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Relatives' and nurses' experiences of sudden death in Accident and Emergency departments: A qualitative study

By

Sharon Anne Newton

A Thesis submitted in partial fulfilment of the requirement for the Degree of Master of Philosophy

The University of Huddersfield

February 2011

## **Abstract**

This qualitative study explored the experience of sudden death in A&E using an interpretive-phenomenological and narrative approach. The purpose of the study was two-fold: firstly, to gain an understanding of sudden death as experienced by bereaved relatives, and secondly, to explore the work of nurses in A&E, in particular their involvement with sudden death. Hence, the study was conducted in two parts. In both parts of this study the participants were engaged in revealing their experiences of sudden and unexpected death.

The first part of the study explored the impact of sudden death on the lives of the bereaved. Semi-structured interviews were undertaken to explore the personal impact and experience of loss. A total of seventeen relatives took part in these semi-structured interviews in which they were invited to discuss their personal experiences of sudden death. The analysis revealed that sudden death is a significant episode in the lives of bereaved relatives. Their experiences detailed how the initial shock surrounding the death permeated all aspects of their life. Analysis of the relatives' interviews led to a comprehensive understanding of the experience of sudden death and its impact in the lives of the bereaved.

In the second part of the study, the experience of sudden death from the perspective of A&E nurses was explored using narrative interviews. Twelve A&E nurses participated in the narrative interviews. Analysis of the nurses' narratives revealed that sudden death is a significant event for A&E nurses. The narratives revealed that working in a contemporary A&E environment is target orientated as opposed to patient focused. This often led to conflict for A&E nurses' as they balanced the workload of a busy environment with the needs of the suddenly bereaved.

In both parts of the study, the use of a qualitative approach enabled different perspectives or realities on the phenomenon of sudden death to be explored. The use of interviews was a deliberate choice in order to facilitate participants to describe and discuss their experiences of sudden death in keeping with phenomenological and narrative approaches.

## **Acknowledgements**

I would like to thank the relatives who participated in this research study. Their openness about their experiences of sudden deaths made this research possible. Their experiences were highly moving and emotional. I am indebted to each of them. I would also like to express my appreciation to the A&E nursing staff who participated. I am grateful for their willingness to talk about their experiences of A&E nursing. It has been my privilege to participate in these conversations and I appreciated the contributions of all who took part.

My appreciation is also extended to my research supervisors for their continued guidance and direction. I would like to thank my first supervisor, Dr John Costello, and my first supervision team Professor Sue Frost, Dr Dallas Cliff and Jane Williams. I am also indebted to my final supervision team of Professor Annie Topping and Jane Williams for their continued support and guidance during the last stage of my research study. Their help and direction has been invaluable.

I would like to thank my husband and family for their enduring love and support during my studies. They have been a constant source of encouragement, spurring me on to attain my goal and were always there to listen and guide me whenever needed.

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## Glossary of Terms

**Accidents:** An unforeseen event or one without an apparent cause; anything that occurs unintentionally or by chance, especially one resulting in damage or harm to an individual or property.

**Accident and Emergency (A&E) Department:**

A&E Major (Type 1) - Major A&E departments are Consultant-led services with full resuscitation facilities. These departments accommodate patients with any degree of accident or emergency. The role of a major A&E department is to assess and treat patients who have unforeseen injuries or illnesses. Major A&E departments are open twenty-four hours a day, three hundred and sixty-five days a year. The Major A&E department is the environment in which this study takes place. (When the term A&E is used in this study it refers to a major A&E).

A&E Single speciality (Type 2) - Single speciality A&E departments are also Consultant-led, but are mono- or single-speciality services e.g. ophthalmology or dental. These departments accommodate emergency patients with conditions that the designated speciality caters for.

A&E Minor (Type 3) - Minor injuries units offer services to emergency patients with minor injuries. These departments may be doctor or nurse-led. They see and treat patients with minor injuries and illnesses and can be routinely accessed without an appointment.

**A&E Reception:** A designated area where all patients who attend A&E register.

**A&E Minor Area:** Patients treated in the minor area present primarily with minor injuries and/or illness. Such patients may still be found to have significant problems, including fractures, dislocations, and lacerations requiring suturing.

**A&E Children's Waiting Area:** Children can present particular challenges in treatment, and so some departments have a dedicated children's area and others employ a play therapist whose job is to put children at ease and to reduce the anxiety caused by visiting the emergency department, as well as providing distraction therapy for simple procedures.

**A&E Major Area:** Patients whose condition is not immediately life threatening will be sent to an area suitable to deal with them and these areas might typically be termed the "majors" area. Patients in this area may be treated for medical or surgical conditions and admitted to hospital for treatment.

**A&E Resuscitation Area:** The resuscitation area is of key importance in most departments and the most serious patients will be dealt with in this area; it contains the equipment and staff required for dealing with immediately life-threatening illnesses and injuries.

**A&E Viewing Room:** A private room used for viewing recently deceased patients in the A&E department.

**A&E Relatives Room:** A comfortable private waiting room set aside for relatives of patients brought into the Emergency Department with serious injuries and conditions.

**A&E Major Incident:** The Civil Contingencies Act offers a definition for certain events under the term "Emergency" but the three terms "disaster", "major incident" and "emergency" may be considered as one and the same. The definition is as

follows: 'An event or situation that threatens serious damage to human welfare, the environment or the security of the United Kingdom'. This definition encompasses a wide range of threats including loss of life, serious injury, homelessness, large scale loss of communications and disruption to health or communication services. In addition to this, under the definition laid out by the Civil Contingency Act, an incident threatening the UK must be so great that responding agencies require resources that are beyond the scope of their normal day-to-day operations.

**A&E Clinical Decisions Unit (CDU):** The CDU is a short stay unit designed to manage conditions that can be treated within 48 hours. For example, patients go to the unit from A&E to wait for results of investigations performed in A&E, for a period of observation, to be referred to a speciality, to arrange future care such as social services, or to have further investigations.

**Advanced Life Support (ALS):** ALS refers to the skills and knowledge that emergency practitioners or personnel possess. The ALS provider may perform advanced procedures and techniques on a patient involving invasive and non-invasive procedures, including, for example, defibrillation or intubation at the time of a life threatening emergency such as a cardiac arrest.

**Advanced Nurse Practitioner (ANP):** A registered nurse who has an expanded knowledge base, with complex decision-making skills and clinical competencies. A master's degree is recommended for entry level.

**Advanced Trauma Life Support (ATLS):** A training programme for doctors, Advanced Practice/Critical Care Paramedics, and A&E staff on the management of acute trauma cases, developed by the American College of Surgeons. Its goal is to teach a simplified and standardised approach to treating trauma patients. Originally designed for emergency situations where only one doctor and one nurse are present, ATLS is now widely accepted as the standard of care for initial assessment and treatment in trauma centres. The premise of the ATLS programme is to treat the greatest threat to life first.

**Advanced Paediatric Life Support:** The APLS provider course is intended to provide training for multi-disciplinary health care professionals in the early recognition of a child in respiratory or circulatory failure and to prevent further deterioration.

**Algorithm:** An algorithm provides a standardised approach to the management of patients in cardiac arrest. Shockable and non-shockable rhythms are viewed in terms of a pathway or algorithm followed as a means to correct the situation.

**Ambulance staff:** Staff who work for the ambulance service, including technicians, paramedics or rapid responders

**Bystander:** Lay people, usually present at the scene of an incident.

**Bystander cardiopulmonary resuscitation:** Lay people, usually present at the scene of an incident, performing basic life support.

**Cardiac arrest:** Cardiac arrest is the cessation of normal circulation of the blood due to the failure of the heart to contract effectively; if this is unexpected it can be termed a sudden cardiac arrest.

**Cardio-respiratory arrest:** The sudden cessation of spontaneous respiration and circulation; it is a potentially reversible life-threatening situation when the techniques associated with cardiopulmonary resuscitation are applied.

**Cardiopulmonary resuscitation:** A highly sophisticated area of medical science and technology aimed at improving the survival of patients who are victims of cardio-respiratory arrest.

**Clinical death:** The interval (approximately 4 min) in which life can be restored through cardiopulmonary resuscitation. Vital organs cannot function without external intervention.

**Coronary Care Unit (CCU):** A coronary care unit is a hospital unit specially staffed and equipped to treat patients with serious cardiac problems. It specialises in the care of patients with heart attacks, unstable angina and various other cardiac conditions that require continuous monitoring and treatment.

**Elective surgery:** Elective surgery is surgery that is not urgently required due to an emergency.

**Emergency nursing:** Defined as the nursing knowledge and skills required for the assessment and management of acute and urgent aspects of illness and injury affecting patients of all age groups with a full spectrum of undifferentiated physical and behavioural problems.

**Emergency medicine:** a field of practice based on the knowledge and skills required for the prevention, diagnosis and management of acute and urgent aspects of illness and injury affecting patients of all age groups with a full spectrum of undifferentiated physical and behavioural disorders. It also encompasses an understanding of the development of pre-hospital and in-hospital emergency medical systems and the skills necessary for this development.

**Family-witnessed resuscitation:** A programme of care that offers family members the opportunity to remain present during the resuscitation of a relative. Support is provided by an experienced trained nurse who is assigned to the family member solely for this purpose.

**High Dependency Unit (HDU):** An area for patients who require more intensive observation, treatment and nursing care than would be usually provided on a general ward. A standard of care between the general ward and full intensive care

**Intensive Care Unit (ICU):** An intensive care unit, also sometimes known as a critical care unit or an intensive therapy department, is a special ward that is found in most hospitals. It provides intensive care, treatment and monitoring for people who are in a critically ill or unstable condition. People in ICUs need constant medical and nursing support to keep their body functioning. They may not be able to breathe on their own and they may have multiple organ failure. Medical equipment takes the place of these functions while the person recovers.

**Intubation and ventilation:** Tracheal intubation, usually referred to as intubation, is the placement of a flexible plastic tube into the windpipe to maintain an open airway or to serve as a conduit through which to administer certain drugs. This invasive medical procedure is frequently performed in critically injured, ill or anaesthetised patients to facilitate positive pressure ventilation of the lungs, including mechanical ventilation, and to prevent the possibility of asphyxiation or airway obstruction.

**Medical Assessment Unit (MAU):** An acute medical assessment unit, or acute admissions unit, is a short-stay department in UK hospitals that is sometimes part of the emergency department, although separate. The MAU acts as a gateway between a patient's general practitioner, the emergency department, and the wards of the hospital. It is usually made up of several bays and has a small number of side-rooms and treatment rooms. They are fully equipped with emergency medical treatment facilities including defibrillators and resuscitation equipment.

**Miscarriage:** Miscarriage or spontaneous abortion is the spontaneous end of a pregnancy at a stage where the embryo or foetus is incapable of surviving, generally defined in humans as being prior to 24 weeks of gestation. Miscarriage is the most common complication of early pregnancy.

**Murder (Homicide):** Murder, as defined in common law countries, is the unlawful killing of another human being with "malice aforethought"; this state of mind generally distinguishes murder from other forms of unlawful homicide (such as manslaughter).

**Myocardial Infarction (MI):** Myocardial infarction or acute myocardial infarction (AMI) is most commonly known as a heart attack, and is the interruption of blood supply to part of the heart, causing heart cells to die. This is most commonly due to occlusion (blockage) of a coronary artery following the rupture of a vulnerable atherosclerotic plaque, which is an unstable collection of lipids (fatty acids) and white blood cells (especially macrophages) in the wall of an artery. The resulting ischemia (restriction in blood supply) and oxygen shortage, if left untreated for a sufficient period of time, can cause damage or death (infarction) of heart muscle tissue (myocardium).

**NHS walk-in centres:** These first opened in 2000 to offer convenient access to a range of NHS services. They are predominantly nurse-led first-contact services available to everyone without need for an appointment. They primarily deal with patients who have minor illnesses and injuries. Most centres are situated in convenient locations that give patients access to services beyond regular office hours. All these facilities offer emergency treatment to patients who have suffered some form of accident or emergency.

**Poisoning:** The physiological state produced by a poison or other toxic substance.

**Road Traffic Collision/Accident (RTC/TRA):** A traffic collision (motor vehicle collision, motor vehicle accident, car accident, or car crash) occurs when a road vehicle collides with another vehicle, pedestrian, animal, road debris, or other geographical or architectural obstacle.

**Suicide:** The act of a person killing them self.

**Sudden cardiac death:** Irreversible cardiopulmonary arrest. A natural death from cardiac causes (Myerberg and Wellens, 2005). The most frequent underlying cause among adults is coronary heart disease.

**Triage:** This refers to the sorting of patients according to the urgency of their clinical needs. Once assessed, the nature and severity of the patient's condition is determined. Patients with serious injuries and illnesses are then seen and treated by medical and nursing staff more rapidly than those with less severe injuries or illnesses.

**Trauma:** Any physical damage to the body caused by violence, accident or fracture.

## Prologue

After qualifying in 1989 following a four year nursing degree in Edinburgh, I worked as a staff nurse in acute medical environments, including a Coronary Care Unit. My intention was to specialise in District Nursing; on application for this I was advised to gain further experience in a broader nursing context. Hence I moved to a large city Accident and Emergency department for career development and to gain the necessary experience.

My initial impression of A&E was one of shock, both in relation to the nature of the work and the A&E staff. I arrived as an outsider in an environment where there was a very close team. I had no A&E experience except as a student nurse. There was no induction, but rather an ethos of “learning on the job”. This role was personally and professionally challenging, associated with a plethora of feelings and self-doubt about whether this was the right role for me. After six months something changed. I found I had penetrated this close team to become one of them. It is difficult to capture and put into words what this change involved. Part of it was connected to being accepted into the team and developing a deeper understanding of A&E nursing, along with a sense that I had found my niche. However, it was often noted by other more experienced A&E nurses that I was not a typical A&E nurse, but no explanation was forthcoming as to why this was the case. On reflection, I think these comments related to my non-judgemental attitude and my desire to care for the person as a whole. My inherent nursing nature has been to respect people of all backgrounds, regardless of their status. I was often scolded by sister for giving tea and sandwiches to regular attendees in A&E (i.e. the homeless) or offering them a place to change, as this would encourage return visits. Treating all patients with respect and dignity and seeing the patient as a person has been fundamental in my nursing work. Working in A&E has meant being involved with people from all ages, all walks of life

and with all nature of injuries and illnesses. This has also included patients who are dead on arrival, who are dying and for whom death may be preventable through resuscitation.

I did not encounter much death during my training or in the other areas in which I had worked. A&E was where I first encountered sudden and unexpected death. One particular incident that remained with me took place on my first night shift about a month after starting in A&E. Ambulance control rang to alert the A&E department to an incoming paediatric emergency. This baby was critically ill and in need of emergency treatment.

I was allocated to care for this baby in the resuscitation room despite being the most junior nurse on duty. I felt particularly anxious about the situation. I was asked by the Charge Nurse to go to the receiving bay to meet the ambulance. Perhaps having sensed my apprehension, the Charge Nurse accompanied me. As the ambulance drew up I observed the mother's ashen face as she watched what was happening to her child. At that point the Charge Nurse turned to me and said "you're doing the relatives". I had never heard this phrase before but made an assumption that this meant looking after any relatives. The Charge Nurse took the baby from the ambulance crew and ran into the resuscitation room. I took the mother into the relative's room, and minutes later the father arrived followed by other relatives.

At that point I felt completely helpless and inept. I had never dealt with relatives before and did not know what to do. No help was forthcoming from any other member of staff and all I could do was what I thought was right. The resuscitation attempt was prolonged and lengthy, with every conceivable intervention being tried to save this young life – this was to no avail and the baby died.

Inside I felt distraught. How was I going to tell this mother her baby was dead? How was I going to break this news? How was I going to care for her and her family? What

was I going to say and do? Somehow I managed to tell the mother and father and other relatives that the baby had died. I explained what had happened in the resuscitation room. The mother requested to see the baby. Being unsure if I was allowed, I sought advice and was informed by a staff nurse that this was acceptable. I found a small Moses basket and wrapped the baby in a sheet, as all clothing had been removed in the resuscitation attempt. The relatives' room was situated near an A&E waiting area and I had to take the baby across the waiting area to the parents. Although I had not planned to do so, I remained with the family for the whole of the night in A&E. Talking, listening, crying, supporting and merely being with them. Being uncertain of when the family should leave I asked other staff for direction and the answer was "you will just know". I was concerned about how I would "just know", but after several hours the family asked about what would happen next and indicated they felt it was time to leave and the family left to go home. Saying goodbye was my last contact with them.

This was my first experience of sudden death in A&E. The whole experience was distressing, shocking and yet challenging. I had no previous experience of "doing the relatives" and wondered whether this was really a role for a novice A&E nurse. At the end of the shift there were no words of comfort from anyone, no one asked how I had coped, what I had done or how I felt. I left A&E in tears unable to tell anyone at either work or at home how I felt.

I reflected on the situation for a long time, and have done so many times since. Despite feeling so inadequate, or perhaps even because of it, I felt I had to try and learn more about sudden death and the care of relatives in A&E. I was interested to know what other staff in A&E felt about sudden death and how they perceived their role in this.

## Chapter One – Introduction and overview of the study

### The reality of sudden death

This is a short extract from one of the relative's interviews that portrays the reality of sudden death.

Betty: *Okay my husband had gone out training he left here about 1820hrs...he was training with a friend and about 8pm the doorbell rang and I thought it was him back and I said to Celia (referring to daughter) go and let your Dad in, he's forgot his keys and when we got there it was Nick (referring to friend), the friend he was training with.*

Sharon: *Right...*

Betty: *He said Dan (referring to husband) had a heart...Dan had to go into hospital, now he'd had to go a time before and I said to him like the last time and he said no its more serious this time... it's the leads what have you...he'd been training he'd stopped...he'd done that once before last time he thought he was just joking...this time he realised it was serious and he'd called for an ambulance and err...he...they were taking him to Hospital...now I said to him like last time and he said no its more serious...and...err...so...you can't stop him doing what he wants to do with his life so Nick went and Celia and I gathered things together to take down to the hospital came into Accident and Emergency and the receptionist took my details and then we hung about. She (referring to receptionist) said Sister will be with you shortly...we hung about we couldn't sit down as we obviously knew something was wrong.*

Sharon: *Yes...*

Betty: *It wasn't like it was the time before and we hung about and hung about and nobody gave us any information at all...and we looked down at one stage...down a corridor and we could see a crash team coming out looking very dejected...and I said to Celia 'what's going on here?'...and...err...we had waited a reasonable amount of time and I think the receptionist realised we'd seen this and we were obviously looking anxious and she...she trotted down and she said she would get Sister and she came back up and collected us and took us into a room and err...I said to her is he still with us and she said no he's not.*

(Interview conducted on 10/10/2000)

This is a short extract from Betty's interview that shows the reality of sudden death.

