usually regulated by the internal organs of the patient – for example breathing machines, heart bypass machines, dialysis machines (for kidney failure), heart muscle assist devices or pacemakers. Whilst all this is going on, a wide range of measurement of complex internal biochemical processes are monitored, as is surveillance of infection.

Several participants within this study demonstrated their overt awareness of the hospital panopticon and used language that suggested that they considered themselves to be captives, one referred to feeling like the “*Prisoner of Zenda*”, another used the phrase “[...] *they agreed to release me [...]*” (Chapter 6, Section 6.1.1., pages 126 & 127). From such examples we can see that through the physical and social construction of modern healthcare, patients themselves were able to perceive and be mindful that they are under the constant gaze of a medical form of the panopticon, a surveillance system that monitors them, even through periods of well being. Several of the patient narratives indicated that they were aware of the precision of the complex machinations of the clinical gaze as well as the body work that was undertaken upon them. Interestingly, patients were able to recognise that the medical panopticon contained flaws, exemplified when the doctors struggled to understand and manage episodes of medical instability. Others had noticed other important constituents of the clinical gaze that included the sophisticated panoptic facilities, the part played by nursing and the important element of research, all of which are readily incorporated into the Foucauldian model.

As the physiological condition of patients improved and their recovery continued, the level of surveillance required was progressively reduced, but it was still considered necessary by the gaze to carefully place the recovering patients into hospital spaces where they could be attended to, if required, by specialist healthcare professionals with a level of proficiency and expertise specific to cardiac recovery that included emergency care. It has been recognised that, with the exception of emergency departments and

acute admission areas, ward areas have become increasingly more specialised and as such there are no longer general ward areas, consequently all patients were managed within specially constructed hospital spaces where they can recover in a situation of improved safety that is consequential to the presence of departmental expertise (Temple, Kirthi and Patterson, 2012). It was during this phase of their recovery that the interviews with the participants were conducted, with the exception of one (Eddie), who was interviewed in the cardiac high dependency unit. At the point of being interviewed, all of the patients had been able to reflect upon their experiences of recovery and many had cause to challenge and question aspects of care delivered by the clinical gaze, perhaps only within the safety and confidentiality of the research interview.

Freidson's (1970) position was that illness is a medical-social construct that holds two deviant trajectories, one that was represented by the biological deviance away from health and a second where a person is permitted to withdraw (but requires regulation) from their obligation to provide a functional contribution to society. Conversely, one could argue that recovery and a return to well being follow two normalisation trajectories, one that incorporates a movement towards health (away from the deviant position of illness) and a second that sees a person re-engage with the requirements of society as they return to take their place in their previous functional role within society. As was evident in the findings, a key recovery milestone was that of being discharged home, and that whilst all of the patients in this study embarked upon a determined path to fully recover, underpinned by their increasing strength and sense of coherence, a number of them expressed concerns and doubt as to how long it would take to return to their desired position of health.

The patients in this research were recovering from a life-threatening illness episode and as we have seen from the published evidence, recovery and good quality survival from cardiac arrest provides a considerable challenge to the medical gaze. A small number of physically and / or psychologically damaged patients, estimated at 2.5% of in-hospital cardiac arrest survivors in the UK data (Nolan et al, 2014) may be more significantly affected by their cardiac arrest and their biography may be (or might become) permanently disrupted, resulting in a protracted period of recovery that may require continuous scrutiny by the clinical gaze. As people in this situation may not be able to return to their previous functional role in society, a third recovery trajectory

position occurs, one where a more prolonged and potentially permanent deviancy arises, whereby patients remain under the eye of what Armstrong described as surveillance medicine (1995). In alignment with Bury's work (1982), seriously debilitating chronic illness that can arise as a consequence of neurological / psychological damage following cardiac arrest raises the issue of significant biographical disruption.

None of the study participants expressed any fears that they would be in this position and all of the patients were confident that they would make a full recovery and return to a health status at least as good as that which they had enjoyed prior to the current situation, they would however continue to comply with the extended lens of the clinical gaze. According to Armstrong (1995), the concept of surveillance medicine moves the focus of the medical panopticon towards a risk / prevention model and away from a lesion centred model, focussing upon prevention and early detection of illness through a societally induced self-regulated process that has been integrated and normalised. One could argue that surveillance medicine model, as an extended panopticon can also be used to oversee the final stages of the rehabilitation of people recovering from illness. The highly specialised medical panoptic space of the hospital is exchanged with a more generalised medical panoptic space, that of the general practitioner within the local community, returning the recovering person back to the risk / prevention, self-regulatory situation. It may be helpful at this point to recall that Bury's account of biographical disruption amongst patient's with chronic illness indicated that some patients were not comfortable in the chronic illness role, which was indicated by their reluctance, denial or outright rejection of the rehabilitation measures offered by the extended lens of the medical gaze (Bury, 1982). One of the participants in this study displayed such tendencies in that they steadfastly rejected all of the support services offered to them as they were considered to represent the over-bearing intrusions of the medical gaze that were neither request nor required.