Her husband, who was relatively fit and healthy, had collapsed suddenly at the gym.

This was unexpected and the last time she had seen her husband he had been well.

The next information she received was that her husband was dead. This was totally

unexpected, sudden and catastrophic for Betty and her family. There was no chance to say goodbye and no opportunity to fulfil their life-long plans.

### **Research Topic**

Sudden death in the Accident and Emergency (A&E) department.

### **Overall Aim**

This research presents two discrete studies that together present insights into the experience of sudden death from the perspective of suddenly bereaved relatives and A&E nurses.

### **Goals**

In part I, the goal was to explore sudden death from the perspective of the bereaved relatives and gain a deeper understanding of the lived experience of sudden death.

In part II, the goal focused on the experience of A&E nurses and explored the work of nurses in A&E, particularly their involvement with sudden death.

### **Summary of subsequent chapters**

The literature review presented in chapter two provides an in-depth understanding of the trajectory of sudden death in the context of A&E. Rather than explaining the stages and transitions that are common following a sudden death, the first study sought to uncover and explore the personal experience of loss and bereavement as a consequence of sudden death. The literature review also relates to the second study and presents as background an overview of emergency nursing in order to contextualise the narrative interviews undertaken with A&E nurses.

Chapter three deals with the methodology used in the research, a qualitative interpretive framework formed the underlying paradigm for both studies. The phenomenology and the narrative methodologies being used for part I and part II respectively. This chapter also discusses the data collection methods and data

analysis for part I and part II of the study and addresses the ethical issues in the study. Ensuring the study was ethically sound required consideration of key issues; for example, informed consent and anonymity for the participants.

Chapters four and five form the results chapters for part I and part II of the study. The themes and sub themes which emerged from the analysis of the data are presented and are discussed with reference to the findings of the literature review.

Chapter six includes the synthesis, discussion and conclusions arising from part I and part II, as well as the limitations of the study. The researcher's reflections and recommendations for future research and action are highlighted.

## **Chapter Two – Sudden death in the A&E environment**

### **Introduction**

The purpose of this chapter is to introduce the A&E environment, its function and purpose and how this is linked to sudden and unexpected death. Analysis of statistics and surveys will enlighten the reader about how death and dying have changed in the United Kingdom (UK) over the last century. Within the UK and within Westernised society generally, death has come to be seen as a “taboo” (Walter, 1999). Associated with this is the assertion that UK and Westernised societies are death-denying; the evidence surrounding this assertion is critically reviewed in this chapter. Whilst reviewing the literature, attention is drawn to the ways in which people die and the characteristics that are usually associated with a “good death” has been highlighted. Following a review of the principles underpinning a good death, and using these as a template for good practice, the last section of the chapter investigates how death occurs in A&E, with specific reference to suddenly-bereaved relatives.

### **The A&E Environment**

#### **Definition of A&E**

The Accident and Emergency department provides immediate assessment, treatment and care for patients of all ages presenting with acute illness or injury of varying severity. The term “Casualty”, referring to a seriously injured patient, derived its meaning from two origins. Firstly, it was predominantly a military word. After a battle the dead, wounded and sick were lumped together as casualties (Sakr & Wadrope, 2000). Secondly, it was associated with a “workhouse casual”<sup>1</sup>, who was

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<sup>1</sup> A *workhouse* was a public institution which housed and fed people who were unable to support themselves (Cambridge Dictionary, 2009)

an irregular and unexpected caller in need of temporary help (Sakr & Wadrope, 2000). Hence the Casualty department developed as an area for patients who had experienced some form of unforeseen accident, where the work load was unpredictable, unplanned, or casual (Guly, 2005).

Within the hospital environment there is no other setting like the A&E department that caters for patients of all ages, with all manner of conditions and complaints, or that deals with the same range of presenting conditions, from major trauma to minor injuries and illnesses. This spectrum of work means that there is a constant flow of patients presenting in A&E and being discharged home, admitted to hospital or dying in A&E on a twenty-four hour basis.

The National Health Service (NHS), which was created in 1948, inherited a number of Casualty departments, most of them substandard with inadequate staffing (Guly, 2005). In 1959, the British Orthopaedic Association recommended major changes to Casualty departments. This new infrastructure was the precursor to the modern UK A&E service. Concerns remained regarding the level of care provided for seriously ill and injured patients (Guly, 2005). These concerns culminated in the Platt Report (1962) that recommended Casualty departments should change in their function and provide a twenty-four hour service. The provision of care to casual attendees should be secondary, thereby prioritising care for seriously ill and injured emergencies. In 1998, further modernisation in A&E was commissioned by the Government in *Reforming Emergency Care* (Department of health, DoH, 2001a) due to dissatisfaction with the A&E service and waiting times. This resulted in major reforms in the emergency service.

Today there are 205 A&E departments in England providing a 24-hour service and the demand for emergency care services continues to rise. In 1992 in England, the attendance figure for new and follow up A&E attendances was 13 million. By 1999, this had risen to 14.6 million, then to 16.5 million in 2003/04 (Health Care Commission, HCC, 2005). Today 18 million people attend A&E departments in

England each year (DoH, 2009), which range in size and capacity and can treat anywhere between 20,000 and 130,000 patients per annum. A typical A&E department treats an average of 60,000 patients per year. These statistics demonstrate that the number of patients attending A&E over the last decade has risen significantly.

The A&E department caters for a diverse client base. These range from patients with minor injuries and patients with serious conditions requiring hospital admission, to patients requiring resuscitation as a result of major trauma or life threatening medical illnesses and patients who die suddenly in A&E. Given the diversity of presenting patients, the A&E department is, by necessity, multifunctional, and the modern A&E department has to represent these multiple purposes in its design.

### **A&E department layout**

The A&E department is a purpose-built facility that caters for a diverse population of patients with different clinical needs. Having an entrance separate to that of the main hospital, A&E is situated near to x-ray and diagnostics services (NHS Estates, 2003). This facilitates rapid diagnosis and transition through A&E. Direct access from A&E to other critical care areas, such as the Intensive Therapy Unit or Operating Theatres, enables the prompt transfer of critically ill patients (NHS Estates, 2003). Accessibility to admitting wards, such as Medical Assessment Unit (MAU), is also a necessity. The A&E department is divided into different areas: minor, major and resuscitation; in close proximity to the resuscitation room is the relatives' room where relatives may wait when accompanying seriously ill patients. Alongside this is a viewing room where patients who have died suddenly in A&E can be viewed by their relatives in privacy.

The main waiting room is separated from the paediatric waiting area, which has recently become standard in A&E with dedicated facilities for children. This protects children from witnessing distressing situations such as violent and aggressive adult

patients (National Service Framework for Children, NSF, 2003). However, due to the difficulty in recruiting paediatric nurses to A&E, this area is not always available for use. The A&E department may also include an observation ward and/or a Clinical Decision Unit for patients who require a short period of additional observation or are waiting for the results of investigations before a discharge destination is decided.

### **Health policy reforms (targets)**

With the election of a new government in 1997 further NHS reforms were set out in the *A First Class Service* document (DoH, 1998) which aimed to ensure clear national standards for quality. The A&E department was not exempt from these changes and numerous developments have since taken place. A&E gained attention from the media in the 1990s due to long delays and increasing waiting times. The Audit Commission (1996 & 1998) reported on A&E services and found:

- long waiting times for emergency treatment or admission
- poor provision for some vulnerable patients such as children
- poor supervision and support for junior doctors
- poor provision and use of information in many departments

A further review was repeated in 2000 as part of the Audit Commission's Acute Hospital Portfolio (2000) and played a vital part in reforming emergency care. The NHS Plan (DoH, 2000) set targets to reduce waiting times in A&E departments. Following on from the NHS plan, a ten year strategy called *Reforming Emergency Care* (DoH, 2001a) was published to drive changes in emergency care, and this set out an ambitious programme of reform. Table 2.1 charts the main targets.

**Table 2.1 Targets for Reforming Emergency Care**

December 2002	Improved ambulance response times: An ambulance will respond to 75% of calls with life-threatening emergencies within eight minutes.
March 2003	75% of patients having a Myocardial Infarction will receive thrombolysis within 20 minutes of their arrival in hospital
March 2004	All patients requesting to see a GP will do so within 48 hours
March 2004	No patient to wait more than 4 hours in an A&E department, from arrival to admission to a bed in the hospital, transfers elsewhere or discharge. The average length of waiting should fall to 75 minutes.

(DoH, 2001a)

The plan stipulated that by 2004 98 per cent of all A&E patients should be seen and discharged or admitted within four hours. However, failure to meet the four hour target was commonplace in A&E for patients with minor problems where longer waits were justified if resources were being used to treat those patients suffering from major life-threatening illnesses and injuries (Rogers et al, 2004). The reforms prompted major changes in the way A&E departments functioned. One such change involved A&E Streaming. Each stream of patients, i.e. minor, major or resuscitation was seen independently from the other streams, with a team of nurses and doctors dedicated to that stream. As a consequence, patients with minor conditions no longer had to wait until a doctor or nurse was released from the resuscitation room before being treated and their wait was significantly reduced. The government reforms encouraged role expansion for nurses, and A&E nurses often expanded their skills through role development and substitution, i.e. adopting tasks that were traditionally associated with medical roles. This was heralded as a way forward in reducing the waiting times for patients with minor injuries and illnesses and contributed to meeting the four hour target.

It is without doubt that the reforms have been effective in reducing waiting times in A&E (HCC, 2006). In England at the beginning of 2003, almost a quarter of patients

spent more than four hours in A&E. By April 2004 95 per cent of patients in A&E left the department within four hours and this rose to 98 per cent in April 2005 (HCC, 2006). Patients using A&E reported spending less time waiting in A&E and noted improved care whilst in A&E.

### **A&E multi-professional teams**

One of the key strengths of the A&E department is teamwork, through which all professional groups and specialities work together, but at the same time are interdependent (Endacott, 2003). There is a large multi-professional team in A&E consisting of Consultants, Staff grades, Specialist Registrars, Senior House Officers and Foundation-level Doctors, Modern Matrons, Nurse Consultants, Clinical Nurse Leaders, Registered Nurses and Emergency Nurse Practitioners. Health Care Assistants, Technicians, Receptionists, Secretaries and Cleaners also form part of the A&E team. Other disciplines, such as Ambulance personnel, Radiographers, Physiotherapists, Occupational Therapists, Mental Health Liaison and District Nurses make up the wider health care team involved in A&E. Endacott (2003) suggests that working in a busy, demanding and stressful environment, such as A&E, means that a certain level of trust, reliance and collaboration is fostered between team members which promotes an environment conducive to cohesiveness and increased morale.

### **A&E nurses**

The diverse population of patients seen in A&E means that nurses will encounter people of all ages with a variety of conditions with different clinical needs. A&E offers enormous scope for developing nursing skills, ranging from wound closure to advanced life support. Studies examining A&E nursing, such as Walsh and Kent (2003) or Dolan and Holt (2007), claim that the fundamental aspects of care, such as physical comfort and psychological support, are as important in A&E nursing as the advanced skills. However, the validity of this statement is questionable, as much of the literature surrounding A&E work concentrates on advanced trauma life support or

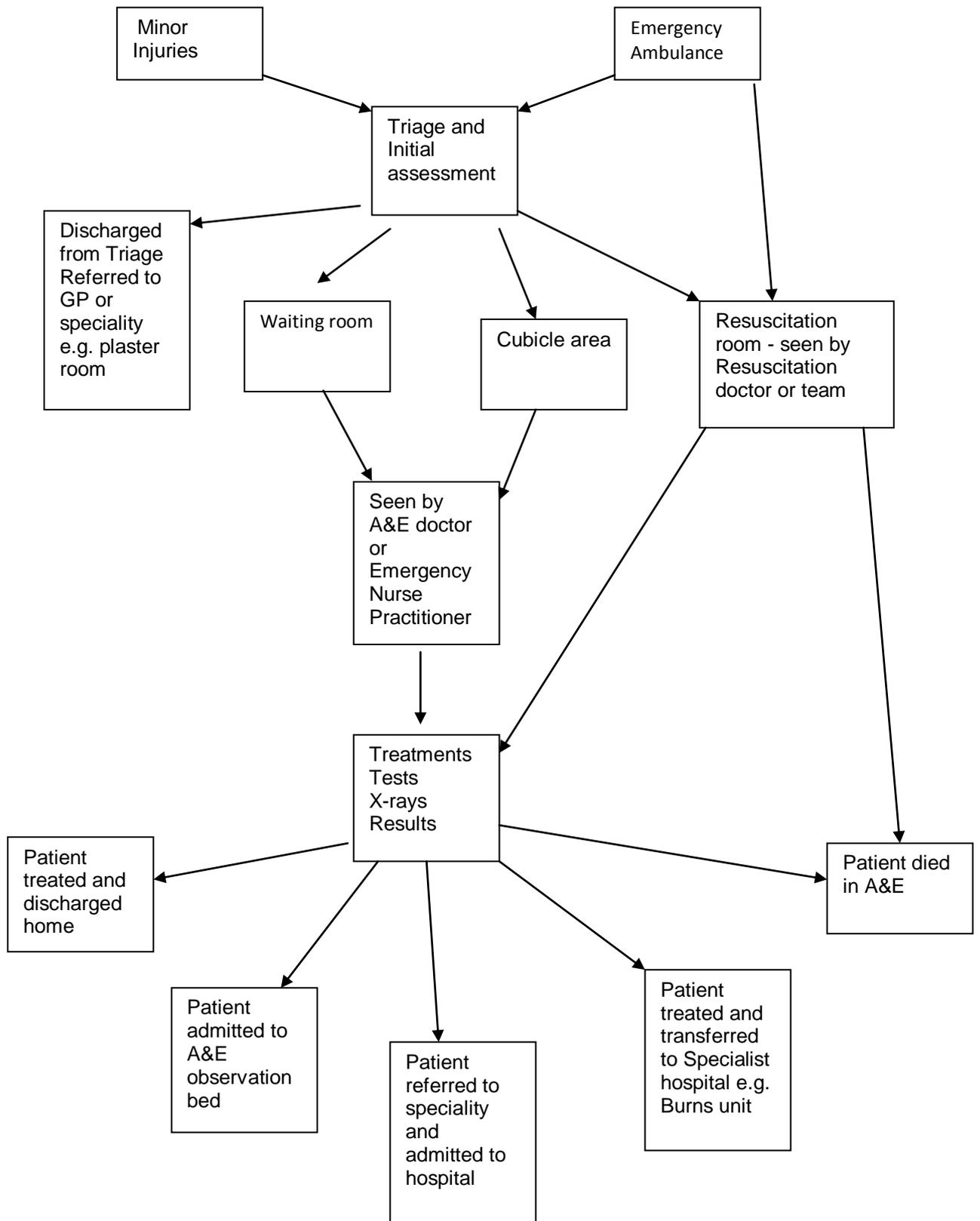
expanded skills such as defibrillation. In contrast to widespread perceptions, few patients attending A&E have life-threatening injuries. Major trauma equates to less than 0.2 per cent of the total A&E activity in England (National Audit Office, NAO, 2010). However, over 50 per cent of patients attending A&E have less serious conditions, such as minor injuries and illnesses (DoH, 2009). Approximately 3.5 million children attend A&E annually in England, the majority of whom did so following a minor trauma (Hospital Episode Statistics, HES, 2009). However, a culture has developed in A&E whereby saving lives is the primary focus of A&E nurses. This culture may persist because of the stimulation generated by the resuscitation or major trauma event, despite its low occurrence, balanced against the instantaneous nature of the work.

Nursing has developed and diversified and nurses are now recognised and defined by their area of speciality, such as A&E nursing. Despite nursing as a whole sharing similar fundamental characteristics, such as caring or listening skills, in each specialist area the nurses share common knowledge, goals, values and beliefs that make their work distinct from other areas. This is true in A&E nursing where nurses come to learn the importance of, for example, acute assessment skills, adaptability, working under pressure, diversity and teamwork. According to Newton and McKenna (2007) socialisation is about learning the norms and values associated with each area. Therefore, new members of staff learning about A&E protocols and procedures must at the same time become integrated and socialised into the A&E culture with its accepted beliefs, such as the culture of curing and the emphasis on resuscitation and life saving.

### **What happens in A&E?**

Traditionally there are two entrances to A&E: one for minor injuries and one for ambulance and resuscitation cases. Figure 2.1 below shows the patient flow through the A&E department.

Figure 2. 1 Patient flow through A&E



On presenting in A&E, a patient is registered and assessed according to the urgency of their clinical needs. Once assessed, the nature and severity of the patient's condition is determined. Essentially, patients with serious injuries and illnesses are seen and treated by medical and nursing staff more rapidly than those with less severe injuries or illnesses.

Patients with minor problems are treated in the minor section. Patients who are stable but need to be confined to a trolley are allocated to the majors' area. Patients in this area usually have a wide range of medical or surgical problems that require further investigation and possible admission. The resuscitation room is a key area of an emergency department where critically ill and injured patients are treated. It contains several individual resuscitation bays, with one dedicated to paediatric resuscitation. This area accommodates men, women and children; often at the same time. Each bay is equipped with a variety of equipment specifically designed to assist in the resuscitation of patients. Of the patients who attended A&E in England between 2008 and 2009, some 7,770 patients required active resuscitation as part of their treatment in A&E (HES, 2010). Often, despite extensive resuscitative attempts, patients die in the A&E resuscitation room.

### **Social organisation of death in A&E**

A death in an acute environment such as A&E presents an alternative script to that in other less acute areas such as a hospice environment (Page & Komaromy, 2005). A patient presenting near to death in A&E usually results in dramatic resuscitation activity whereby staff follow resuscitation protocols, perform Cardio-pulmonary Resuscitation (CPR), give drugs, or intubate (Timmermans, 1999). The goal is to save life or, perhaps more realistically, to delay death. Every aspect of the emergency procedure reinforces the impression that sudden death is an untoward or unwanted event (Timmermans, 1999). The event is highly focused, and may last from minutes to hours depending on the patient's condition and response to

treatment. The approach may appear technical and mechanistic (Moller, 2000; Timmermans, 2005). Being prepared and educated for emergency situations means A&E staff are suitably equipped to deal with any form of emergency. Following protocols for resuscitation and advanced life support enables A&E staff to establish order in what might appear to be a chaotic situation. This is particularly relevant if the resuscitation is being witnessed by family members. Therefore, in A&E sudden death is constructed as a medical or traumatic emergency that is potentially reversible (Page & Komaromy, 2005). Any remote possibility of survival means that death may be averted. The emphasis is on life saving and is a fundamental part of the work in which A&E nurses participate.