### **7.5.1 Listening to the patient's voice**

It is evident from the findings within this study that Freidson's model (1970) continues to resonate in the modern context. The participants have testified, through their narrative accounts, that physicians continue to use their knowledge / power base to exert their influence and afford themselves a superior air of authority, which could be



considered to be self-serving and beyond that which is in the best interests of their patients. Doctors are much more than merely gatekeepers and guardians of the sick role.

The dominant model of healthcare in the UK continues to place doctors at the forefront of healthcare delivery. In the context of placing the patient at the centre of healthcare activity, it is reasonable therefore to consider that the patients experiences of recovery from their cardiac arrest, their perceptions of the doctor / patient relationship and their position within the sociology of illness are intrinsically important findings which inform our understanding and adds to the canon that is pertinent to the patient experience. Whilst written into contemporary patient-centred policy statements (alluded to in the introduction), it would appear from the experiences of the patients in this study that the ideals around patient-centredness and active patient involvement in healthcare are far from being implemented. This merits consideration as to the possibilities of how such a major cultural change can be achieved within the clinical panopticon. For patients to become genuinely empowered as active participants in the decisions regarding their care the whole doctor / patient relationship issue requires a paradigm shift that necessitates a full re-construction that embodies all of the constituent members of the multi-professional healthcare team, not just at the high level of healthcare management, but at every level so that it can be positively influential in the recovery of patients following a period of illness. As discussed previously, elements of a Parsonian situation whereby by the physician's role, supported by the legal gaze, still clearly holds a powerful, authoritarian societal position as the illness legitimising agent of the state (supported and developed further by Balogh (1981)), which is there to ensure that the person in the sick role is returned from their deviant position to normal functional status as a net contributor to society, at least within the acute hospital setting.

### **7.5.2 The ward round**

The doctor / patient relationship experiences of the patients recovery from cardiac arrest detailed in this study were perfectly exemplified for many patients when they encountered the ward round and many patients perceived this as a subtly intimidating and uncomfortable interaction with the clinical gaze. Although it is recognised as a complex procedure (Herring, Desai and Caldwell, 2011), put in simple terms, the

purpose of the ward round would be to conduct a review of the recovery progress of the patient against a previously agreed patient management plan, which would result in a revision to the on-going plan. Typically, during a hospital ward round a group of clinicians would visit the patient, the group would be mostly comprised of doctors, but nurses and other health care professionals would often be present. The group would conventionally be dressed in their working clothes, that being professional attire, whereas the patient would usually be dressed in clothing associated with sleeping, such as pyjamas, nightgown and / or a dressing gown. The agents of the medical gaze would be surrounded by numerous clinical accoutrements (medical notes, medical trolleys and instruments or equipment necessary for clinical examination) and as many of the clinical participants would know each other they would have an established professional rapport, thus a definitive hierarchy would exist within the construction of the group (Pedersen, 2012). At the start of the individual patient encounter the ward round group would stand above and around the patient, whilst the patient would be seated or lying in their bed. The recollections of ward round provided by Eddie, Gordon and Philip (Chapter 6, section 6.2.3) provided a range of examples of the inadequacies of this briefest of encounters between the patient and the senior doctors that occurred during the ward round.

When considering the patient experience of the ward round and all of its bio-semiotic and technical complexities, it would appear that the significantly dominant power / knowledge hierarchy is one which is purposively constructed to assert the authority of the medical gaze. It is a process that clearly places the patient in a position of vulnerability and weakness. It is of interest that Herring and colleagues (2011) postulated that in the absence of any evidence-based national standard, their novel systematic approach to conducting ward rounds offered patients an improvement in both the quality and safety of their care. However, despite their seemingly progressive approach and their acknowledgement of the complexities of the ward round, Herring and colleagues (2011) failed to recognise that their structured approach contains a significant paradox. Firstly, at no point in the paper did the authors place any notable value as to how listening to the patient narrative and involving the patient in their care might improve the patient's experience of recovery and eventual outcome. Secondly, it could be argued that the authors approach is almost entirely centred upon improving the technical and non-technical weaknesses inherent within the medical gaze and the

hospital panopticon. Herein it is evident that even contemporary medical approaches retain the conventional power / knowledge gradient whilst the empowerment and involvement of the patient as a quality indicator of care is ill considered. The experiences recounted within the articulations of the patients in this study indicated that the power/knowledge relationship between the doctor and the patient is still very much weighted towards the medical gaze. As the patient at the centre of the attention of the medical gaze during the ward round, Eddie was able to express his frustrations at how the doctors failed to engage with him or actively involve him in its deliberations in planning his care (Chapter 6, page 150).