### **A&E philosophy – a life-saving ethos**

One of the primary aims of the A&E philosophy is the preservation of life (Dolan & Holt 2007; Timmermans, 1998). In the event of a patient being critically ill or injured, the focus in A&E often involves life-saving interventions through active resuscitation. Advanced life support measures involving CPR are employed where the sudden demise of a patient is perceived as unexpected, untimely and potentially, through skilled intervention, seen as reversible (Walker, 2008). Hope et al (2003) suggested three outcomes following resuscitation: immediate death, prolongation of life in a state similar to that prior to the arrest, and prolongation of life in a state that is worse than that prior to the collapse. In the event of a sudden illness where CPR is needed, the survival rates for patients are poor – see table 2.2

**Table 2.2 Survival rates post Cardiac Arrest**

<b>Type of Arrest</b>	<b>*ROSC</b>	<b>Survival</b>
Witnessed In-Hospital Cardiac Arrest	48%	22%
Un-witnessed In-Hospital Cardiac Arrest	21%	1%
Bystander CPR	40%	4%
No Bystander CPR	15%	2%
Defibrillation within 3-5 minutes	74%	30%

(American Heart Association, 2007; Resuscitation Council, 2010)

The majority of resuscitation attempts are unsuccessful. In a survey by Peberdy et al (2003) of 14,720 patients who experienced an in-hospital cardiac arrest, less than 20 per cent survived to go home. Despite these figures, Hope et al (2003) suggested that resuscitation measures have become routine therapy in most hospital settings. Timmermans (1999) suggested that resuscitation has become an inherent part of A&E work and that there is an unspoken subtext that resuscitation always takes place; therefore, the overuse of resuscitation defines staffs' experiences of sudden death. Associated with this is an expectation of cure within society and the elusive search for the postponement of death.

Health care in the 21<sup>st</sup> century has become characterised by medical and technological innovation. Subsequent improvement in the treatment of complex diseases and conditions means that more people survive today than in the past (World Health Organisation, WHO, 2008). The A&E environment is orientated towards advanced technology, resuscitation, defibrillation, invasive procedures and interventions. All these resuscitation practices are aimed at improving the survival rate of critically ill and injured patients, supporting a life-saving ethos.

## **Death**

### **Definition of death**

Defining death is challenging and problematic. Coming to the conclusion that an individual has died is difficult because as medicine and technology have advanced, more interventions have been discovered that can prolong life and avert death.

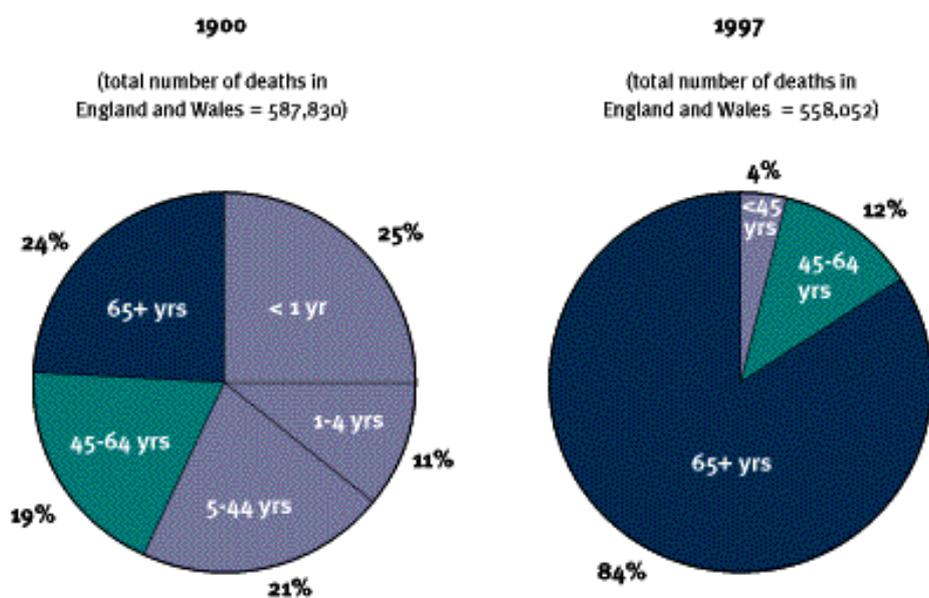
Therefore, in the past the definition of death was when a person's heart and breathing had stopped. As technology developed, the means of restarting the heart and breathing have become a reality. Thus the phase between life and death has expanded.

Hershenov (2003) argues that death is a biological concept that should be determined solely by biological factors. Defining death from a biological perspective originally focused on the cessation of heartbeat and breathing. Before the 1960s human death was primarily understood and diagnosed by cardio-pulmonary criteria (Rodabough, 2003). The irreversible cessation of heartbeat and breathing constituted the death of the person. On the basis of the confirmed and persistent absence of these vital signs, a person was declared dead (Rodabough, 2003). This longstanding definition of death was critically undermined by developments in medical technology. For a period of time after the heart has stopped and respiration has ceased, the patient may still potentially be resuscitated and their life restored (Walker, 2008). The development of CPR and defibrillation meant that the heartbeat and breathing could be restarted, rendering this definition inadequate. With the cardio-pulmonary definition of death undermined, an alternate definition of death was sought. Attention was then drawn to the concept of brain death. In brain death, people are considered dead when the electrical activity in their brain ceases (Rodabough, 2003). In conclusion, Bernat (2009) suggests that human death is determined in two ways: demonstrating the irreversible cessation of all brain clinical functions and the permanent cessation of circulatory and respiratory functions.

It would appear, therefore, that a clear definition of death is difficult to ascertain. Medical and technological advances mean that cessation of respiration and circulation can no longer be the only parameters used to define death as it may be possible with intervention for patients to start breathing and regain their heartbeat. Consequently, the boundary between life and death is sometimes difficult to ascertain so perhaps the emphasis on life-saving measures in the A&E environment is justified in the light of the difficulties in determining death. The next section analyses the statistics concerning death and dying.

Just 100 years ago, many people died at an early age in the UK. Infant and maternal mortalities were high with over 50 per cent of deaths occurring in people under the age of forty-five; therefore, fewer people reached old age (Boyer, 2004). The average life expectancy in 1900 was around 50 years of age (Office of National Statistics, ONS, 2008); see Figure 2.2. In comparison, in 2007, only four per cent of deaths occurred in the under-45 age group (ONS, 2008).

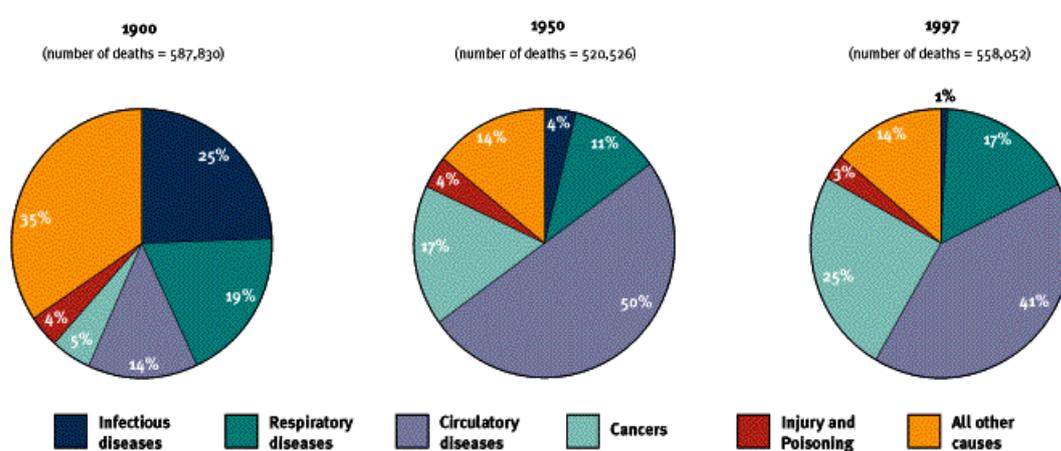
**Figure 2.2 Age at death at the start and end of the 20th century**



(ONS, 2008)

Today, the UK average life expectancy has increased and is 77.2 years for men and 81.5 years for women (ONS, 2008). According to Boyer (2004), scientific and medical advances, such as the introduction of antibiotics and immunisations, and improvements in health and safety, sanitation, hygiene, living conditions and nutrition, have all contributed to people living longer. The diseases causing death have changed in the UK over the last century; see Figure 2.3.

**Figure 2.3 Causes of death in the UK at the start, middle and end of the twentieth century**



(ONS, 1998)

At the start of the last century, deaths resulted from ill-defined causes or infectious diseases. After the Second World War, heart disease, stroke and cancer became the leading causes of death (WHO, 2008). Heart and circulatory disease is the UK's biggest cause of death; in 2007, cardio-vascular disease (CVD) accounted for 34% of deaths in the UK; that is over 90,000 deaths a year (British Heart Foundation, BHF, 2009). Deaths in A&E do not just result from cardiac conditions; deaths also occur as a result of respiratory problems, toxicity, poisoning, suicide, anaphylaxis or injury. Severe injuries, such as road traffic accidents or falls, are also common causes of death across all ages in the UK and result in over 16,000 deaths per year in England and Wales (ONS, 2006). Injury is now the leading cause of death in people under the age of thirty-five in England and Wales. The sort of trauma has changed in response

to changing lifestyles; for example there are now faster road traffic accidents in motorway collisions.

At the start of the last century approximately 85 per cent of people died in their own homes, with workhouses being the second most common place of death (DoH, 2008). By the mid-twentieth century around 50 per cent of people died at home (DoH, 2008). Today less than one-fifth (18.5 per cent) of deaths in England and Wales take place at home and more than half (58.3 per cent) occur in hospital (DoH, 2008; ONS, 2009). As a result the population has less exposure to the experience of death in the home environment; instead, death is most often experienced within a hospital environment. Here death is medically managed, often with minimal involvement of the family members.

In 1900, most people died in their own homes and acute infections were a much more common cause of death; therefore, a far higher proportion of all deaths occurred in childhood or early adult life. This meant that society as a whole was generally more accustomed to experiencing death. Societal changes mean that fewer people die at home and more deaths occur in a hospital environment. Hence, familiarity with death within society as a whole has decreased.

### **Death denying society**

The diminishing involvement with death has led to the assertion that some Westernised societies are “death denying”. Zimmerman (2007) suggests a reluctance to speak about death and dying has permeated many areas of society. Pecchinenda (2007 p.169) concurs, stating that modern Westernised society is distinguished “by its evident refusal of the concept of death.” He further argues that Westernised society has adopted collective defence strategies which have become more or less internalised to mitigate the disturbing effects of death. These strategies include, for example, an emphasis on youthfulness, health and wellbeing, and the sequestration of older people into institutions.

Other transformations within society have contributed to the notion that Westernised society is death denying. For example, in UK society there have been changes in the roles, structure and responsibilities of families. Murray et al (2005) suggested the contribution of social re-organisation, geographical mobility and intergenerational geographic distance within families means that there are increasing numbers of family members living further apart. This has led to fragmented family and social circles. A consequence of this is that modern individuals are more detached from tradition, place and kinship, leading to reduced intergenerational contact (Walter, 2007). Therefore, there are fewer opportunities for younger family members to have contact with older generations and to participate in death-related experiences. During the second half of the twentieth century the burden of care, once assumed by family, was passed on to others, such as nurses and doctors (Cooter et al, 2003); as a result, more people died in hospital rather than at home. Froggatt (2001) argues death has become sequestered and institutionally confined in response to a transforming culture that is increasingly fearful of dying.

As a consequence of advances in science and technology, modern health care systems have developed to cure illnesses, prolong life and ultimately defer the process of dying (Page & Komaromy, 2005). If illnesses can be cured or deferred to a chronic status and death delayed or averted, this contributes to an ethos of death denial and the link between death and illness is broken. Moreover, death has become medicalised (Al-Qurainy et al, 2009); an event that takes place within hospitals, often surrounded by machinery and technology, with an emphasis on cure rather than care. Whilst attempting to defer death, Timmermans (2005) argues that death has undeniably become more technical and medically oriented. Similarly, Green (2008) suggests that death has become redefined in terms of a technical and medical process and has taken on the status of a disease. Western medicine may see death as a potentially curable disease that is potentially reversible; this is particularly true in A&E where prolonged resuscitation attempts take place

(Timmermans, 2005). However, Al-Qurainy et al (2009) warn that with this comes an expectation of cure.

The assumption that all life can be saved is fuelled, in part, by the media, which tends to dramatise death and dying to an extent that rarely resembles the reality of death. This often creates a false impression of death and dying, such as portraying more successful outcomes to critical illness and injuries. Television portrayals of medical dramas have been significant in influencing the public about medical issues. A mixed method study by Nava et al (2008) used questionnaires and interviews to examine the influence of the media on patient's knowledge regarding the outcome of CPR. They demonstrated that patients overestimated the success rate of CPR and that their perception of survival post CPR is much higher than is reported in current literature. For example, the American Heart Association (2007) reports that survival rates are poor following CPR (see Table 2.2). The majority of resuscitation attempts are unsuccessful and end in the death of the patient.

The notion of Westernised society being death denying has prompted much debate. Walter (1999) first coined the phrase "death taboo" to reflect how society avoided discussions about death and dying. Kellehear (2007) uses the "death taboo" as their underlying argument supporting the notion that much of Westernised society is death denying, meaning there is avoidance of death and death-related issues within society. In contrast Arnason and Hafsteinsson (2003) argue that society is now becoming more open to the subject of death after a revival of the discourse around death and dying. The hospice movement may have contributed to this increased discourse in society surrounding death and dying. Lee (2008) argues that a growing engagement in death and death-related issues would suggest that if there was ever a taboo, it is now no longer in effect. Lee's (2008) argument is debateable given that it conflicts with the large amount of evidence to the contrary; see, for example, Kellehear (2007) or Walter (1999; 2007).

## **Views of death as good and bad**

The previous section examined the debates surrounding the contention that contemporary Westernised society is death denying. Death has become a private matter, somewhat removed from society and sequestered into institutions and hospitals. Exposure to death and dying for the majority of the population has decreased. As a result, death has become something unknown, feared or denied, or is seen as a failure on someone's part. There are now reliable statistics concerning life expectancy, age at death and location of death, but less is known about the experience of death. The purpose of this section is to clarify what, in a general sense, is meant by a "good death", and to review the notion of a good death by analysing the characteristics that are usually associated with a good death.

Different periods in history have held different views about what constitutes a good death. For example, for the Greeks a good death took place at home where the dying person was closely surrounded by friends and family, allowing time for farewells. For the Romans, physical contact between the dying and the bereaved was important, with a relative kissing the deceased to catch the departing soul (Howarth & Leaman, 2001). Although interesting, time constraints inhibit a wider analysis of the historical aspects of a good death. The point, however, is that at different times in history the concept of a good death held different meanings. Today, a good death may equally hold different meanings depending on the context in which it takes place.

Aries (1981 p 28) suggested a good or "tame" death is one in which the dying person

"acted as a manager of ceremonies, presiding over his/her last days of life, conducting farewells, giving blessings and seeking pardons."

This death was a public event, taking place at the dying person's home with family, fellow workers and members of the community present (Aries, 1981). The tame death is contrasted with the "wild" death of modern society, where the dying person is hidden deep inside a hospital and isolated from the outside world (Aries, 1981).

A formal definition of a good death is provided by The Institute of Medicine (1997, p.24)

“...one that is: free from avoidable distress and suffering for patients, families, and caregivers; in general accord with patients’ families’ wishes; and reasonably consistent with clinical, cultural, and ethical standards.”

In this definition the emphasis is medically oriented; that it is to relieve pain or distress, and to be clinically and ethically sound. According to Seymour (2001 p.128)

a

“good death is characterised predominantly by reference to ideas about the facilitation of awareness of dying, development of conscious self identity, and social and psychological preparations for death.”

McNamara (2004) concurs that the good death is one with an open awareness of dying, where the patient and family are aware of the impending death, there is an acceptance of death, the patient’s business is settled and there is a relief of suffering. The trajectory of death is discussed by Glaser and Strauss (1965) with reference to the patterns of death. They identify different patterns of dying: sudden death, lingering death, the certainty of dying on time, and the vacillating death. They also describe a good death. The good death as defined under the auspices of modern medicine meant that there was bureaucratic control of death in order to minimise the disruptive nature of death. This description of a good death is good for hospital staff but not for patients. Thus, this type of death would fall into Aries’ (1981) definition of a “wild death”. Further insight into the “wild death” is discussed by Sudnow (1967) and concerns the ostracism of dying patients in the hospital environment. Sudnow (1967) observes the social death of patients in hospital, which is the point at which hospital staff ceases to interact socially with the dying person. Sudnow (1967) recounts several indicators that were evident in the behaviour of hospital staff; for example, speaking about the patient in the third

person whilst in the presence of the patient, or socially ignoring patients they believed showed no hope of recovery.

These definitions lead to a notion of a good death, and, conversely, a bad death. A good death from an individual's perspective is one in which that individual is surrounded by their friends and family in a calm environment, prior to a death that is peaceful, dignified and pain free. It may be argued that each person has a different perspective about what would, for them, constitute a good death. However, for many it would include being treated as an individual, with dignity and respect, without pain or other symptoms, in familiar surroundings and in the company of close family and/or friends. The literature discussed thus far has helped identify the different characteristics that are associated with a good death. These characteristics fall neatly within the twelve characteristics of a good death and are outlined in Table 2.3.

**Table 2.3 Characteristics of a good death**

- To know when death is coming and to understand what can be expected.
- To be able to retain control of what happens.
- To be afforded dignity and privacy.
- To have control over pain relief and other symptom control.
- To have choice and control over where death occurs (at home or elsewhere).
- To have access to information and expertise of whatever kind is necessary.
- To have access to any spiritual or emotional support required.
- To have access to hospice care in any location, not only in hospital.
- To have control over who is present and who shares the end.
- To be able to issue advance directives, which ensure wishes are respected.
- To have time to say goodbye and control over other aspects of timing.
- To be able to leave when it is time to go and not to have life prolonged pointlessly.

(Debate of the Age Health and Care Study Group, 1999 cited in Smith, 2000)

The extent to which people are able to die in the way they would prefer depends greatly on who is looking after them and where they die. By understanding the importance of what both the patient and family members report about the events surrounding death, nurses can improve the quality of end-of-life care. A&E nurses will at some point encounter relatives who have been suddenly bereaved and will need to know how to care for and support these relatives. Understanding more about death, the theories of death and the terms associated with death is a good starting point.

### **Theories and models**

There are numerous theories or models that have influenced the understanding of death, dying and grief. Each provides a particular theoretical framework or perspective for understanding the nature of loss and grief and the impact of death on the bereaved. According to Field and Payne (2003), understanding theories and models can help nurses offer an initial and sensitive response to loss, assessing both its impact and the relatives' reactions, and thus identify when additional support is required. Some of the main theories and models are summarised in Table 2.4.

**Table 2.4 Theories and models of bereavement**

<b>Theorist</b>	<b>Perspective</b>	<b>Definition of theory</b>
Freud (1957; original work 1917)	Psychoanalytical	The work of bereavement is initiated in order to break the attachment with their loved one. This enables the person to be freed to attach to someone else.
Linderman (1944)	Psychoanalytical	Grief work is needed to be freed from the bondage to the deceased.
Fenichel (1945) or Sullivan (1956)	Sociological	Sociological perspectives on grief suggest that bereavement should be understood within a social context.
Pollock (1961)	Psychiatry & Adaptation	A series of adaptations to the loss take place involving Shock, Grief, Separation and Reparation.
Engel (1961)	Medicalisation & Phases	Likens grief to a disease. The bereaved feel wounded or broken. Phases of grief split into: shock and disbelief, developing, awareness, restitution, resolving the loss, idealisation and outcome.
Caplan (1964)	Crisis theory	Strategies developed to solve problems generated by prior crises may help the individual cope more effectively with future events and crises.
Averill (1968)	Psychological & Physiological	A socio-biological theory of bereavement. A stereotypical set of psychological and physiological reactions generally denoted as "grief" are universal among people.
Kubler-Ross (1969)	Psychiatry/Stages	Five stages of coping with grief: denial and isolation, anger, bargaining, depression and acceptance.
Parkes (1972)	Psychosocial & Adaptation	Grief involves a person relinquishing their set of assumptions about the world and developing new ones to fit the new circumstances, thus continuing the theme of severing the bonds with the deceased.
Smith (1976)	Existentialism & Phenomenology	Grief is analysed on three levels: Macro-level – relationship of the individual to society, Intermediate – relationship with friends and family, Micro-level – an individual level.
Bowlby (1980)	Psychoanalytical & Attachment	Four phases of grief: numbing, yearning and searching for the lost one, disorganisation and despair and reorganisation. Grief is a form of separation anxiety.
Bankoff (1983)	Social & Phases	Two main phases of grief: the "crisis-loss" phase < 18 months from death and the "transition" phase which was 18-36 months after death.
Rando (1984)	Psychology & Thanatology	Three tasks of grief necessary to understand the experience of grief: emancipation from the bondage, readjustment, and formation of new relationships.
Carter (1989)	Thematic	Identified 9 themes of grief from narratives of bereaved people.
Worden (1992)	Task	Four tasks of mourning: accept the reality of loss, experience the pain of grief, adjust to new environment, and withdraw emotional energy and re-invest.
Klass, Silverman & Nickman (1996)	Post modern	New model of grief: resolution of grief involves continuing bonds that survivor maintains with the deceased, can be a healthy part of survivor's ongoing life.
Neimeyer (2001)	Meaning Reconstruction	Healthy adjustment in bereavement is helped when the bereaved has the ability to find meaning related to the loss.
Doka (2002)	Disenfranchised Grief	Some losses cannot be openly acknowledged, publicly mourned or socially supported, resulting in the bereaved feeling isolated and a complicated grief reaction may occur.

Much of the early writing on the subject of bereavement occurred during the first part of the twentieth century. It was written from the point of view of Western psychiatrists such as Freud (1957) or Linderman (1944). Collectively, these theories advanced an argument that grieving and mourning are the processes through which the bereaved person adjusts to their loss within a specific timeframe. This enables the bereaved to disengage from the deceased person and to reinvest in new relationships.

Essentially, the bereaved come to terms with their new ways of life, adapt to the loss and learn to cope with a world that no longer contains the deceased by cutting the ties with them. Both Bowlby (1980) and Parkes (1972) offer a theory in which bereavement is understood in terms of a psychosocial transition. They suggest that certain events, such as a death, lead to major changes in an individual's "internal assumptive worlds" (Parkes, 1972, p.71). These assumptive worlds are made up of a series of models that form the person's inner world. It is the interaction between a person's assumptive internal models and their external environment that determines the ways in which they experience events. Hence, grief involves a person relinquishing their set of assumptions about the world and developing new ones to fit the new circumstances, again continuing the theme of severing the ties with the deceased (Parkes, 1972). Bereavement is seen as a process of adaptation to the loss and a transition that occurs over a period of time. In addition to these theories are the stage theories. Kubler-Ross (1969) suggests five distinct stages: denial and isolation, anger, bargaining, depression, and finally acceptance. Any person who is bereaved or dealing with loss moves through these stages sequentially, so each individual will, in response to a death, work towards resolving their bereavement by moving through a predictable template of stages. However, an individual may become fixed in any stage, preventing their movement to the next stage and obstructing the resolution of their grieving process (Kubler-Ross, 1968). Therefore, it can be seen that there are expectations and theoretical concepts of what is considered normal regarding bereavement.

Similarly, Wright (1996) investigated relatives' responses to sudden death in the A&E department and found nine common emotional responses, including denial, withdrawal, anger, acceptance, isolation, bargaining, crying, sobbing and weeping. This research prompted a cultural change in A&E nursing and how A&E nurses responded to the needs of the relatives at the time of a sudden and unexpected death. Wright's work led to the development of specialist bereavement rooms in A&E where suddenly-bereaved relatives could wait shielded from other aspects of the A&E environment.

A different perspective on grief has come to the fore called the "continuing bonds theory" (see Klass et al, 1996; Moules, 1998). This theory challenges the commonly held view that grief is finite and time-limited. Klass et al (1996) do not see bereavement or grieving as ever being fully resolved or culminating in closure or recovery; instead, the work of grieving and mourning is to maintain the presence of the deceased in the web of family and social relationships by establishing a continuing role for them within the lives of the bereaved. As the relatives move on with their lives to find new roles and directions, they still experience the past as very much a part of who they are. The deceased are both present and not present at the same time. It is possible to be both bereft and not bereft simultaneously; to have a sense of continuity and yet know nothing will ever be the same. The reality is that there is an inner system that continues to be centred on the person who is no longer physically present. The inner reality may encourage the relatives to carry on. This bond may shift so it is not as central to the lives of the bereaved and it may take on a new form in time, but the connection is still there.

A number of theories have been explored to explain death and bereavement. The terms "bereavement", "loss", "grief" and "mourning" have been used throughout this first section and are often used inter-changeably; however, they each have a distinct meaning which will be presented in the next section.

## **Terms associated with death – loss, grief, grief work, bereavement and mourning**

Loss is the state of being deprived of someone or something which is valued (Martin & Doka, 2000). Bereavement follows loss; the original definition of bereavement was “to be robbed” (Cambridge Dictionary, 2009). In contemporary society, bereavement is most commonly associated with the death of a person and is understood as the objective state of having lost someone significant (Corr et al, 2009). Grief is the expression of an individual's response to loss (Howarth and Leaman, 2001). Whilst the terms “bereavement” and “grief” are often used interchangeably, the latter can be seen as the emotional reaction to the former. It has been suggested by Kaltman and Bonanno (2003) that a sudden death, as compared to an anticipated death, exaggerates the reactions of grief for the bereaved. In sudden death the relatives do not have time to prepare for this unanticipated event, or the time to develop a prepared support network.

There is no singular phenomenon associated with the expression of grief; instead, grief is expressed in a variety of ways depending on the individual. Grief is rarely as ordered or as predictable as some theorists might suggest, such as Kubler-Ross, (1969). The manifestations of grief are expressed in various ways and are summarised in Table 2.5.

**Table 2.5 Manifestations of grief**

<b>Physical</b>	Fatigue; headaches; physical tension; digestive problems; changes in sleeping or eating patterns and/or amounts; flare-up of chronic or old medical problems; crying; tightness in chest or throat; noise sensitivity; muscular tension.
<b>Emotional</b>	Anxiety; abandonment; anger; relief; fear; guilt; restlessness; irritability; loneliness; confusion; sadness; relief; freedom; depression; sense of hopelessness; feeling overwhelmed; shock; numbness; feelings of powerlessness or helplessness.
<b>Cognitive</b>	Difficulty concentrating; memory impairment; decreased ability to problem solve, calculate or make decisions; absentmindedness; increased daydreams and/or night dreams or nightmares; being preoccupied with thoughts of the deceased; hearing, seeing or sensing the presence of the deceased; disbelief; sense of depersonalisation.
<b>Behavioural</b>	Withdrawal from family, friends and peers; silence; lack of interest or over interest in things that distract; never wanting to be alone; carrying treasured objects of the deceased; avoiding reminders of the deceased; not talking about the death.
<b>Spiritual</b>	Questioning beliefs and values; asking "why" questions; not finding meaning in things at this time; re-evaluation of life; change in church habits; changes in relationships with family, friends and co-workers; change in relationship with oneself.

(Ferrell & Coyle, 2006)

The set of behaviours that allows a person to express these emotions is known as mourning. In most cultures, after a death the social norm is for people to mourn. Mourning is defined as the culturally-patterned expressions or rituals that accompany loss and allow others to recognise that a person is bereaved (Corr et al, 2009). Mourning, therefore, refers to the cultural behaviours in which the bereaved participate or are expected to participate following a death. Mourning behaviour is specific to each individual culture or society - that is, each culture has distinct mourning customs and rituals. By observing certain rituals the significance of the loss is recognised (Corr et al, 2009). The period of mourning, which varies from one culture to the next, facilitates grief.

The notion of grief work has been used in theoretical literature for many years. In this process the bereaved work through their grief. Traditionally, grief work has been conceptualised as a cognitive, behavioural and emotional experience that assists the

bereaved to move through the stages of bereavement to arrive at a place where grief is no longer experienced, at which point it is thought that the bereaved person has successfully resolved their loss. Such marginalization of bereavement reflects a discourse in which the primary goal of grief work is the severing of ties with the deceased in order to be able to reinvest in new attachments. Freud (1957) and others, such as Linderman, (1944) have produced models that construct grief as a goal-directed activity rather than a state of being. This means letting go of the deceased and moving on in order to return to normal functioning. Departure from these activities may lead to the assumption that the mourning behaviour or length of mourning was an indication of abnormal grief. However, other theorists, such as Klass et al (1996) and Marwit and Klass (1995), state that grief work does not require the mourner to emotionally disengage with the deceased, but rather that the bereaved maintain emotional bonds with the dead person. Every person is an individual and, as such, their experience of death is unique; the nature and intensity of their grief reactions are affected by a variety of factors.

### **Factors affecting the grief reaction**

The common assumption that those who experience a death will, after time, resume their normal life is typically not the case (Stroebe et al, 2001; Carnelly et al, 2006). Perhaps it would be more accurate to say the bereaved emerge from a bereavement experience with a new definition of normal as they adjust to life without their family member (Stroebe et al, 2001). In some cases, the circumstances surrounding a death can present particular challenges for the bereaved. When present, these factors may lead to a more complicated bereavement trajectory. Based on the experiences of bereaved individuals, Walsh and Crumbie (2007) identify five main factors that may influence the nature of the grieving process. These include the mode of death, the nature of the attachment, who the person was, historical antecedents, and personality and social variables.

### **Mode of death**

Most deaths are difficult, but a death which is sudden, unexpected, unanticipated or traumatic is particularly difficult and often complex. How the person died has a considerable impact on the grief reaction. In sudden deaths individuals may express more anxiety and lack of personal control as they will have had little or no time to prepare. Death as a result of natural causes, even if unexpected, may cause fewer problems than if the death was traumatic. Traumatic deaths, such as road traffic accidents, suicide or murder, have a significant impact on how relatives come to terms with that death. The nature of sudden death makes the reality of what has happened particularly difficult to accept and is likely to result in a desperate search for meaning and understanding.

### **Nature of attachment**

The nature of the attachment, such as the intensity, strength, security or closeness of the relationship and family, are important in the grieving process and how quickly, if ever, relatives will come to terms with a death. This is because the meaning of the death is different for the bereaved depending on their relationship with the deceased. For example the nature of the grief is different depending on whether the relative was wife, husband, mother, father or child.

### **Who the person was**

The duration, depth and quality of a relationship will have a significant impact on the grief response of any individual. The loss through death of someone who has been a long-standing and important part of a person's life will be deeply felt. However, the quality of a relationship is not based on the passage of time, and it is important that assumptions are never made about the depth of someone's grief on that basis.

Families are made up of a complex web of relationships. An appreciation of the deceased's position in that family and their relationship to the bereaved may have an impact on their grief.

### **Historical antecedents**

Previous life crises, particularly a sudden death, will present as a major factor in how the bereaved cope with the present situation. If the bereaved have experienced previous life crises with a good or reasonable outcome, this may help in their present situation. Prior experience of loss may prepare the individual for future losses.

However, multiple losses and an accumulation of grief may sensitise an individual to future loss. Simultaneous life crises, such as an illness, may compound the present loss.

### **Personality and social variables**

The bereaved individual's personality and life experiences will have a significant bearing on how they respond to loss in their lives. How they learned to deal with loss within the family unit, their upbringing, culture and beliefs will all impact on the way they grieve. According to Costello (2000), an individual's developmental stage, age and sex will all have an impact on how that individual deals with a death. The social subculture to which the person belongs provides the individual with the rituals and guidelines for grieving.

## **Sudden Death**

### **Definition**

Sudden death is a death which is unexpected and occurs without any warning or period of known illness, resulting from an acute illness or injury (Brysiewicz, 2008). In A&E, deaths are sudden or unexpected and occur immediately or within a very short period after arrival in A&E. Sudden deaths may result from a variety of causes, such as myocardial infarction, respiratory arrest, poisoning, accident or suicide. One of the most common causes of sudden death is cardiac problems; this is known as sudden cardiac death (Wedro, 2007). This generally occurs less than one hour from the onset of symptoms, and in the absence of any prior condition that would appear fatal

(Myerberg & Wellens, 2005). It is a potentially reversible life-threatening situation when the techniques associated with cardio-pulmonary resuscitation are applied. A sudden death, as the name implies, is a death which occurs unexpectedly and without prior warning. It may in some cases be reversible. In the A&E department resuscitation measures, in the form of cardiopulmonary resuscitation or advanced trauma life support, are employed in an attempt to reverse sudden deaths and prolong life.

### **Statistics about sudden deaths**

Approximately 500,000 deaths occur each year in England (DoH, 2008). A total of 23,102 patients were brought to an A&E department and died suddenly in England between 2008 and 2009 (HES, 2010); this equates to approximately five per cent of the total number of deaths per year in England. Alongside this, 1,934 patients were brought in to A&E already dead in the same time period (HES, 2010). There are on an average 445 sudden deaths per week across the 205 A&E departments, and 37 brought-in-dead patients. This means that every A&E department in England will see an average of two sudden deaths per week, and so this is arguably a significant event within the A&E environment.

### **Aspects of sudden death**

A review of the bereavement literature reveals that deaths that are sudden or that involve violence, trauma or suicide (Clements et al, 2003) are more likely to create exaggerated and potentially complicated grief responses (Currier et al, 2006). These deaths are perceived by relatives as untimely and unfair, often intensifying the feelings of disbelief, shock and anger (DeRanieri et al, 2002). Without the ability or time to prepare mentally and emotionally, the surviving relatives and family members can become overwhelmed by sudden death (Clements & Henry, 2001). Sudden death allows no anticipation or time for preparation for the loss, which often creates difficulty for the surviving relatives in coming to terms with the death itself (Clements

& Burgess, 2002). Although there is agreement that grief is the reaction to loss (Corr et al, 2009), there is disagreement on when this process should end. The more traditional theorists, such as Freud (1957) and Linderman (1944) argue that there is a timeframe and a definitive end to grief. It would appear that for grief to be resolved there needs to be reinvestment (Freud, 1957), resolution (Parkes, 1986) or acceptance (Kubler-Ross, 1969), and that this normally occurs within a specified timeframe. However, people struggling with integration of grief into their lives, which is often the case after sudden death; have often been perceived as having abnormal grief reactions. Therefore, grief has been classified into a variety of categories, as shown in Table 2.6.

**Table 2.6 Classifications of grief**

<b>Grief</b>	<b>Classification</b>
Normal	The normal emotional response to loss usually resulting from death; the bereaved reach a point at which they can remember the deceased without the extensive pain they experienced earlier.
Pathological	Involves a maladaptive reaction to bereavement that manifests as psychological and physical impairments. The boundary between where normal grief ends and pathological grief begins is vague.
Unresolved/ Prolonged	When there appears to be a total absence of mourning and grief, and the bereaved do not experience any of the usual grief reactions.
Chronic	The bereaved have trouble finding closure and returning to normal activities over an extended amount of time. The intensity of the grief does not diminish over time
Dysfunctional	The state in which the bereaved experiences prolonged unresolved grief and engages in dysfunctional activities.
Exaggerated	Certain manifestations, such as guilt, fear, anger or despair, become highly intensified. May include nightmares, abnormal behaviours, phobias and abnormal fears, and thoughts of suicide.
Complicated	An abnormal response to bereavement that includes unrelieved yearning for the dead person, the complete loss of previous positive beliefs or worldviews, and a general inability to function.
Disenfranchised	Occurs when a grieving person's loss can't be openly acknowledged or is one that society does not accept as a real. For example losses related to AIDS, miscarriage, or loss of a homosexual partner.

(Ferrell & Coyle, 2006; Hawton, 2007)

Klass et al (1996) contest the idea that there is a normal grief reaction such that anyone who deviates from that norm or timeframe is manifesting behaviour that is pathological. Sudden death is an unexpected event and complex situation, and so

the grief process is very different to anticipated or expected death. The grief response following sudden loss is often intensified as there is no opportunity to prepare for the loss. This can generate intense emotions and grief reactions such as shock, numbness or anger. According to De Groot et al (2007), following a sudden death, relatives may experience a greater sense of vulnerability and anxiety and are often in need of considerable support. Since the death was not anticipated, relatives may be left with a sense of unfinished business. This may lead to a futile search for meaning in trying to understand what happened. Parkes (2002) suggested that loss by sudden death is a risk factor in the grieving process which may lead to complicated grief reactions. Although all bereaved individuals are at risk from abnormal grief reactions (Mitchell et al, 2005), Qin et al (2002) argue that sudden death predisposes relatives to a much greater risk of subsequent complicated grief and suicidal ideation.

### **Comparison of a good death with a death in A&E**

Although recently there appears to have been a revival in the discourse around death and dying it would seem that in contemporary society there is still ambivalence concerning death and dying. Perhaps what is more significant is the way in which people die and whether it is a good death. The A&E department is the environment in which this study is located. The concept of a good death is not one normally associated with death in A&E, for example Scott (2007) argues that death in A&E is stripped of the characteristics associated with a good death experience. The characteristics underpinning a good death are outlined in Table 2.3 and form the template for good practice. In this chapter these characteristics are used to guide the discussion in relation to sudden death in A&E.

### ***“To know when death is coming and to understand what can be expected”***

Describing the death scenario in A&E is fraught with difficulty because of the many different clinical situations that can precede death. The evidence suggests that death

in A&E is often sudden and frequently unexpected (Wisten & Zingmark, 2007). The first principle underpinning a good death is to know when death is coming and to know what is expected; sudden death affords none of this – for either the patient or the relative (Hallgrimsdottir, 2000). Sudden death can occur anywhere, at any time and transcends all cultural and social parameters. Death may also happen on the way to A&E in which case the patient is pronounced dead on arrival.