The participants clearly indicated that within this medically constructed and socially awkward situation (the ward round) there was a very limited opportunity to develop any level of professional social rapport or even an opportunity to request information as to the details of the strategy for their on-going care, most importantly the patient was seemingly denied an opportunity to ask. Eddie and Philip did not feel as though they could ask questions on a one-to-one basis with the doctors / consultants because they were always in a group and they talked to one another, about him and over him, not to him or with him. Patients wanted to ask simple, basic questions but did not feel that they could make the connection because of the physical structure of the ward round – a group of intimidating doctors looking down upon them in their medicalised space in their roles as a vulnerable patients. Like Philip, Eddie would have much preferred an informal chat, on his terms, with the consultant.

Eddie's perception was that the first consultant he saw every morning went away shaking his head, appearing to not know what to do and not sure what the problem was with the Eddie's heart, leaving the Eddie to think "*what the hell was going on here?*" This went on for a week. Here the medical gaze appeared insensitive, but it may have not been mindful of its negative bio-semiotic transmission to its patient. Later in his admission, a new consultant came along to see Eddie who was more decisive and decided to operate immediately and Eddie was significantly re-assured by this as he knew where he was (in terms of a treatment plan) and was now better placed to think and plan his important life decisions. Despite this, the consultant still failed to offer Eddie an opportunity to discuss both the treatment plan and the discharge plan with him.

Eddie and Philip also commented on the apparent lack of continuity with staff. When looking for comfort (from within a position of fear and vulnerability) both Eddie and Philip felt that it was important to see comforting and familiar faces and recognised that whilst this does not affect direct care, they thought that seeing the same staff and establishing a rapport would have provided further reassurance and trust. Eddie could not understand why this is not considered and he placed a high value upon the setting up of rapport, of getting to know people and the human touch of care and compassion; for example, sharing a bit of life history, which he regarded as strongly positive as a nursing quality. Consequently, he didn't see the modern method of allocating staff is in the best interests of patients.

Whilst refining the processes of the medical gaze that are pertinent to the system of conducting a safe and efficient ward round, it would be helpful for the clinicians of the medical gaze to be mindful and appreciative as to how important the ward round is to the patient experience, particularly during their recovery. Patients clearly see this briefest of encounters as an important, integral component of their care, offering as it does, an opportunity for a meaningful, effective, mutually beneficial communication opportunity for the patient to gauge their recovery progress and actively participate in the planning of their care.

### **7.5.3 The nursing gaze**

Early therapeutic interventions aimed at supporting and enhancing the patient's generalised resistance resources and strengthening their sense of coherence are likely to positively influence their recovery, therefore it follows that nurses, as agents of the clinical gaze have a pivotal role in providing the necessary care. Nurses are professionally encouraged to provide care with compassion (Nursing Midwifery Council, 2013) and amongst others, Benner (1984) indicated that through a professional, caring partnership with the patient, the establishment of hope, confidence and trust, befitting of compassionate care, enhances the healing process and positively influences a patient's recovery from illness. In a care collaborative, doctors would also be expected to engage in effective, patient-centred communication across all levels of the medical hierarchy.

During the interviews the informants appeared very clear about the part played by doctors in the context of their recovery experiences, but patients appeared less clear about their experiences of interacting with nurses and other agents of the medical gaze. This may have been consequential to a number of factors, such as over-lapping job roles, a lack of familiarity with the colour coding of uniforms, or simply limited communication skills when introducing themselves to patients, which has been a focus of a campaign to enhance compassionate care (Hellomynameis.org.uk, 2014). At times it was difficult to ascertain from the participant narratives as to whether they were commenting upon qualified nurses or healthcare assistants. Nevertheless, many of the informants in this study did comment specifically about their positive and negative experiences of how they were nursed and how nursing appeared to be managed during aspects of their care and recovery.

As a subtext to their experiences of recovery, study participants identified that the part played by nursing in the delivery of care aimed at enhancing the recovery of patients incorporated a wide range of qualities. Alongside the traditional nursing role of providing patients supportive care with their activities of daily living that included intimate care upon the body of the patient (recognised by some as necessary, unpleasant work conducted by more junior or less qualified staff), good nursing care provision was also perceived through the provision of accurate, integrated and supportive information. However, considerable variability in the quality of nursing care was an experience of many patients which merits attention, at least in terms of providing patients with a voice, through an open forum for disclosure followed by an explanation as to why this may be so.

Good quality, personally directed care was often associated with being comforted, particularly where professional rapport had been developed. In terms of psychological care, many patients welcomed the familiar comforting elements of personal communication exchanges in the form of polite greetings that occur when people meet and the everyday small-talk that often arises, but they also commented on the beneficial comforting effect that was provided through the sensitive use of language and the comfort of physical touch. Several participants identified how at a moment of existential personal terror and vulnerability, where their family members were not available or accessible, nursing staff provided them with comfort, care and reassurance. One

participant remarked that the nurses had reassuringly reached out to him at a point he had felt very vulnerable, lonely and tearful.