***“To be able to retain control of what happens”***

Following on from the above principle, a lack of control is apparent in sudden death. The events leading up to the patient’s critical illness or injury are usually sudden and uncontrolled. There is no sense of control for the patient, who is helpless to change the course of the situation. Relatives being informed of the patient’s critical status may feel unable to maintain a sense of control. If the patient dies, the relatives may continue to feel that the situation is out of control, and may experience a whole range of new feelings in response to the news of the sudden death.

***“To be afforded dignity and privacy”***

One of the most significant themes in the characteristics underpinning a good death incorporates dignity and privacy. The resuscitation room is the designated area for the treatment of patients who arrive in a serious life-threatening condition. This room is divided into bays; although each bay is divided by curtains and portable screens, this affords little privacy for patients. The noise, smells and sounds of bodily functions are immediately noticeable to anyone entering this area. It is also not usually possible to segregate male or female patients; so a female patient may be in a bay next to a male patient. During the resuscitation event clothing may be removed or cut off. Patients often lay exposed and naked whilst extensive resuscitation procedures, such as external cardiac massage or insertion of intravenous lines into the groin or neck areas, are performed (Page & Komaromy, 2005). The resuscitation room, one of the busiest and most accessed areas of the department, is the place where one of

the most intimate events, i.e. death, takes place. Therefore, sudden death in the A&E environment is not associated with a dignified death.

Extending this principle to the care of the relatives, similar challenges regarding privacy and dignity can be noted. The A&E department is one of the most public areas in the hospital. Upon arrival in the A&E department, irrespective of their mode of arrival, relatives are required to register the patient at reception. The reception area forms part of a large waiting area and is where all A&E patients are registered. This means that the relative has to queue at the A&E reception and register the patient's details. This can be a daunting experience for the relatives of critically ill and dying patients in the A&E department, where delays may seem like an unnecessary burden. Once the registration process is complete, the relatives may then have to wait in the main reception. Whilst waiting, the public nature of this environment and activities therein become apparent. Waiting in a busy, noisy and often chaotic waiting area affords little privacy or dignity for the relatives who may be upset and distressed.

***“To have control over pain relief and other symptom control”***

Often, patients who have suffered a major trauma may experience intractable pain which is difficult to control or alleviate, even with strong analgesia (Heaston et al, 2006). Other symptoms, for example dyspnoea, may be equally distressing for patients and impede a sense of control. Some of the life-saving measures, for example insertion of chest drains, may induce pain, despite local anaesthesia (Heaston et al, 2006). Relatives witnessing pain and discomfort immediately prior to death may find it distressing. This may occur if relatives are present in the resuscitation area. Achieving a pain-free or symptom-free sudden death is unlikely (Scott, 2007), and may preclude any sense of control for both patients and relatives.

***“To have choice and control over where death occurs (at home or elsewhere)”***

The sudden death scenario affords no choice or control as to where the event takes place. Essentially, a sudden death can occur in any location and at any time. Often, patients will collapse in public areas and be brought to the A&E department via an

emergency ambulance. Accidents and other traumas also usually take place outside of the home. The preferred scenario of a patient dying at home surrounded by family member's bears little resemblance to the sudden death scenario in the A&E department.

***“To have access to information and expertise of whatever kind is necessary”***

A&E is a fast-paced and transient environment. The emergency team are often faced with making rapid clinical decisions based on minimal patient information, with vague or incomplete histories. In sudden death, there is may be only limited clinical information available about the circumstances immediately prior to the death; preceding events often remain unknown. This can contribute to the distress felt by relatives, who may have unanswered questions regarding the circumstances leading up to the death. The sudden death scenario is often difficult to understand, appears inexplicable and makes little sense.

***“To have control over who is present and who shares the end” & “To have time to say goodbye and control over other aspects of timing”***

Evidently, one of the factors underpinning a good death is the presence of family and friends and having the opportunity to say goodbye. In A&E the patient has no control over who is present at the time of death. Often the patient is surrounded by a plethora of staff undertaking extensive and invasive resuscitation measures. When relatives accompany the patient to A&E they may be excluded from the resuscitation area as the issue of the presence of relatives in the resuscitation room is controversial. However, the presence of relatives immediately prior to death may be helpful for both the patient and relative. For example, a family presence may provide comfort to the patient, and it may help relatives come to terms with the death more easily and reduce the emotional stress of bereavement.

***“To be able to issue advance directives which ensure wishes are respected”***

Often in the sudden death scenario, the patient is brought to the A&E department in a critical condition, unconscious and unable to communicate. In this situation, A&E staff

are unable to ascertain what the patient's wishes and preferences are, if any, regarding end of life care if no obvious advance directive is in place. In these circumstances, professional, ethical and legal directives come in to force which mean that resuscitation must be attempted. In the absence of "do not attempt resuscitation" orders, Holleran (2002) argues that emergency staff have little choice other than to begin or continue resuscitation unless or until it is certain that the situation is futile.

***"To be able to leave when it is time to go and not to have life prolonged pointlessly"***

Institutional settings are seen as unfortunate places in which to die; especially in relation to the often unwanted technological aspects of death that are found in acute environments such as the A&E department (Costello, 2001; Timmermans, 1999).

Advanced Life Support measures are employed where deaths are perceived as unexpected, untimely and potentially, through skilled intervention, reversible. When death is viewed as reversible, prolonged resuscitation attempts may ensue.

Therefore, death in the A&E department has become increasingly technical and mechanistic. Continued and extensive resuscitation attempts, although at times necessary (in cases of near drowning for example), may depersonalise the patient. Page and Komaromy (2005) assert that sometimes the person being resuscitated is discussed in terms of clinical parameters. Sudden death can necessitate prolonged resuscitation attempts, which may appear technical and invasive. This is not in keeping with the notion of a good death which is peaceful and dignified at the end.

The investigation of how death occurs in the A&E department revealed the following information: death is sudden and unexpected, usually resulting from a difficult or complex situation; there is no warning and hence no preparation for either the patient or relatives; a lack of control infuses the situation; there is little choice regarding the place of death, about who is present, or about symptom control; due to the critical nature of the patient's condition there is no opportunity to inform the patient about

impending death or discuss end-of-life options; and the resuscitation event, which is often extensive and lengthy, may pre-empt an undignified death which affords little privacy.

Having investigated how death takes place in the A&E environment, it is easy to see how Scott (2007) is justified in her statement that death in A&E is not associated with a good death but one stripped of the characteristics associated with a good death experience. That said the intention is not to lay blame but to bring attention to the reality of death in A&E. This section has hinted at the impact of sudden death on the surviving relatives. "How people die remains in the memory of those who live on" (Saunders cited in *End-of-life Strategy*, 2005).

### **Support for relatives after a death**

The preceding analysis has demonstrated that death in A&E cannot be regarded as possessing the qualities ascribed to a "good death". It has already been established that the A&E department is a busy and fast paced environment, designed as a place of transition. A&E staff deal with an increasing number of patients with a wide variety of presenting conditions who are cared for according to the severity and seriousness of their complaint. Within this type of environment it is difficult to comprehend how support for bereaved relatives can be effective in the immediate timeframe following a sudden death. The next section analyses this support and has been divided into two main sections – immediately prior to and then after the death.

### **Support immediately prior to the death**

#### **Initial reception**

When a patient is critically ill or injured they are brought to A&E via the emergency ambulance service and usually treated in the resuscitation room. Depending on the situation, the relatives may have accompanied the patient, or they may arrive in A&E independently or be brought by police. The reception is important and creates an initial impression for the relatives. Demonstrations of concern and support from

health care professionals have been shown to influence relatives' perceptions of the care that their loved one received prior to death (Jurkovich et al, 2000; Li et al, 2002). Kirchoff et al, (2002) studied family members who had experienced the death of a loved one. Their results indicate that nurses and physicians who went out of their way to be available to family members were valued for their genuineness and that this enhanced the confidence and satisfaction of family members. On the contrary, Warren (2002) reported that family members who perceived staff as uncaring and unavailable rated their experiences as dissatisfying. Communicating and delivering information in this time-critical period means that the relatives have some opportunity to understand the severity of the situation. It is also important to provide the information in clear understandable terms, avoiding the use of euphemisms.

### **Family presence in resuscitation**

The issue of the family presence<sup>2</sup> during an adult resuscitation is controversial and has stimulated much debate over the past two decades, giving rise to a growing body of literature and guidelines for practice. Given the plethora of literature regarding family presence, it warrants consideration in a separate section. The literature review revealed a total of 97 articles related to family presence. The first reported study into family presence was conducted by Doyle et al (1987), which was followed by a number of studies detailing both the positive and negative aspects of such practice. It is without doubt that the issue of family presence is a significant issue, as well as a controversial one. The literature suggests that witnessing the resuscitation attempt may help relatives come to terms with death more easily and reduce the emotional stress of bereavement. Although this practice is encouraged, it is not without contention. Table 2.7 contains a summary of the main advantages and disadvantages of family presence as reported by the literature.

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<sup>2</sup> *Family presence* refers to the family being present at the attempt to resuscitate the patient

**Table 2.7 Advantages and disadvantages of family presence**

**Advantages**

Gives families an opportunity to say goodbye  
Families are aware of the efforts taken to try and revive the patients  
They are witnesses to everything necessary being carried out  
Families feel like they supported the patient and did not leave them alone  
The fear and worry of families are lessened  
It has a positive effect on the grieving and coping processes  
Patient and family are considered as a whole.  
Family-centred care is provided  
Professional behaviours are displayed

**Disadvantages**

CPR is a very traumatic event for family members to witness  
There is the possibility of repercussions (e.g. complaints)  
Families may interfere with procedures  
The resuscitation team may feel uncomfortable  
It has a negative effect on patients' privacy and confidentiality  
Lack of space for the patients' families in the resuscitation room  
It may have a negative effect on the technical performance of the resuscitation team  
If there are incorrect procedures litigation may occur  
When CPR is unsuccessful there may reduce confidence in the physician  
It may increase the stress on the team  
Families may not be able to endure this situation e.g. faint.  
Resuscitation team may have to care for family members instead of taking care of the patient, and their work would be hindered

In A&E family presence during adult resuscitation is becoming more accepted in practice but remains controversial. A&E staff fear that relatives who are present may interfere with the resuscitation procedure (Helmer et al, 2000; Ong et al, 2004). This interference may alter the course of the resuscitation attempt, rendering it ineffective (Goodenough & Brysiewicz, 2003; Yanturali et al, 2005). Some concerns are related to safety issues, such as lack of space in the resuscitation room to accommodate relatives (Booth et al, 2004; Macey et al, 2006). Booth et al (2004), Macey et al (2006) and Ong et al (2004) all cited preventing psychological distress as being the main reason for A&E staff to exclude families from the resuscitation room. Yanturali et al (2005) argued that the main concern was about making the decision to stop the resuscitative attempts. Despite these negative points, staff conceded that witnessing resuscitation may help the relatives come to terms with both the gravity of the

situation and the dying process. This subject remains controversial and, like much in A&E nursing, the solution to the problem is not simple.

### **Support immediately after the death**

At the time of death, the focus of care is on the needs of the family (Anstey & Lewis, 2001). Nurses must expect to encounter the relatives' overwhelming sense of shock, numbness, disorientation and, in some circumstances, overt distress and anguish (Field and Payne, 2003). Whenever possible, the family should be given as much time as they want to say their goodbyes (Kinghorn & Duncan, 2005). Caring for the body in a respectful and appropriate way is crucial, as is supporting individuals in their particular rituals and mourning customs (Anstey & Lewis, 2001). Legal and medical interventions, such as postmortems, may be necessary and giving information to relatives about such matters needs to be handled sensitively. Giving and receiving information at this time is very important and it is vital that nurses have accurate, up-to-date knowledge to give (Anstey & Lewis, 2001). For example, this could include giving details of when to collect the death certificate, or how and when to register the death. While nurses cannot take away the pain, providing factual information may make it easier for bereaved people to complete the practical and legal tasks that must be undertaken (Kinghorn & Duncan, 2005). Providing written information for relatives to take away may also be helpful as, in their grief, they may be unable to absorb verbal information

The use of a caring, sensitive approach by a well-informed, sympathetic health care professional who is able to provide clear, concise information and answer questions can positively impact and facilitate the grieving process of relatives (Jurkovich et al, 2000; Klein & Alexander, 2003). Hence interactions with health care professionals at the time of death can have a profound impact on the relatives.

## **Justifying involvement with relatives**

The research cited within this study has highlighted that for many relatives sudden death is one of the most significant and stressful events they may have experienced (Wisten & Zingmark, 2007). All loss may be considered difficult, but when a death is sudden and unexpected the bereaved relatives' reactions may be more severe and complicated than when death is expected (Currier et al, 2006; Parkes, 2008). The impact of sudden death may be a precursor to acute psychological responses (Wright, 1999) and according to Kaul (2001), this requires immediate intervention. Immediately after a sudden death the relatives may experience a number of acute grief reactions, such as numbness, disbelief or anger, combined with an overwhelming sense of isolation and vulnerability (Ferrell & Coyle, 2006). The pain associated with sudden death is evident, and may never be erased, but with careful and sensitive intervention it can be made more manageable (Wright, 1996). Relatives need help and support during this critical period, particularly if in an unfamiliar hospital environment and faced with a situation which they may never have previously encountered. According to Fauri et al (2000) it would appear that it is within A&E units that death and bereavement have most significance, as the environments are often clinical and unfamiliar to relatives. Experiences around the time of death and afterwards can influence the grief process and the longer-term health of bereaved people (DoH, 2005). As such, a sudden death in A&E and how it is managed has the potential to have a great impact on the ensuing bereavement process for bereaved relatives. In A&E, nurses are regularly required to help people cope with the trauma of sudden death (Scott, 2007). They do this by offering support and by creating an environment that allow the bereaved to deal effectively with the crisis (Kent & McDowell, 2004). However, if nurses do not have the necessary skills and knowledge they are unlikely to be able to provide the level of support needed. Supporting suddenly-bereaved relatives is difficult and stressful for A&E nurses, particularly informing relatives of a sudden and unexpected death (Kent & McDowell,

2004; Li et al, 2002; Scott, 2007). In a qualitative study by Socorro et al (2001), A&E nurses felt unprepared for their role in caring for relatives following sudden death. Staff may feel uncomfortable and ill equipped to deal with the bereaved relatives' emotional responses and acute grief reactions. However, A&E nurses are in a unique position to facilitate relatives' grief reactions in the early stages of bereavement. Education, mentorship and ongoing support are therefore essential so that A&E nurses can understand people's responses to sudden bereavement and react in an effective way. In the literature, it has been indicated that the emotional needs of relatives are not always met by A&E staff (Kent & McDowell, 2004). The manner in which relatives are informed of a death can have a profound effect on the bereavement process and long-term outcomes of relatives (Clements et al, 2003; Jurkovich et al, 2000). The literature reveals that many individuals who are suddenly bereaved state that hospital staff informed them of the death in ways that were inexpert and uncaring, and that this had a detrimental effect on their grieving and made the impact of the death more devastating for them (Spalls & Callis, 1997; Wright, 1996). The literature notes the importance of listening to someone who is bereaved, being with them and witnessing their grief, and suggests that this may be one of the most important services an A&E nurse can provide for someone who is suddenly bereaved (Casarett et al, 2001; Weaver, 2000). This resonates with the work of Benner (1984) who emphasised the humanistic quality of "presence".

## **Conclusion**

The aim of this literature review was to acquire a fuller understanding of the A&E environment and the context in which sudden death takes place. The review examined the main theories, models and perspectives associated with death, dying and sudden death. These gave insight into how the bereaved may react to and cope with sudden death. Clarity was brought to the terms "bereavement", "loss", "grief" and "mourning", which are often used inter-changeably in bereavement literature. The

factors affecting the grief reaction were discussed, including the impact these may have on suddenly-bereaved relatives and their ensuing bereavement experience. In the final section, the chapter explored the principles underpinning a good death and these were used to guide the discussion surrounding the reality of sudden death in A&E. The next chapter draws attention to the methodological and ethical issues arising from both part I and part II of the study.

## **Chapter Three: The aims, methodological approach, research design and ethical considerations**

### **Introduction**

This research presents two discrete studies that together give insights into the experience of sudden death from the perspective of the bereaved and of A&E nurses. The literature review highlighted the complex nature of sudden death. This chapter presents the aims for the studies and the methodologies used in this research, namely phenomenology in part I and narrative in part II. It discusses the data collection methods and data analysis for both parts of the study and holistically addresses the ethical issues surrounding the study. Ensuring the study was ethically sound required consideration of key issues such as informed consent and anonymity for the participants.

### **Aims**

The literature review served as the background for the aims of the study. In part I of the study the specific aims are:

1. To identify the number and type of sudden deaths occurring in the A&E department.
2. To explore family members experiences of sudden death in the A&E environment.
3. To explore the impact of sudden death on family members who have been suddenly bereaved.

The literature review also relates to part II of the study and presents as background an overview of emergency nursing in order to contextualise the narrative interviews undertaken with A&E nurses. The specific aims for part II are:

4. To explore the context in which sudden death takes place in A&E.

5. To explore the A&E nurses' experiences of caring for family members who have been suddenly bereaved

### **The research paradigm**

All research is based on underlying assumptions (Lacey, 2006); in essence, these assumptions relate to the worldview of the researcher and their view of reality. The conceptual framework is sometimes referred to as the research paradigm (Mertens, 2005). A paradigm is defined as a worldview (Patton, 2002), or “a basic set of beliefs that guide action” (Denzin and Lincoln 2005: 158). Hence, a paradigm is a framework that articulates the researcher’s assumptions or values about reality, truth and research. This forms the basis for comprehending and interpreting social reality (Cohen et al, 2000). There are four research paradigms: positivism, interpretivism, critical theory and postmodernism (Gephart & Richardson, 2007; Guba and Lincoln 1994). The assumptions underlying each paradigm vary; therefore, the ways in which the researcher adopting a particular tradition or paradigm sees the world will influence and direct the methods, data collection and analysis. Interpretive research, the paradigm underpinning this study, assumes that reality is socially constructed and that the researcher becomes the vehicle by which reality is revealed (Berger and Luckman, 1966; Burr, 1995). This means that there is no objective reality waiting to be discovered and replicated by others, which is in contrast to the assumptions of the positivist paradigm. Instead, interpretive research is consistent with the construction of the social world characterised by the interactions between the researcher and the participants and through which the researcher’s interpretations play a key role in the study (Mertens, 2005). Table 3.1 summarises the interpretive framework.