The lack of continuity of care from particular nursing staff was raised as an issue that negatively affected their care and recovery. The participants were aware that the lack of continuity of care was not limited to medical staff, the day to day changes in nursing staff was identified as a problem for them and whilst they understood the logistical challenge. It was suggested by one patient that better management of the nurses shift allocation pattern and duty rostering would improve the continuity of care, which he felt would better promote the development of a more effective care relationship between the patient and the nurse, which may then improve the patient experience of recovery.

Participants also recognised that the job role of nurses was important, integral constituent with both the technical and non-technical workings of the medical gaze, this included observations by patients of the activity of the gaze that occurred around focal gathering points, usually where communication hubs were placed. The ward / departmental nursing stations were visible to mobile patients and in critical care areas centralised heart monitoring screens and x-ray viewers are housed for physiological observation purposes. There were also a number of examples of considerable communication failure that negatively affected the patients perception of the care of the medical gaze, one such example arose when a blood sample was taken where the patient was offered no explanation whatsoever as to the purpose of the sample and it made him feel as though he was just a number and saw it as a lost opportunity for human interaction. Another patient was aware that he courted a nurse's displeasure by simply using his call bell to ask for help. Similar issues arose around the timing of nighttime medication. Whilst patients understood that nurses had a job to do, numerous patients recounted the experience of having been woken during the night to receive medication. The provision of oral or inhalational medication appears to be driven by a temporal system entrenched within the medical gaze and at the convenience of the medical gaze, rather than in a negotiated, informed and consensual approach that involves the patient (Jarman et al, 2002). Some patients felt that on occasions nurses waited until they (the patient) dropped off to sleep before being approached to take their medication. However, as recorded in the findings of this research, there were much

more serious failings within nursing and its intended provision of person-centred compassionate care that indicate a major flaw in the regulation and maintenance of the nursing gaze (chapter 6, section 6.2.2), which included accounts of a lack of attention to the needs of the individual, whereby it could be perceived that nursing was more concerned with its role in the clinical gaze, rather than being attentive to the needs of its patients. As stated in the findings, it was apparent that (along with medicine) nursing fails to find time to listen to the voice of the patient, accordingly such insights into what patients experienced during their recovery had only been revealed as a consequence of undertaking of this research study, which I found disappointing.

It is clear that the evidence provided by the narrative accounts of the participants in this research has provided a rich seam of material that could be used to better inform the architects of the clinical gaze that there is much to be done to improve the patients experience of recovery from cardiac arrest, much of which will form the basis of the recommendations for practice that have emerged from this dissertation.

#### **7.5.4 The medical gaze and the insider role**

The insider role is widely used as a general term to identify that the researcher has conducted the research within their own organisation (Drake, 2010). As a researcher conducting my research within my usual workplace I was therefore placed in an insider role and this situation has attracted criticism in terms of academic objectivity and rigor. According to Brannick and Coghlan (2007), critics (positivists) of insider research have suggested that such an approach brings into question the academic rigor of the work as the researcher has a relationship and significant interests within the organisation and is therefore unable to maintain objectivity. Conversely, it has been argued that such criticisms have been negated by the adoption of a constructivist position that incorporated epistemic and methodologically reflexivity (Brannick and Coghlan, 2007). The potential for a conflict by being placed in an apparently simultaneous role of being a researcher and that of a health care professional had been anticipated and arose as a discussion point in a supervision meeting just prior to the commencement of the interviewing, the matter had also been extensively addressed in the literature (Jack, 2008). As this had been my stated epistemic and philosophical position I was confident that the highest level of methodological rigor had been applied to the collection and

analysis of the data. Darra (2008) indicated that there were advantages to being an insider researcher and those advantages included holding significant knowledge and expertise in the context of having a genuine grasp of the situational insights towards the experiences of the participants, these benefits were used in the context of my research methodology.

During the course of the discussions with my supervisory team I acknowledged my dual researcher/insider role, but defended my stated position that first and foremost I was a professional clinician and that my research role was temporary. However, I accepted that there was an important and delicate balance to be managed. This led to an agreed strategy for the conduct of the interviewing, ordinarily, for the duration of each of the interviews, I was predominantly in the role of the researcher, but at my professional discretion and in the best interest of the patient, it was agreed that if circumstances arose, I would switch role into one of a clinician. This was justified by using the following example; Firstly, in accordance with good ethical practice (Darra, 2008) I had declared my professional identity when securing the recruitment of the participants to the study. Secondly, if a patient that I was interviewing, who was recovering from cardiac arrest was to collapse in front of me, my legal duty of care and professional obligation to the patient would have led me to intervene. Furthermore, clinical colleagues would have looked to me to lead such an intervention, being that my professional status was as a nurse consultant for resuscitation.

The issue of clinical intervention during the interview actually arose during the collection of the data and when I undertook the coding of the data I was careful to record the number of times I intervened by providing clinical information at the request of the participant. As a response to direct questions from the participants (deferred or otherwise), I made a total of 174 insider interventions during the course of 14 interviews (there was one interview where no insider issues arose). With the exception of one incident, which is discussed later, this did not present me with any difficulties, which was in part due to having already achieved an established epistemological and philosophical position that explicitly incorporated a reflexive approach to qualitative interviewing (as detailed in Chapter 3, section 3.1.1.). Secondly, the *a priori* discussions held with my supervisors had provided me with a level of confidence in arriving at a decision as to when it was appropriate to intervene or when it was more appropriate to defer



answering the enquiry until the interview had concluded. I perceived that my use of language, appearance and behaviour did not change when answering the insider questions. Accordingly, one could then argue that my role change was not overtly noticed by the informants and from their perspective constituted a conventional participatory research-centred communication process. The only occasions where a role change may have become obvious as I switched into my clinical role was when I deferred a question that I could not answer without reference to information sources pertinent to the patient's clinical care that could only be answered at the conclusion of the interview. This may have been further helped by my anticipatory action, in that, in keeping with good ethical practice, I had informed patients in the contact meetings prior to the interviews commencing, that although I was a clinician, I would be in the role of a researcher for the duration of the interview. Furthermore, I wore a suit, or at least formal work clothing (rather than a nursing uniform) whilst conducting the interviews, this meant that there were no explicit visual signals to constantly remind the participants that I was a nurse in a research role.

An additional aspect of the insider role is one that is concerned with easier access to the subject matter of the research and associated information, this was recognised as a common situation for insider researchers (Brannick and Coghlan, 2007). For example, I held a very senior position within my organisation and this potentially facilitated a high level of access to participant related information, including medical and nursing case notes, electronic patient records that an outsider would not be able to access. Despite having open access to these sources of information, as a matter of good clinical practice I explicitly included gaining access to such information in the research protocol. Interestingly, there were a number of occasions that arose where ward staff offered information to me prior to being asked or prior to my provision of proof of identity and / or my legitimate, formal research role.

The only significant challenge to my insider role that I experienced occurred during an impromptu ward round conducted by four cardiothoracic surgeons during my interview with Gordon. The event was detailed in the section 6.2.3 (page 156) of the findings concerned with the medical gaze, a similar but retrospective role conflict occurred with the way the medical gaze viewed the discharge planning of Stephen, but both were framed by my insider knowledge of the patient's thoughts and feelings that

they failed to successfully address when presented with an opportunity by the medical gaze. It was my assumption that both participants were inadvertently intimidated by the psychological dominance and socially constructed superiority of the medical gaze. An additional role conflict of patient advocacy, as a professional expectation of being a nursing professional came to the fore in Gordon's case based upon my knowledge of Gordon's view of his care management plan and how he failed to address his concerns with the medical gaze, ordinarily I would have taken a position of advocating for the patient. However, two important premises had not been determined. Firstly, as I was in the research role and had only acquired knowledge of Gordon's view of his expectation regarding his on-going care as a direct consequence of being in that research role. Secondly, I made an immediate decision to remain passive as I did not have Gordon's explicit permission to act as his advocate and this was not a situation that I had anticipated arising. With the benefit of hindsight, I might have included such a possibility within the research protocol and the preliminary discussions, which served to clarifying one's research / clinical role. Interestingly, I could not find any references to such events within the insider literature and as such this type of event should be considered for publication and dissemination.

## **7.6 Recommendations for practice**

The important work of Prinjha, Field and Rowan (2009), which involved patients recovering from a period in the ICU, identified that only a small number of patients had found attending a follow-up clinic (3 months post-discharge from hospital) to be of benefit to their long-term recovery and that many had not. Despite these findings, I had anticipated that the informants in my study would have found the idea of attending a post-cardiac arrest follow-up clinic appealing and to be of benefit to their longer-term recovery. However, during the interviews it became very clear that that this was not the case, at best one or two patients were indifferent to the idea, the rest were politely dismissive, preferring to leave the hospital experience and its associations with the medical gaze behind them.

When I considered the existential anxieties, the feeling of loss (regarding their sense of self) and the search for coherence that patients experienced when consciousness was regained, I arrived at a key theoretical premise in that this could be

the precise point in the recovery journey where interventional care to support the patient would be best placed. Secondly, in terms of providing timely and appropriate care to the patient, I also recognised that opportunities for therapeutic intervention may have been missed. Each patient in this study developed generalised resistance resources that improved their resilience and strengthened their sense of coherence (supported their life-experiences and their personality). However, one could also theorise that the continuation of patient-centred psychological care by appropriately trained, experienced and skilled medical or nursing staff could further help patient to overcome the effects of the physiological dysfunction and the psychological chaos of cardiac arrest. This may be best provided by staff that are familiar to the patient, having already established a professional rapport with the patient during the earlier phase of the recovery period.