**Table 3.1 Interpretive framework**

Ontological (nature of reality)	Multiple realities socially constructed by individuals
Epistemological (nature of knowledge)	Gained through understanding the meaning of the process/experience
Axiological (role of values)	Researcher's subjective values, intuition and biases are important and openly acknowledged
Methodological (methodology)	Qualitative phenomenology, ethnography, case study, grounded theory

(Adapted from Gephart & Richardson, 2007)

Interpretive research provides a deep insight into the lived experience from the participant's perspective. In order to understand why people act as they do it is necessary to understand the meanings and significance human beings give to their actions. As such, people involved in a particular situation or who experience phenomena such as sudden death are best placed to describe and make sense of their experiences.

**Research design of Part I: Exploring the relative's experience of sudden and unexpected death in A&E.**

**Phenomenological approach**

In a broad sense, the purpose of phenomenology is to describe particular phenomena, or the appearance of things, as lived experiences (Speziale & Carpenter, 2007). Phenomenologists contend that knowledge and understanding are embedded in experiences of everyday life, and therefore cannot be quantified by scientific and objective means (Findlay, 2008). Phenomenological methods bring to the fore the experiences and perceptions of individuals from their own perspectives. A phenomenological analysis does not aim to discover causes and so does not involve hypothesis testing, nor is it guided by scientific models. Instead, the goal is to clarify the meanings of phenomena from lived experiences (Findlay, 2008; Todres & Holloway, 2006). The phenomenological movement was initiated by Husserl (1859-1938) as a philosophy (Findlay, 2008; Todres & Holloway, 2006). Later theorists,

such as Heidegger (1889-1976), recast phenomenology, moving away from a philosophical discipline towards existential and hermeneutic (interpretive) dimensions (Findlay, 2008; Todres & Holloway, 2006). Therefore, phenomenology has evolved both as a philosophical context for inquiry and as a research method. Three main phenomenological frameworks exist (Polit et al, 2001): descriptive (Husserlian), interpretive (Heideggerian) and the Dutch framework (Van Manen). Common to all three approaches is that the researcher assumes a readiness to listen to the descriptions of the lived experiences as described by the participants. In the interpretive method, chosen for the first part of this study, the researcher uses his or her prior knowledge and insights to interpret and uncover hidden meanings, with the goal of producing a vivid textual representation of the phenomenon described (Kleiman, 2004). Heidegger opposes the notion that meaning is totally neutral and unsullied by the researcher's own beliefs, values and views of the world (Findlay, 2008; Todres & Holloway, 2006); rather the researcher brings certain background expectations and meanings that will have a bearing in the act of understanding. What the researcher represents and who they are is important and cannot be ignored or bracketed, i.e. setting aside pre-judgements (Todres & Holloway, 2006) as in Husserl's theory. Within interpretive phenomenology there is no detached view from which to gather data and the researcher's personal experiences and prejudices are acknowledged as exerting a profound influence on the understanding of the phenomenon, and thus important in the interpretation (Dowling, 2004). In recognizing the importance of acknowledging personal experiences and prejudices, every effort was made by the researcher to highlight these throughout the course of this study. Any personal biases, personal experiences of sudden death, professional knowledge of the subject and any presumptions for caring for bereaved relatives have been openly discussed and acknowledged.

## **The A&E department**

According to Glaser (2001), one of the main steps in any research study is to locate a suitable site where the phenomenon of interest occurs. A large A&E department in the North West region of England provided the sample population for the first part of this study. The A&E department was part of one NHS Trust but was on two separate hospital sites, and the medical and nursing staff rotated between the two sites. The staffing of the establishment was in keeping with the specified national recommendations. The two sites provided facilities for all types of accidents and emergencies including children, trauma and major accidents, and both were open 24 hours a day, 365 days per year. On average 70,000 new patients and 6,000 returning patients per annum attended this A&E. Approximately 200 sudden deaths per year were reported, making this department an ideal environment from which to recruit participants in order to explore the phenomenon of sudden and unexpected death.

## **The sample**

Purposive sampling was the approach adopted for the selection of participants in the first part of the study. Purposive sampling is where individuals are selected based on their experience and prior knowledge of a specific issue (Burns & Grove, 2005; Gay & Airasian, 2003; Speziale & Carpenter, 2007). As with any sampling method purposive sampling has limitations. For example, with purposive sampling participants are selected based on the judgement of the interviewer, which could involve bias (Munhall, 2007); however, this bias is conscious and openly acknowledged. The researcher selects participants who have the desired knowledge and experience of the phenomenon under investigation (Patton, 2002), which is ideal when using an interpretive-phenomenological approach where the aim is to understand and describe a particular phenomenon from the perspective of those who have experienced it.

### **Inclusion and exclusion criteria**

Inclusion and exclusion criteria were formulated and are shown in Table 3.2. These were constructed being mindful of the moral requirement to protect the wellbeing of participants, which is particularly important when investigating an experience that may evoke painful memories, such as sudden death.

**Table 3.2 Participant inclusion and exclusion criteria in part I of study**

<b>Inclusion Criteria</b>	<b>Exclusion Criteria</b>
Deceased > 18 years old Adult deaths included	Deceased < 18years old All infant/child/maternity deaths excluded
Relatives > 18 years old	Relatives < 18 years old
Relatives present in A&E at time of death	Relatives not in attendance in A&E at time of death or immediately after death
Relatives are next of kin living within the catchment areas of the hospitals	Non next of kin or kin living outside the catchment area for the hospital are excluded
Relatives must be approached/interviewed six months or more from time of death occurring	Relatives must not be approached/interviewed within six months of death occurring
Relatives not injured in incident/accident leading to death of relative	Relatives injured in incident/accident leading to death of relative
No subsequent death once interview arranged	Subsequent death once interview arranged

### **Approaching the relatives**

Following ethical approval (see Appendix 1) a total of 122 potential informants were invited to participate by letter. An information sheet and consent form accompanied this letter (see Appendix 2). Having completed the necessary consent form, the relatives were then contacted by the researcher by telephone and a mutually convenient date, time and venue were arranged for the interviews to take place. Twenty people responded to the invitation; of these 15 relatives ultimately agreed to take part and five declined, giving a response rate of 16%. Low response rates are common in bereavement research (Stroebe et al, 2003), which is probably unsurprising given the nature and sensitivity of the research subject. Recording data about why participants decline to participate can enhance the validity and reliability of the research findings (Patton, 2002). Therefore, all correspondence from participants

who accepted and declined was kept. The relatives who declined stated they did not feel they had anything to add to this study; this is debateable given the nature of their letters, but their responses were positive and encouraging about the study.

### **Conducting semi-structured interviews**

In phenomenological research, data are commonly collected through interviews. An interview is “an interchange of views between people” (Kvale & Brinkman, 2009, p.2). For the first part of the study, semi-structured interviews with an interview guide were used (see Appendix 3). The semi-structured interview as a research instrument can be used effectively to explore and understand perceptions, feelings, emotions, behaviour, stories and events (Gay & Airasian, 2003; Marshall & Rossman, 2010; May, 2001). This facilitates in-depth knowledge and detail of the research topic, and therefore richer and thicker data is obtained (Kvale & Brinkman, 2009; May, 2001). Face-to-face interviews are advantageous, particularly when exploring sensitive issues such as sudden death, as the non-verbal communication can be captured and documented in the transcribing process; moreover, the researcher’s presence has the potential to reinforce to informants that their contribution is valued, and that their story is precious and symbolically worth the investment of a researcher’s time. Interviews are time consuming, including the time prior to and conducting the interview, and subsequently transcribing and analysing the data (Tod, 2006). A sample size of ten to fifteen is claimed to be adequate in interpretative phenomenological studies provided participants are able to give rich descriptions of the phenomenon (Speziale & Carpenter, 2007). In this part of the study, 15 interviews were carried out involving 17 relatives. Participants were encouraged to tell their story of events from their own perspectives, and all the participants provided rich descriptions of their experience of sudden and unexpected death. In addition to the semi-structured interviews, data were recorded in the form of field notes and demographic information. Field notes documented after the interviews contained

information about any factors that influenced the data collection process, such as the setting where it took place, the flow of the conversation and notes to inform the analysis.

### **Tape recording**

Essential to data collection is the creation of a record. The use of the tape recorder in interviews allows an accurate record of the conversation to be maintained (Flick, 2009; Patton, 2002). Tape recording allows the researcher to substantiate the findings with verbatim quotes from the transcription (Rapley, 2004). This lends more credibility to what participants have said than if the researcher is dependent on recall and note taking alone. Although tape recording the interview enables an accurate account of the interview to be produced, it does have limitations. The use of the tape recorder may make both parties self conscious and make the interview seem artificial or constricting. It is also without doubt that transcription is time consuming (Bryman, 2001; Tod, 2006). Transcribing does not merely involve the transference of words from tape to page, when people are in conversation only a small proportion of the message is communicated in the actual words used (Oliver et al, 2005); a larger proportion is transmitted in the ways people speak – tone, pauses and silences, and inflection are good indicators of a whole range of feelings and meanings (Oliver et al, 2005).

One relative participant did not want the interview to be recorded because she did not want her voice recorded. Therefore, handwritten notes were taken in that interview and were accompanied by copious field notes written up directly after the interview. All the other interviews were audio-taped and transcribed verbatim by the researcher. The transcripts included annotations detailing the feelings and emotions expressed; for example, crying, laughter, anger or disbelief.

## The participants

Fifteen relatives agreed to participate, and two spontaneously participated on the day (n=17). The participants varied in age and relationship to the deceased. Table 3:3 shows the participant's pseudonym and the relationship to the deceased.

**Table 3.3 Participants in part I**

<b>Pseudonym</b>	<b>Relationship to deceased</b>
Alan	Husband
Betty	Wife
Eva	Wife
Delia	Wife
Edward	Husband
Fran	Daughter
Grace	Wife
Helen	Daughter
Isobel	Daughter
Jane	Wife
Kate	Daughter
Louise	Sister
Maureen	Wife
Nigel	Son
Nicola	Daughter-in-law
Olwyn	Wife
Olga	Mother-in-law

Information about a participant's story from the data collected in the interview may be summarised in a cameo (Holloway & Jefferson, 2000). Cameos for each of the relatives are contained in Appendix 4. The use of cameos was intended to bring a sense of who the participant was and their relationship with the deceased.

### **Data collection and data analysis for part I of the study**

Although a clear distinction between data gathering and data analysis is commonly made in quantitative research, such a distinction is problematic for many qualitative researchers. This is because data collection and data analysis often take place concurrently with analysis beginning soon after the first data are collected. Written and verbal consent were obtained from all participants prior to the interviews being conducted; once these had been obtained the interviews took place. Immediately after the interview, notes were made about the interview. Table 3.4 shows an example of the notes made following Olwyn's interview.

**Table 3.4 Example of notes made following an interview**

“when Olwyn started to talk about how she had been informed about the death of her husband I was surprised at how this information was broken to her – she did not understand what a cardiac arrest was, she did not understand that her husband had died until the charge nurse said we tried to save him and then she realised he was dead”

A research diary was also kept throughout the course of this study to keep a log of different issues, such as the progress of the study, supervision meetings and feedback, or thoughts about the interviews. Table 3.5 shows an example of an extract from the research diary

**Table 3.5 Example of notes from research diary made after the relative interviews**

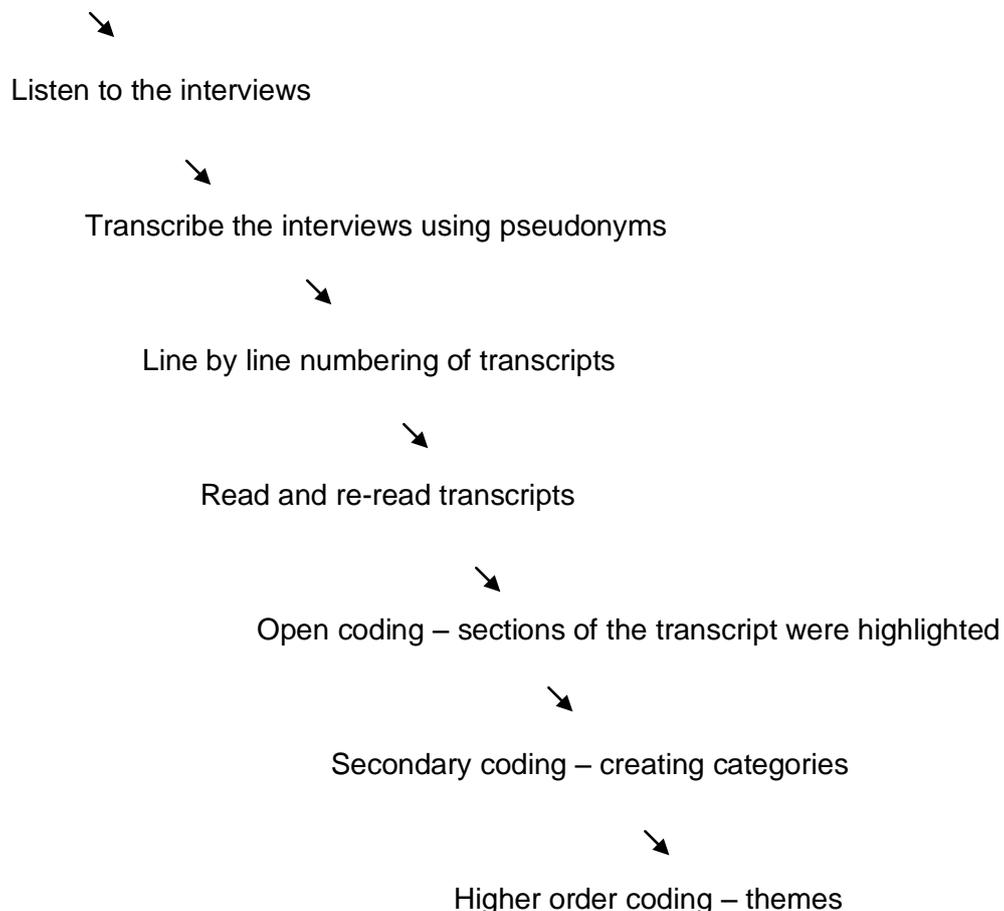
“I was really shocked after speaking to the relatives and exploring their experiences of sudden death to find that not all relatives had a positive experience of sudden death in A&E. I thought that all nurses cared for suddenly bereaved relatives to the highest possible standard but the relatives' interviews revealed this was not the case. As I listened to their experiences I was at times embarrassed and concerned at what I heard and they highlighted many different things which had a negative impact on them. These things really stood out. This was a real turning point in the work and a catalyst to consider more about nurses in A&E and their role in sudden death.”

The field notes and diary logged a coherent record of ideas, information and activities. Moreover, they also captured issues that were important to the research, such as how the news of death is broken. During the analysis, this information stimulated reflective thinking about the research and about the issues that were highlighted.

All the tape-recorded interviews were transcribed verbatim by the researcher. This ensured that all transcripts were true to their original sources. The transcription took place as soon as possible after each interview while it was still fresh in the researcher's mind. A copy of the transcript was sent to the relative for verification purposes, i.e. to check that the content of the interview was a true account of what had been discussed. Another copy of the transcript was kept for analysis. All transcripts and tapes were kept in a safe and secure place that was only accessible to the researcher, as specified in the Local Research Ethics Committee (LREC) application. During this process the transcripts were read and re-read and notes made in the margins to highlight significant points. The steps in the data collection and analysis are shown in Flow chart 3.1.

**Figure 3.1 Steps in the data collection and analysis for part I**

Conduct interviews



Following the open coding, the highlighted sections of the transcripts were cut up and grouped together in envelopes to create categories. This involved gathering sections of the transcripts that seemed to fit together and that seemed to capture the substance of a topic. This served as the basis for the different themes that emerged from the analysis. A worked example of this process is contained in Appendix 5.

In conclusion, phenomenology was the methodology chosen for part I of this research study because it's underlying philosophy and processes are considered very effective in disclosing the experiences of individuals who have lived through a phenomenon such as sudden death. As indicated in the introduction, this study was conducted in two parts. Part II followed on from Part I and the next section details the narrative approach and research design used for the second study.

## **Research design of Part II: Exploring the A&E nurse's experience of sudden and unexpected death in A&E**

### **Narrative approach**

People are storytellers; they tell stories about their experiences and the meanings that these have had in their lives. All cultures and societies have stories or narratives connected to their past, present and sometimes their future. Narrative research has become commonplace in the field of nursing education and curriculum development and also forms an essential feature of professional debates and scholarly discourse on nursing (Freshwater and Stickley 2004). However, the study of narrative is not confined to nursing alone but is an integral part of many different disciplines.

As a distinct form of interpretive qualitative research, a narrative inquiry is the process of gathering information through the collection of stories, reporting individual experiences, and discussing the meaning of those experiences for the individual (Andrews et al, 2008; Connelly & Clandinin, 1990). Therefore, narratives enable the exploration of everyday practice and create meaning out of those experiences.

The telling of narratives has been acknowledged as important, not only for portrayal of a past event, but also for the subjectivity of that construction and what it can reveal about the storyteller as an individual and the society by which they are shaped and in which, at the same time, they are a shaping agent (Dyer & Keller-Cohen, 2000; Richmond, 2002). While narratives may not be an exact representation of an experience, they contribute to understanding because of the opportunity they offer to listeners and readers to engage in that experience from which they might otherwise be excluded.

In an organization such as the NHS, narratives can create meaning for the professionals about their own actions and work. In nursing, narratives are an important medium through which nurses can be heard, speak about their experiences and bring meaning to their lives as nurses. This may be significant for a discipline that is often perceived as voiceless, or rather that its voice lacks the power of other more influential accounts of health care (Hallam, 2000). Stories told to researchers provide a window into how an individual understands what has occurred in their experience (Andrews et al, 2008). In the second part of this study, narratives provide a unique opportunity to explore the experiences of A&E nurses, particularly about sudden death. Some stories, of which those about sudden death are an example, are more memorable or moving than others, and thus may have more power to share, reinforce or transform.

Narratives have three main features: firstly, they have a beginning, a series of unfolding events and an ending; secondly, narratives assume both a narrator and listener whose different viewpoints affect how the story is told; and thirdly, narratives are concerned with individuals, rather than simply reporting what they do or what is done to them. They are concerned with how individuals feel and how others feel about them (Findlay, 2004). There are different types of narratives, personal, cultural, social, and professional. Each is authored by the individual, and shaped and constructed by their own individual experience of life as well as those around them.

Labov and Waletzky (1997) suggest narratives concerning personal experiences normally unfold in four basic stages: an orientation, which introduces the story's setting and characters; the main backbone of the story; a stage of evaluation that makes explicit how the events in the story affected the narrator; and finally, a resolution to the story. The narratives in this second part of the study consist of personal and professional narratives from A&E nurses concerning their experiences of A&E nursing, sudden death and bereavement.