The therapeutic intervention envisaged would be to conduct coherence work with the patient, and if they so desired, this could include the involvement of their partners / friends. The coherence work could be centred upon talking through those events surrounding the cardiac arrest that the patient identified as important to them and then listening and responding to their worries, fears and anxieties. It is suggested that these interventions could be conducted within a confidential (psychologically safe) environment at a time that is at the convenience of the patient, once they had regained consciousness and become fully cognisant, with full mental capacity. The suggested intervention could enable the patient to make greater sense of their situation, helping them to reduce their existential anxieties and regain their sense of self at a point in their recovery which would otherwise be delayed or absent. This approach is supported by Antonovsky's concept of salutogenesis and the utilisation of generalised resistance resources (Antonovsky, 1996). The achievement of an enhanced recovery trajectory that moves the patient positively towards a position of health and away from an illness state is in keeping with the salutogenic position. At the point of discharge from hospital, it may also be pertinent to explicitly identify (within the discharge summary) to the patient's general practitioner that the patient has recovered from cardiac arrest and that whilst psychological support has been provided, it may need to be continued.

Whilst the suggested intervention detailed above requires formal evaluation and merits further research, in the time that has elapsed since conducting this research, a number of opportunities arose for me to provide early intervention psychological care

with patients recovering from cardiac arrest. The therapeutic interactions that were undertaken lasted about 20 minutes and were followed by three or four further (10 – 15 minute) sessions over the course of the following days, which was determined by the patient and activity ceased at a natural point, just prior to discharge from hospital.

The patients that received this intervention, that I have called coherence work, were in the very early phase of recovery and were experiencing existential crises and searching for coherence. In terms of a risk / benefit analysis, the balance was in favour of conducting this coherence work, as the evidence base provided by this research supported the proposed therapeutic intervention and through the conduct of the research interviews there was little or no evidence of any risk. Secondly, as a patient-centred practitioner, the intervention was conducted with the explicit consent and inclusion of the patient and I had no professional or personal issue in withdrawing from the intervention, if requested to do so by the patient. In essence, it was a matter of professional judgement and I considered that the nursing care that I provided to these patients was likely to be beneficial to their recovery and there was no evidence that conducting such an intervention would be detrimental to them.

## **7.7 Limitations of the study**

The number of participants recruited to the study (16) was less than the number planned (30) and whilst every effort was made to recruit a sample of patients that reached theoretical saturation, changes in my job role that occurred during the recruitment stage of the research led to a reduction in the time that I was present at the hospital. This limited my accessibility to potential recruits and it also affected the time available to conduct follow-up contact visits with those who had indicated their agreement to participate and a number of potential recruits were lost to the study. As was mentioned in the methodology chapter, a technological failing with the digital recording device led to the unfortunate loss of an entire interview, which further reduced the quantity of data for analysis. However, the data from the 15 subjects that was captured during a 12-month period was considered sufficient and provided detailed and novel insights into their recovery experiences and their encounter with the medical gaze.

A further limitation in the design of the research was related to the recruitment criteria, which excluded non-English speaking participants. This had been necessary to avoid the logistic complexities of engaging and funding a potential diverse range of interpreters, as well as the potential affect that the involvement of a third-party could have had upon the rigor of a research process that was reliant upon hearing the true voice of the informant.

Had time permitted, the conduct of a second, theoretical informed interview with each of the participants at three months after their discharge from hospital could have provided further important insights into their experience of recovery. This may have enabled participants to articulate their experiences over a longer period and enabled a reflective view of the hospital phase of recovery and provided further insights into their interactions with the clinical gaze.

Another aspect of this research that merited consideration, if time had permitted, was to consider the views and opinions from a representative sample drawn from the ranks of health care professionals who populate the medical gaze. Obtaining a perspective of a patient-centred approach to recovery from cardiac arrest from the members of the medical gaze using individual qualitative interviews and / or focus groups would have added an additional dimension to the findings, particularly around perceptions of appropriate support and interventions.

## **7.8 Further research**

On completion of this doctoral dissertation I intend to undertake further qualitative research to test the theoretical construct of providing coherence work to enhance the immediate recovery of patients surviving cardiac arrest. As stated in the previous section, a second interview with the same cohort would have provided additional insights into the progress of their recovery, one that bridged the gap between the hospital panopticon and the extended medical gaze in the community. However this was not possible, but conducting qualitative interviews with patients recovering from cardiac arrest shortly after discharge would still be useful and should be considered. Similarly, obtaining a perspective of how the medical gaze perceives its interaction and attention to the important psychological aspects pertinent to the recovery experiences of

patients would also provide important insights. This could provide further evidence as to how best improve the knowledge of the patient experience and motivate the members of the gaze to be increasingly mindful of the psychological aspects of compassionate care and embrace concept of providing a holistic focus on the patient.

## **7.9 Concluding remarks**

The research journey that culminated in this study commenced in 2007 and the design and focus of the study went through a number of manifestations, but all retained the comparatively simple premise of wanting to gain a more detailed understanding of what patients experience when they are recovering from cardiac arrest. I have gained a range of invaluable and most interesting insights into the complexities of how patients face their recovery journey and how most successfully recover from their cardiac arrest, an often complex journey which commenced with their initial awakening from an unexpected period of unconsciousness.

Having already presented the summary findings at a national resuscitation conference (Resuscitation Council UK, 2014b), it is hoped that I will be able to continue to articulate and present the findings of this research widely through seminars, workshops, conference proceedings and peer reviewed publications. Eventually, it is hoped that the provision of coherence work, as a distinct patient-centred therapeutic intervention, may become an integral component within the post-resuscitation care bundle, supported by a suitable training package in order that interested parties can acquire the requisite knowledge, skills and experience to conduct similar interventions to improve the patient experience of recovery from cardiac arrest.

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## **Appendix 1.**

### **Outline Interview Checklist.**

The interview is designed to provide the patient with an opportunity to express their actual experience of recovering from cardiac arrest and hopes to incorporate their thoughts, perceptions, fears, worries and concerns. The research is interested in the early part of their recovery and the commencement of their rehabilitation, including links to other appropriate care pathways. The impact of this that this type of critical event may have had upon (self-determined aspects) their 'self' is also of significant interest to the researcher.

The 'questions' that follow are not designed to be asked in a structured format; rather they are designed to act as an 'aide memoire' to the researcher.

This research project is using in-depth qualitative interviewing strategies that uses a grounded approach. This methodology will enable the patient to detail their experiences of recovering from cardiac arrest, in their own words.

The researcher will have detailed knowledge of the circumstances of each patient's medical condition and the course of their treatment and recovery. Preliminary contact with the recovering patient will be made by way of conventional professional care.

### **Suggested Questions.**

(The 'suggested questions' below will be subject to field assessment with 2-3 pilot interviews).

How are you today?

Tell me how you came to be in hospital...tell me your story...

What do you understand about what has happened to you?

What do you know of the events that led to your hospital stay?

You (may) know that you have suffered a cardiac arrest (your heart stopped and was restarted) have you had any thoughts about that..?

How have you found your care and treatment during this time?

Is there anything that you would have liked to have been done differently in the way that staff have cared for you?

Do you think you have received enough information from the doctors / nurses / physiotherapists about your care?

What information would you like to have had about your condition or your care?

Have you been told anything about what happens now with your care?

Do you have any expectations of what will happen to you now?

Is there anything that you would like help with when you leave the hospital?

Is there anything that you are especially worried about when you leave hospital?

Have you had any visitors since you have been in hospital?

Have you had any help, support, guidance or information other than that provided by the hospital support?

Would you like your family / friends / colleagues to receive training in CPR?

Would you like an opportunity to talk to a healthcare expert about your cardiac arrest?

Would you like to come back to the hospital to talk to people about your healthcare needs?

## Appendix 2.

### Participant Information Sheet

#### Surviving cardiac arrest; patient's experiences of the in-hospital phase of recovery

You are being invited you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish.

- **Part 1** tells you the purpose of this study and what will happen to you if you take part.
- **Part 2** gives you more detailed information about the conduct of the study.

Please do not hesitate to ask me (Ken Spearpoint; contact details page 4.) if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

#### Part 1.

##### What is the Purpose of the Study?

The purpose of this study is to help in understanding the real life experiences of people who are recovering from cardiac arrest. It is hoped that the information obtained will help to improve the care and support provided for these people.

### **Why have I been chosen?**

I am inviting you to take part because you are somebody that is going through the experience of recovering from a cardiac arrest and I am very interested to hear your story. I plan to interview about 30 people in similar situations.

### **Do I have to take part?**

No. It is up to you to decide whether you wish to take part. If you decide to take part you are still free to withdraw at any time, without giving any reasons. Your decision to withdraw at any time, or decision not to take part, will not affect the standard of care that you receive.

### **What will happen to me if I take part?**

If you agree to take part your participation will involve me interviewing you for about an hour: The interview will be electronically recorded using a small digital recorder. When I analyse what you have said, all information will be anonymised; this means that it will be impossible to identify anybody taking part.

### **What do I have to do?**

If you agree to participate in this study I will ask you to complete a consent form. I will then arrange with you a good time for us to conduct the interview.

### **Are there any risks?**

No. The interview should not present you with any risk and you are free to withdraw your consent at any time.

**What are the possible benefits of taking part?**

The benefit of you participating in this study is that the information provided should help to improve the care and support provided to other people following recovery from cardiac arrest, unfortunately it may not directly benefit you.

**What if there is a problem?**

It is unlikely that something may go wrong during an interview study, however if this does happen it will be dealt with immediately. Detailed information on this is given in Part 2.

**Will my taking part in this study be kept confidential?**

Yes. All the information about your participation in this study will be kept confidential. The details are included in Part 2.

**What happens when the research study finishes?**

If you wish I will send you a summary of the findings when the study finishes.