### **The A&E department**

One A&E department, housed on three sites, but all part of the same NHS Trust based in Yorkshire & Humber was the setting for the part II of this study. This was a different location from part I of the study. The A&E department provides a service for approximately 185,000 new patients per annum and 13,000 returning patients. The staffing establishment in the A&E department was in keeping with the specified national recommendations and the department provides 24 hour A&E services.

### **The sample**

Purposive sampling was the approach used in part II for the selection of the participants. The sample consisted of experienced A&E nurses. A total of 70 A&E nurses were invited to participate. Twelve nurses who met the criteria for inclusion responded to the invitation to participate and were interviewed.

### **Inclusion and exclusion criteria**

The inclusion and exclusion criteria for nurse participants in the second part of the study are described in Table 3.6.

**Table 3.6 Participant inclusion and exclusion criteria for part II of study**

<b>Inclusion criteria</b>	<b>Exclusion criteria</b>
Nurses working in A&E	Nurses not working in A&E
Nurses working one of the three designated A&E departments	Nurses not working in one of the three designated A&E departments
A&E nurses at grade E,F or G <sup>3</sup>	Nurses at grade D, C, B or A <sup>4</sup>
Nurses may be interviewed if they had no personal bereavement within six months of the interview.	Nurses may not be interviewed if they had a personal bereavement within six months of the interview.

### **Approaching the nurses**

Nurses who met the inclusion criteria were invited to participate in the study via a personal letter. The letter contained an invitation to participate, an information leaflet about the study and a consent form (see Appendix 6). If the participant wished to participate after reading the information, the original intention was for them to complete the consent form and return it to the researcher. In reality this only happened at one of the three designated A&E sites where the researcher was relatively unknown to the staff. At the other two A&E sites, because the researcher was employed there, the staff responded in person offering to participate. In all cases written consent was obtained prior to any interviews taking place.

### **Conducting narrative interviews**

The narrative approach is firmly grounded in qualitative traditions and emphasises the fact that much of human life is conducted through stories. People are storytellers and give narrative accounts of their experiences and the meaning they have in their lives (Reisman, 1993). For researchers looking for a research design that reports personal stories, narrative research may be ideal as it seeks to understand and represent experiences through the stories that individuals live and tell (Cresswell, 2002). Narrative interviews were used in the second part of the study to capture A&E

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<sup>3</sup> Equivalent to Agenda for Change (AFC) Upper Band 5, 6 & 7

<sup>4</sup> Equivalent to AFC Lower Band 5, 4, 3, 2, 1

nurses' stories, drawing out their experiences of everyday life in the A&E department. In particular, emphasis was placed on the nurse participants' constructions surrounding sudden and unexpected death. A copy of the interview guide used for the narrative interviews is contained in Appendix 7. Eleven interviews took place in a private area away from the main A&E department and one took place in the participant's home at their request. All the interviews were tape recorded and transcribed by the researcher.

### **The participants**

Twelve nurses (n=12) agreed to participate. Table 3.7 provides details of the nurse participants' pseudonyms, their number of years registered as a nurse and their number of years experience in A&E nursing.

**Table 3.7 The participants in part II**

<b>Pseudonym</b>	<b>No. of years as nurse</b>	<b>No. of years in A&amp;E</b>
Maria	22	10
Chloe	5	3
Jenny	34	25
Karen	17	7
Katherine	23	10
Lynne	14	14
Mandy	15	15
Di	23	23
Gary	3	3
Jean	25	24
Laura	11	8
Sandy	27	18
Mean	18.25 years	13.33 years

The length of time in nursing ranged from 3 to 34 years, with the mean being 18.25 years. The length of time in A&E ranged from 3 to 25 years with the mean being 13.33 years.

### **Data collection & Data analysis for part II of the study**

Template analysis is a way of thematically analysing qualitative data and was used in part II of the study. It involves the development of a coding “template”, which summarises the themes identified in a data set, and organises them in a meaningful and useful manner (Crabtree & Miller, 1999; King, 2004; Miles & Huberman, 1994). Narrative transcripts are lengthy and detailed and can be overwhelming for researchers; template analysis provides a framework to capture the richness of the data and at the same time helps organise the data collected into a structure with codes and themes.

Analysis of the data for the nurse interviews followed a template approach as described by King (2004). This approach works well with small data sets or when the researcher knows what issues they are searching for. Therefore, this methodology was useful in part II of this study in which, although exploratory in nature, the researcher had identified a priori issues: A&E nurse’s experience of everyday life in the A&E department and their experiences of sudden and unexpected death.

Analysis often, though not always, starts with some a priori codes that are usually set out in the interview guide and which were informed by the literature and identify themes strongly expected to be relevant to the analysis. Once any a priori themes are defined, the first step of the analysis proper is to begin reading through the data, marking in some way any segments that appear to tell the researcher something of relevance to the research questions. Where such segments correspond to a priori themes, they are coded as such. This initial template is then applied to the whole data set, and modified in the light of careful consideration of each transcript. Once a final version is defined, and all transcripts have been coded to it, the template serves

as the basis for the researcher's interpretation, illumination of the data set, and the writing-up of findings (King 2004). The main steps in the data collection and analysis for part II of the study are shown in the flow chart in Figure 3.2.

**Figure 3.2 Steps in the data collection and analysis for part II**

Define a priori themes - interview prompts



Conduct interviews



Transcribe interviews



Read and re-read transcripts to familiarise with data



Carry out initial coding of data and placed in excel file



Produce initial template



Develop template by applying it to the full data set



Use final template to help interpret and write up findings

Once the template analysis was completed, a thematic map of the data displayed the emergent themes in a visual format; no data was left un-coded.

### **Writing up the analysis**

Prior to any formal writing up, maps were formulated which contained the themes from the analysis. The maps for the relative and nurse analysis are contained in the findings chapters for the respective part. These maps were presented to this study's research supervisors who had read the interview transcripts. Constructive feedback

was given as a means of verifying the data and peer checking; this is one example of how dependability and rigour was maintained within the study. The emergent themes were written up in a cohesive manner to enable the reader to understand what has been discovered and were supported by numerous quotes from the relatives' and nurses' stories.

## **Ensuring Rigour**

### **Issues related to validity and reliability**

One of the central issues facing any researcher involves establishing the validity and reliability of the claims made by the research (Lindlof & Taylor, 2002). The issue of rigour in qualitative research has been the topic of much debate in recent years (Polit & Beck, 2008; Rolfe, 2006). Part of this debate revolves around whether the reliability and validity of quantitative and qualitative research can be judged using the same criteria.

Lincoln and Guba (1985) proposed alternative criteria for judging the trustworthiness or soundness of qualitative research and identified four components related to trustworthiness: credibility, transferability, dependability, and confirmability. Credibility concerns establishing that the results of qualitative research are credible or believable from the perspective of a participant in the research; that is, whether or not the research findings represent a "credible" conceptual interpretation of the data drawn from the participants' original data. Transferability is the degree to which the findings of this inquiry can be applied or transferred beyond the bounds of the project. Dependability is an assessment of the quality of the integrated processes of data collection, data analysis and theory generation. Finally, confirmability is a measure of how well the inquiry's findings are supported by the data collected and refers to the degree to which the results could be confirmed or corroborated by others.

In both parts of this study, trustworthiness was enhanced through a number of strategies. Regular meetings were held with academic research supervisors who scrutinised the work and gave verbal and written feedback throughout the whole of this study. These meetings were documented in the research diary along with the feedback. A presentation of the study was also made at a University where verbal feedback was given on the project by other postgraduate research candidates. The credibility of the researcher is especially important in qualitative research, as it is this person who is the major instrument in data collection and analysis (Patton, 2002). The background of the researcher has been highlighted throughout the study and her involvement in A&E nursing and sudden death has been explicit from the onset, as has the reflexive approach to the impact of the researcher themselves in the research process. A journal was used to reflect on the research project and at the time of the interviews handwritten notes were made by the researcher following the interviews. Table 3.8 shows a journal excerpt.

**Table 3.8 Journal excerpt**

“This was my first interview, I felt very anxious prior to meeting with Alan the participant, but he was a lovely gentleman who had lost his wife through sudden death. As the interview started I felt that we connected almost immediately, he had a story to tell me about his experience of sudden death and I think he wanted someone to know about what had happened to him. The interview flowed well and there were no difficult silences. It was very sad at the end of the interview when he took me out to the garden to show me where his wife’s ashes had been buried...his loss was so real... The impact of sudden death is far more reaching than what I first realised and I did not realise the huge importance that caring for a relative has in A&E – it makes a big difference to the relatives.”

(Notes made on 5 June 2000 after first interview)

The participants had first-hand experience of sudden death and this enhanced the credibility of the data collected as the participants were able to relate in depth to the impact this had on their lives. Prolonged engagement with the data led to thick descriptions of the subject of sudden death and its impact on suddenly bereaved relatives; this promoted credibility as it conveyed the actual situation that was being explored and was supported by verbatim quotes from the participants.

After each interview the tape recording was transcribed verbatim by the researcher. Lincoln and Guba (1985) encourage checks to ensure the accuracy of the data; to this end, each of the participants was sent a copy of their transcript to check for accuracy. The emphasis was that the participants should consider whether their dialogues and words matched what they meant, and that the transcript accurately captured what they said in their interviews.

From the outset of this study, with appropriate supervision, a clear plan for the research was developed and information regarding the organisations involved, the number of participants approached, the response rate, the data collection methods and the timeframe over which the data was to be collected have been explicit. For example, information was forthcoming about the way in which data would be gathered and how this would be dealt with by the researcher i.e. transcribing the tape recordings and keeping tapes secure. The aim of this was to ensure that this study was conducted in a manner that was in keeping with the good conduct standard required for trustworthy research.

The next section presents the ethical aspects of the study as a whole. It must be highlighted that ethical issues were considered right from the outset of the study.

### **Ethical considerations**

Increasing amounts of attention are being drawn to ethical issues in research involving human subjects (Bradbury-Jones & Alcock, 2010). These are summarised by Orb et al (2001) as an inherent respect for the participants, a clear demonstration of the benefits of the study (which outweigh the risks to participants), avoiding harm to the participants, and ensuring justice and fairness to all parties involved. Concern for the welfare of the participants and having respect for their wishes is an integral part of any research. Notwithstanding the sensitive nature of the phenomenon under exploration, many ethical challenges presented themselves in both parts of this study. Ensuring the study was ethically sound required consideration of key issues

such as informed consent, access, avoiding harm, confidentiality and anonymity for the participants; these will now be discussed in turn.

### **Informed consent**

Informed consent is important, not least because this demonstrates an inherent level of respect for participants within the study. Equally important is that consent is given voluntarily and without coercion (Patton, 2002), so any participants should have the legal capacity to give consent. Informed consent is obtained when an individual participates based upon a clear appreciation and understanding of the facts, implications and future consequences of their action (Patton, 2002). Informed consent is not a once-and-forever permission, rather it is an on-going process of informed participation (Denzin & Lincoln, 2005), and so consent must be seen as a process rather than as a one off event.

In part I, 15 relatives agreed to participate and be interviewed; each had completed and returned the written consent form. When two of the interviews took place, two other relatives spontaneously decided to participate in the interview. In one of the interviews it was the participant's wife and in the other it was the participant's mother. This obviously presented an ethical dilemma as neither had given their informed consent to participate. At that time it seemed inappropriate, almost rude, to interrupt the interview to gain formal consent. Once the interview was completed, their full consent to use the contribution for research purposes was obtained retrospectively by providing the participants with the information sheet about the study and giving them the opportunity to discuss any issues related to the study prior to signing the consent form.

In part II, 12 A&E nurses agreed to participate and informed consent was obtained from all nurse participants prior to the interviews taking place.

## **Gaining access**

Gaining access to participants is not always straightforward, as gatekeepers can facilitate or impede a researcher's access (Hodgson, 2001). In essence gatekeepers are the people who have the power to grant or withhold access to the research field. Research involving patients, relatives or staff is subject to local research ethics committee (LREC) approval. The LREC ensures that public safety is maintained by considering the ethical and legal compliance requirements of research designs, thereby minimising distress or harm to those individuals participating in the research (DoH, 2001b). As this research involved interviewing the relatives of deceased patients and A&E nursing staff, permission was sought and granted from the LREC on two separate occasions, once for each part of the study. Permission to access patient records in order to access relatives and staff was granted by the A&E Directorate Lead, A&E Consultants, A&E Manager, Hospital Research and Development Department and LREC. Prior to submission of documentation to the relevant LRECs, approval was first obtained from the University of Manchester Research Ethics Panel for study I and the University of Huddersfield School Research Ethics Panel (SREP) for study II.

Adhering to the principles of good practice as outlined in the Research Governance Framework (DoH, 2001b) is important to ensure participant wellbeing. I was obligated to ensure that participants were safeguarded by keeping to the agreed protocols outlined in the study. As the sole researcher it was important to ensure the ethical principles laid down were upheld, including adhering to the inclusion and exclusion criteria, obtaining informed consent and protecting confidentiality and anonymity.

## **Confidentiality**

Padgett (2008) emphasised the importance of protecting the identity of research participants. In order to maintain the participants' confidentiality, the research must be presented in such a way that others do not become aware of how a particular

participant has responded (Leedy & Ormrod, 2001). In this study, confidentiality was maintained by removing any identifying information, including the participants' names, addresses, hospitals or workplaces. The participants were assured that identifying information would not be made available to anyone.

### **Anonymity**

All personal data should be concealed and only made public behind "a shield of anonymity" (Denzin & Lincoln, 2005:145). Anonymity means that the participants will remain anonymous throughout the study (Barbour, 2007). This is a guarantee of privacy, but it is sometimes difficult to accomplish. For example, in this study the nurse participants were drawn from three A&E departments in close proximity and where the participants were all known to each other; there was potentially the chance that other staff may know who had participated. Therefore, protecting the nurse participants' anonymity became a major ethical concern. In order to achieve this any interviews that took place did so in private, away from the A&E department in a separate area and pseudonyms are used in place of the nurse participants' real names.

These ethical challenges persist when writing up a research study where the participants' anonymity must continue to be maintained (Barbour, 2007). In this study a small sample was recruited for both parts of the research, and this increases the risk of participants being identified, particularly in the second part of the study where the nurse participants were known to each other. To ensure anonymity pseudonyms were created and the identity of participants was known only to the researcher. A file linking names and pseudonyms was kept in a secure password-protected place only accessible to the researcher. The participants were informed that the final work would contain anonymous verbatim quotations but were assured that their names would not be associated with, or included in, the text of the thesis.

### **Participant wellbeing**

Given the sensitive nature of the topic under investigation, the wellbeing of the participants before, during and after the study was paramount. For example, during the interviews with both the relatives and the nurses, the participants often became upset and cried. When this happened the offer of a break was given and the interview did not re-start until the participant was ready to do so. At the conclusion of the interview and once the tape recorder was turned off there was a period of debriefing. This involved a general discussion between the researcher and the participant to ensure they had come through the interview safely. Information on how to contact the researcher at a later stage was given to all the relative and nurse participants in case they needed further assistance.

### **“Being Native” to A&E**

The difficulties of conducting research in one’s work place are undeniable. A desire to remain unobtrusive while being in close quarters with familiar informants is difficult (Colbourne & Sque, 2005). The main criticism offered in the literature is that the researcher may lack critical distance and may fail to see viewpoints other than the one the researcher is used to. Patton (2002: 49), however, argues that “distance is no guarantee of objectivity”. As research is seldom value free a good researcher must learn to see his or her version of reality as only one of many possible ways of viewing the world (Coyle and Williams, 2000). Arguably, when nurses conduct research in familiar surroundings they have their own niche in that setting and others (i.e. staff and patients) may have role expectations associated with their “normal” work-related position rather than as a researcher (Colbourne and Sque, 2005). I did not engage in any pretence to hide the fact that I was a nurse or that I worked in A&E, and I recognise that I am an insider and accustomed to the culture of A&E nursing. It might be said, and it is an appropriate criticism to level, that I came to this study from an assumed position of knowing (Pellatt, 2003). Being an A&E nurse

meant that I had encountered sudden and unexpected death on numerous occasions and it was this, in part, that engendered my interest in the topic. In addition, outside of my role as an A&E nurse I have personally encountered sudden and expected death. Hence I came to this study with both prior personal experience of sudden and unexpected death and a professional perspective.

### **Reflexivity**

According to Munhall (2007), in an effort to avoid bias and maintain objectivity, quantitative researchers study phenomena and research subjects in a detached manner and one in which they are not involved. This detached and objective role is encouraged by quantitative researchers to ensure no contamination of the data takes place. However, the interpretive-phenomenological approach acknowledges that researchers and the research itself cannot be separated in any meaningful way (Findlay, 2008). The researcher uses interactions between themselves and the participants to get closer to the meaning of the phenomena under study. Therefore, this approach recognises that the researcher both influences and is influenced by the process of conducting research. Holloway (2005) suggests that reflexivity is as an essential component of all social research; making explicit the reciprocal relationship between researcher and researched is a key aspect of this. Holloway (2005) continues that during the research study and process it is important for researchers to reflect on who they are, on their perspectives and attitudes, and on their thoughts and beliefs. From my perspective, I am a white, middle-class female with working-class roots. I was aware that how I presented myself, my image, my clothes, my uniform, my accent and the language I used would all have an impact on the participants who I met in this study. In addition to how I presented myself, other factors, such as my personal outlook on life, my beliefs and my attitudes, could have a bearing on my relationship with the participants. For example my belief about how relatives should be cared for in A&E following a sudden death is significant and I was

aware that this would have an impact on the nature of the relationship and rapport that developed between me and the participants.

In qualitative studies, the researcher usually serves as the instrument through which data are collected (Patton, 2002). The quality of the information gained in any interview is largely dependent on the interviewer. The interviewer uses his or her skills as the research instrument using the responses of the participant to guide the data collection by probing for further information when needed for depth and clarity. As a consequence, rigour is needed throughout the whole process to ensure the trustworthiness, credibility and honesty of the research (Sofaer, 2002; Richmond, 2002). According to Marshall and Rossman (2010) the role of the qualitative researcher is not one that is objective and detached or apparently neutral, but one that is inseparable from the personal values and assumptions that he or she brings to the research as part of life's experience. The qualitative paradigm assumes the position that biases and presumptions are to be made visible to the reader rather than assuming they are non-existent or can be controlled. Throughout this study I was open and honest about my own values and beliefs.

## **Conclusion**

This chapter examined the issues surrounding the aims, methodology, methods, data collection and analysis. In both parts of the study the use of a qualitative approach enabled different perspectives or realities on the phenomenon of sudden death to be explored. In part I, a phenomenological approach was adopted to explore sudden and unexpected death as experienced by bereaved relatives in the A&E environment. Semi-structured interviews were analysed and provided rich descriptions of sudden death as experienced by relatives. In part II, a narrative approach was employed to explore A&E nurses' experiences of sudden death in the context of the A&E environment. Narrative interviews were analysed by means of

template analysis which provided an in-depth understanding of A&E nurses experiences of sudden death.