**Part 2****Will my taking part in this study be kept confidential?**

All information collected in this study will only be accessible by the researcher. The information collected will be kept on a secure computer with password protection only accessible to the researcher. All the information you provide will be treated confidentially. You will not be identified in any report or publication arising from this project.

**What will happen to the results of the research study?**

When the study is finished the researcher will write a report of the findings as part of his research study. A summary of the findings will be available to participants when the study is finished.



**Who is organising and funding the research?**

This research is being undertaken as part of a Doctorate in Health Research at the University of Hertfordshire.

**Who has reviewed the study?**

All research in the NHS is looked at by independent group of people called a Research Ethics Committee to protect your safety, rights, well being and dignity.

This study has been reviewed and given favourable opinion by Imperial College Healthcare NHS Trust Research Ethics Committee.

**What if there is a problem?**

As this is an interview study it is unlikely that anything could go wrong. However, if you have a concern about any aspect of this study, you should ask to speak with the researcher who will do his best to answer your questions. Please contact him in the first instance.

Ken Spearpoint  
Consultant Nurse, Resuscitation  
Department of Anaesthetics & Intensive Care,  
Hammersmith House  
Hammersmith Hospital  
London. W12 0HS.

Tel: 020 3313 2697

[Ken.spearpoint@imperial.nhs.uk](mailto:Ken.spearpoint@imperial.nhs.uk)

If you remain unhappy and wish to complain formally, you can do this by contacting the Patient Advice and Liaison Service (PALS) at Hammersmith Hospital;

**Walk-in PALS office:** Ground floor, south corridor (near C-block), Hammersmith Hospital.

Please telephone 020 3313 0088 to check opening hours

**PALS address:** PALS manager, Charing Cross Hospital, Fulham Palace Road, London W6 8RF

**Telephone:** 020 3313 3322, Monday to Friday, from 09.30 to 17.00

An answerphone system operates at busy times and out of hours.

Please leave a message and your telephone number and a member of staff will call you back

**Fax:** 020 3313 0087

**Email:** [pals@imperial.nhs.uk](mailto:pals@imperial.nhs.uk)

Thank you for reading this information sheet, which you may keep.

**CONSENT FORM**

**Title of Project:**

Surviving cardiac arrest; patient's experiences of the in-hospital phase of recovery

**Name of Researcher:**

Mr Ken Spearpoint, Consultant Nurse, Resuscitation

**Please initial box**

1. I confirm that I have read and understand the information sheet (version1.3) for the above study. I have had an opportunity to consider the information, ask questions and have had these answered satisfactorily.
  
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without my medical care or legal rights being affected.
  
3. I understand that the interview will be electronically recorded and that direct quotes may be used anonymously in papers, presentations and the researchers dissertation. I agree to this.
  
4. I agree to take part in the above study.

\_\_\_\_\_  
Name of Participant      Date                      Signature

\_\_\_\_\_  
Name of Person      Date                      Signature  
taking consent

When completed, 1 copy for participant; 1 copy for researcher site file; 1 copy to be kept in medical notes.

JRO reference: JR0HH0375  
Study Number: 12/LO/0202



## Health Research Authority

**NRES Committee London - Bromley**

South West REC Centre  
Whitefriars  
Level 3, Block B  
Lewins Mead  
Bristol  
BS1 2NT

Telephone: 01173421386  
Facsimile: 01173420445

29 February 2012

Mr Kenneth G Spearpoint  
Nurse Consultant, Resuscitation  
Imperial College Healthcare NHS Trust  
Dept. of Anaesthesia  
Hammersmith Hospital  
London  
W12 0HS

Dear Mr Spearpoint,

**Study title:** Surviving cardiac arrest: patients' experiences of the in-hospital phase of recovery.  
**REC reference:** 12/LO/0202  
**Protocol number:** not applicable

Thank you for your letter responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved by the sub-committee.

### Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

### Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

### Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

*Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.*

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. Confirmation should also be provided to host organisations together with relevant documentation.

### Approved documents

The documents reviewed and approved by the Committee are:

Document	Version	Date
Covering Letter		18 January 2012
Evidence of insurance or indemnity		02 August 2011
Investigator CV	CV for Ken Spearpoint	
Letter from Sponsor		19 January 2012
Other: CV for Pof Hilary Thomas		
Participant Consent Form: Consent Form	1.3	13 November 2011
Participant Information Sheet: Participant Information Sheet	1.3	13 November 2011
Protocol	1.2	13 December 2011
REC application		19 January 2012
Response to Request for Further Information		14 February 2012

### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

### After ethical review

#### Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports

- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

#### Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

12/LO/0202
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Please quote this number on all correspondence
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With the Committee's best wishes for the success of this project

Yours sincerely,



pp Ms Carol Jones  
Chair

Email: [Ubh-tr.CityandEastREC@nhs.net](mailto:Ubh-tr.CityandEastREC@nhs.net)

Enclosures: *"After ethical review – guidance for researchers"*

Copy to: *Prof. John Senior*

*Miss Rebecca Ward, Imperial College Healthcare NHS Trust*