As with any research process it is important to consider the ethical concerns and challenges presented during the course of the study. The ethical considerations in this study have been explored and explanations given as to how they were addressed. Relatives and A&E nurses were invited to participate in the study only after rigorous ethical approval was granted. The latter part of the chapter highlighted the importance of ensuring quality and rigour in qualitative research.

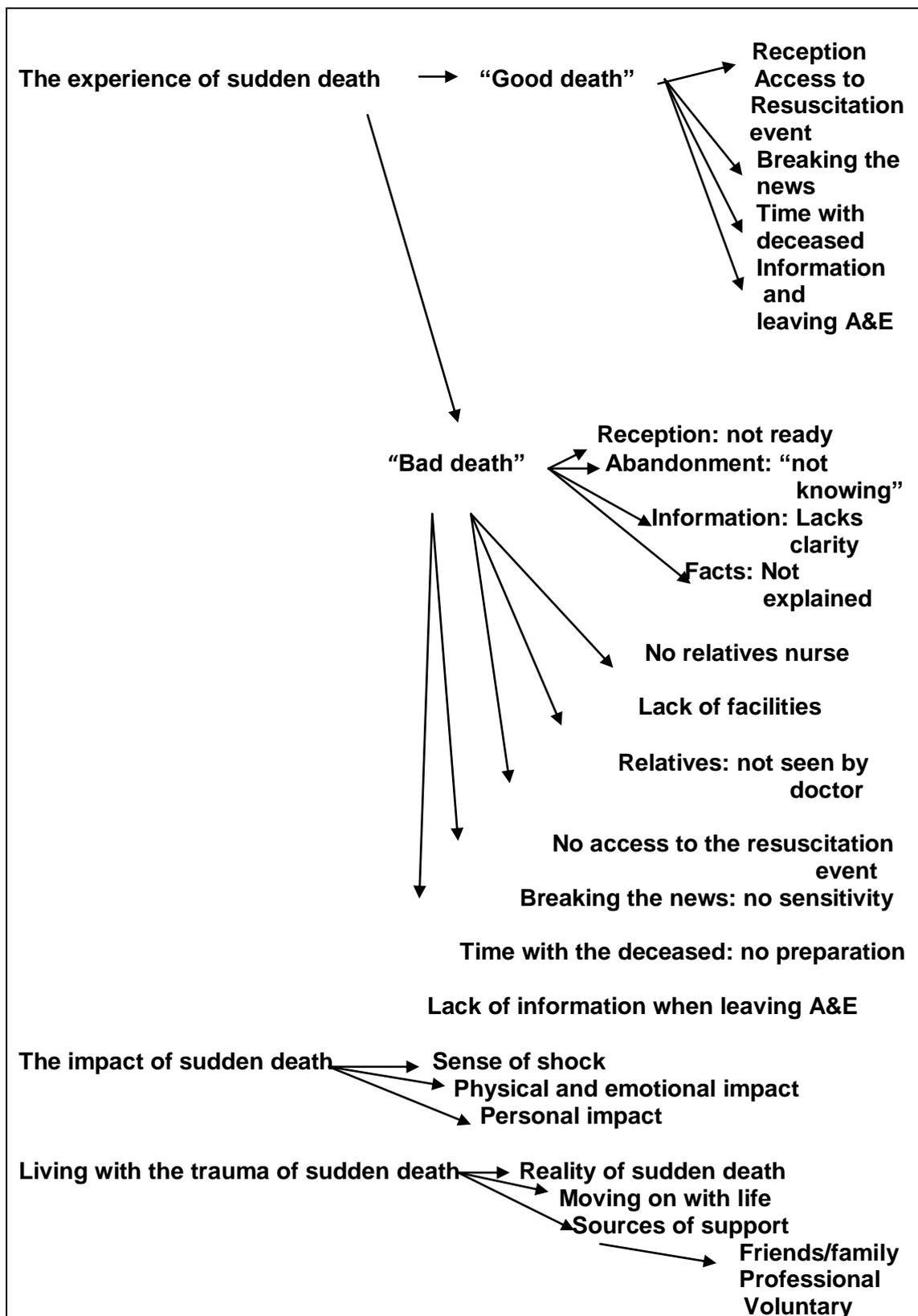
The next chapter presents the findings from part I of the study which are presented in such a way to enable the reader to understand the lived experience and impact of sudden death.

## **Chapter Four - Findings and discussion from the relatives interviews: “Broken” the impact of sudden and unexpected death**

### **Introduction**

In Chapter Three, the approach adopted to access relatives of people who had died suddenly and the methods of analysis were explained. This chapter presents supporting demographical information and the findings from the semi-structured interviews conducted with suddenly bereaved relatives. The intention in this chapter is to uncover and explore the personal experience of bereavement as a consequence of sudden death. The main themes that resulted from the interviews confirmed some of the familiar characteristics associated with sudden death, such as shock, feelings of helplessness, sadness, guilt, anger and frustration, which have been widely researched and supported by the literature. The findings that emerged from the content analysis are classified under three main themes the experience of sudden death, the impact of sudden death and living with the trauma of sudden death. A thematic map presents the main themes and sub themes for the chapter – see Figure 4.1.

Figure 4. 1 Thematic Map for part I



## Demography

A total of 285 adult deaths took place between January 1999 and June 2000 in the A&E department. This equates with the national average of 4-5 deaths per week at that time (BAAEM & RCN, 1995). However, only 173 deaths could be included in the initial analysis; the other 112 cases could not be reviewed because of the unexpected closure of one of the A&E departments during the course of the project. Of the patients who died, 106 were male and 67 were female. The average age at time of death was 71. The youngest age at time of death was 21 and the oldest was 96. There were a number of different causes of death documented in the A&E notes. The majority of sudden deaths were medical in origin rather than due to trauma. In Chapter Two, the analysis of the literature regarding the causes of sudden death demonstrated that cardiac and circulatory diseases are the leading cause of death in the UK (BHF, 2009). The causes of death in the first part of the study as specified in the A&E notes are noted in Table 4.1.

**Table 4.1 Causes of death as documented in A&E notes**

<b>Cause of death</b>					
11 (6%) trauma	RTA (n=2)	Choking (n=3)	Head Injury: fall (n=3)	Head Injury: assault (n=1)	Drowning (n=2)
162 (94%) medical	Cardiac Arrests (n=104)	Respiratory Problems (n=18)	Myocardial Infarct (n=10)	Cerebral Events (n=2)	Others e.g. Overdoses (n=28)

The most common cause of death documented in the A&E notes was cardiac arrest, which accounted for 104 cases. This is a provisional cause of death provided by the presiding A&E doctor present at the moment of death; however, the exact cause of death must be confirmed by post mortem findings. Whether or not a post mortem takes place is determined by the Coroner who oversees all records of sudden death; in the majority of cases, a post mortem is instructed.

## **Part I: Reflections of the interview process**

In part I of the study, 15 interviews were carried out involving 17 relatives. The participants were encouraged to tell their story of events from their own perspectives, and all the participants provided rich descriptions of their experience of sudden and unexpected death. The interviews took place in the participant's homes at a time and date that was convenient to them. The interviews lasted between one and two hours. All the interviews followed a similar pattern commencing with a general introduction and discussion. This encouraged the participant to relax and helped them become less conscious of the tape recorder. The interview naturally progressed into answering questions about their experiences of sudden death. At the end of the interview the tape recorder was switched off and a period of de-briefing took place to ensure the participant's well-being following the interview. At the end of the interview the researcher ensured the participants had the appropriate contact details if any follow up was required.

As a novice researcher the interview schedule was initially used in the interviews. As the interviews progressed the need for the interview schedule diminished. Often the participants would start talking about their experiences of sudden death in A&E and how they coped after leaving A&E which negated the use of the interview schedule. In addition to the semi-structured interviews, data were recorded in the form of field notes and demographic information. Field notes documented after the interviews contained information about any factors that influenced the data collection process, such as the where it took place, the flow of the conversation and notes to inform the analysis. Each interview flowed well and although challenging provided rich descriptions of the participant's experiences of sudden and unexpected death in the A&E department and thereafter.

## **The experience of sudden death in A&E**

Chapter Two discussed the concept of a “good death”, and, conversely, its mirror image which emerged in this study described as a “bad death”. The terms “good” and “bad” deaths have been used to best represent the different experiences of the relatives’ involved in this study who attended A&E around the time of death. A number of themes and sub-themes emerged from the analysis which forms the main body of this chapter. The experiences of the participants who reported a “good death” are discussed in the next section.

### **A “good” sudden death experience**

#### **Reception**

The participants reported that a named A&E nurse was allocated to them in the department. This nurse met the participants at their point of entry, either in the ambulance bay or at A&E reception. The literature review highlighted that allocating a nurse to the bereaved family creates an atmosphere of mutual trust and understanding (BAAEM & RCN, 1995; Hallgrimsdottir, 2000; Li et al, 2002). This nurse did not remain with the families for the whole of the time in A&E and appeared to execute a number of roles that could largely be deemed as being supportive. One of their functions was to act as liaison between the resuscitation team and the family and to keep the family informed of the patient’s condition. Another function was more generally to “look after” the relatives, such as making tea and assisting with making and receiving phone calls. All the participants described the interaction between themselves, other family members and the named nurse positively. For example, as Alan described:

*“She was very good ..Very kind” (referring to the A&E nurse)*

For these participants, their first impression of the A&E nurse was positive and the rapport that developed between them and the nurse was recognised. This nurse

appeared to act and respond differently according to the individual situation. Edward reported:

*“that same evening, you see, the nurse was very good, ... and emm and I was taken to a room given a drink and emm spoken with and then err I think err I don’t know emm certainly a Senior nurse emm asked if she could phone anybody ... which she did.”*

Maureen recalled:

*“I seem to recall ... yes, a nurse came to me ... I don’t know what degree of position she had but she was a nurse and was very nice with me. I must have had about 2 or 3 cups of sugary tea and I don’t have sugar in tea but she insisted on putting sugar in the tea (Maureen and Sharon Joint laughter)”*

The reception by a nurse who either remained with, or had continued contact with, the relatives appeared to be important to the participants. The nurse assisted the participants practically, and communicated vital information about the patient’s progress. The literature review noted the importance of privacy at the time of sudden death and discussed the use of a family room to facilitate this (BAEM & RCN, 1995; Wright, 1996). However, being taken into a separate and private family or relatives’ room symbolically signalled the seriousness of the situation for the participants.

### **Family presence during resuscitation**

The participants were offered access to the resuscitation room during their relative’s resuscitation attempt. Alan witnessed the resuscitation attempt in A&E and was present as the resuscitation came to an end and his wife died. Alan said:

*“We sat there in A&E she was breathing ... So I said to my sons ‘this is it’ and then her heart stopped and... Yes ... (tearful pause) ... then they certified her.”*

Kate witnessed the resuscitation and events immediately prior to her mother’s death and said:

*“and then they came to fetch me to say she had deteriorated ... (tearful) ... Then ... (tearful) ... she (the nurse) stayed with me.”*

The fact that both Alan and Kate had been present with their relatives at the end of their life was a source of comfort to them. Isobel's father collapsed at home and she witnessed the subsequent resuscitation attempt by the ambulance crew. She said:

*“and there was a nurse there and she said to me ‘do you want to go in with him in the room’ ... whatever they call it the resuscitation ... and I said ‘no’ and (pause) ... and I thought ‘no’ because it would be messy you know...”*

Maureen witnessed the resuscitation of her husband by the paramedics and found this experience traumatic; she said:

*“No I didn't wish to go in, (referring to the resuscitation attempt in A&E) ... When he was being worked on in the bedroom I could hear the machines and what not all going upstairs in the bedroom ... (tearful)”*

Access to the resuscitation room to witness the resuscitation attempt was accepted by some relatives and declined by others. As discussed in the literature review, the issue of family presence in the resuscitation room remains controversial. Some relatives may wish to be present during resuscitation and there is evidence to indicate that in most situations this not only helps relatives come to terms with the death when it occurs, but may also enable them to cope better with the loss in the long term (Kirby, 2003; Robinson et al, 1998; Wright, 1996). The unexpected nature of sudden death means that bereaved relatives may feel guilty because they were not able to be present at the time of death, and this can impede them from coming to terms with the death (Robinson et al, 1998); witnessed resuscitation may alleviate this feeling. The Resuscitation Council (UK) (1996) and the RCN (2002) recommend that family members should be allowed to witness resuscitation because of its identified benefits. However, it is important that relatives are accompanied by a nurse who can explain the procedures and provide support.

### **Breaking the news**

The participants were informed of their relative's death either by both a nurse and a doctor together, or by a nurse followed by a doctor who confirmed what the nurse

had said. The salient points raised by these participants were that this news was delivered in a sensitive way in privacy with a clear message, and in an unrushed or unhurried manner. As Isobel explained:

*“the nurse said the doctors have tried everything they can, I’m really sorry he’s died.”*

Some of the participants stated they “knew” their relative had died prior to being informed by any of the staff. Maureen reported:

*“a doctor came to me and said ‘I don’t suppose it’s really ... what you want to hear what I’m going to tell you’ and I said ‘no’, because I said, ‘I know’”*

Jane said:

*“I knew when I saw her come in what she was going to tell me. You know, but although I didn’t want to accept it I knew when, when I left him, when they took him into the room. Erm, she just said, ‘I’m sorry Mrs. J’ and I think I said to her, ‘He’s died hasn’t he?’ And she said, ‘Yes, I’m sorry.’ And she sat with me. She was lovely ... Yeah, she was lovely.”*

When death had occurred, the way in which this news was communicated to the relatives appeared important. The sensitivity surrounding the delivery of this news, how the bearer of this news presented themselves to the participants, the clarity of the message and the delivery, including the pace and manner, seemed to be important, and made receiving the “bad news” a positive experience for these participants. The nurse or doctor remaining with the relatives was also identified in these accounts, suggesting that this had some resonance or significance, even though most of this time was spent in silence. The literature notes the importance of listening to someone who is bereaved, being with them and witnessing their grief, and suggests that this may be one of the most important services a nurse can provide for someone who is suddenly bereaved (Casarett et al, 2001; Sutton, 1998). This resonates with the work of Benner (1984), who emphasised the humanistic qualities of “presence”, its reciprocal nature and the value it brings to the nurse-patient relationship.

## Spending time with the deceased

The participants were offered the opportunity to spend time with their deceased relative. Some declined and felt unable to see their relative. Nigel, for example, could not face seeing his relative. Nigel stated:

*"I couldn't ... I'm not strong enough to do that."*

For the remaining participants spending time with their relative seemed to provide comfort yet engendered some distress. The actions of the nurse who accompanied them appeared to make this distressing experience a little easier. Helen was worried about her son who was only eighteen and had never seen a dead person before but wanted to see his grandfather. Helen recounted:

*"I think in a sense it could have been very traumatic for him (referring to her son) but emm ... (pause) they were very helpful ... And he said the nurse was very kind, she sort of hovered in the door way and that gave him some space but didn't intrude at all so for him it was a good experience. Young as he was I felt it had been a good experience for him, you know something that he may never fear again really"*

Eva reported:

*"When I went in you know I stood at the door for a few minutes like because I was a bit frightened of what my reaction might be and I went in and I looked at him and then I felt a bit better because he didn't look as bad as I expected him to do like so that was a help as well yeah it was it really was helpful."*

These participants felt that the opportunity to be with their relative immediately after their death, although difficult, was comforting. The presence of the nurse made this experience easier. The literature acknowledges that it is important for bereaved relatives to view the body after death. It is thought that spending time with the deceased person can facilitate grieving and reduce feelings of guilt after sudden death (Chapple & Ziebland, 2010; Vanezis & McGee, 1999). In situations where the patient is badly injured or disfigured, the way a person imagines the patient might look in these circumstances is usually worse than the reality (Wright, 1996). Wright (1996) continues that bereaved relatives may regret not having seen the body following sudden death, but few regret having viewed it.

## **Information and leaving A&E**

The participants all received written and verbal information detailing what to do after a sudden death from the nurse. This information included practical information about, for example, contacting the bereavement office, registering the death and collecting the death certificate. The issue of a post mortem was also discussed. Kate stated:

*“They kept coming to talk to me and they had said they didn’t know whether or not ... (pause) ... they would have to do a post mortem.”*

After a sudden death the Coroner investigates the case and decides whether or not a post mortem is required. When the participants were ready to go home the nurse ensured they left A&E department with all the relevant information. On leaving A&E, all the participants were informed that they or their family could return at any time to see their relative. Edward explained:

*“They told us that if we phoned and ... we could come back and see her at the hospital.”*

The possibility of seeing and spending more time with their relative if needed was appreciated.

In this first section the actions of the A&E nurse left a positive lasting impression for the bereaved relatives at the time of sudden death; as a result, the relatives encountered what would appear to be a “good” sudden death experience. The following section reports on the experiences of the remaining participants. These relatives reported a less positive experience, and is described here as a “bad” sudden death.

## **A “bad” sudden death experience**

### **Reception: not ready for the relatives**

The participants reported no initial reception on arrival at A&E. After reporting to the main A&E reception, their details were taken but they were not met by a nurse. The relatives described a significant time delay before the receptionists alerted nursing

staff to their presence. For example: Betty and her family were instructed to sit in the A&E waiting room. Betty explained:

*“We couldn’t sit down as we obviously knew something was wrong.”*

Delia said:

*“and they said well go and give them all your particulars you know in the reception ... eventually they took details off me.”*

Delia experienced frustration at having to wait when her priority was to find out about her husband. Betty continued:

*“This is one of the things that we found very distressing the fact that we were left ... Perhaps she knew what was going on, I don’t know, and we were left standing there.”*

Louise arrived at the hospital unaccompanied and inadvertently went in the ambulance entrance and recalled the following situation:

*“On the way there I could see this guy cleaning this trolley ... with the blood on it and it was obviously ... my brother’s just come off there ... (pause) ... not nice really.”*

This initial poor reception, delay and waiting in the main waiting area caused distress for the participants at a particularly difficult and sensitive time.

### **Abandonment: “Not knowing”**

The participants experienced either a delay or absence of information about their relatives. In the following short sentence, Betty sums up the feelings engendered by having to wait without any information about her husband:

*“and we hung about and hung about and nobody gave us any information at all ... and we looked down at one stage ... down a corridor and we could see a crash team coming out looking very dejected.”*

At this point Betty and her family assumed that the situation for her husband did not appear positive. This was a traumatic experience for Betty and there is a real sense of abandonment at this critical time. The lack of information compounded the feeling of not knowing. Betty stated:

*“you know they were very comforting and offered you all that (referring to A&E staff) but ... its ... there’s no explanation at all so you don’t know.”*

Interestingly, in this account the nursing staff offered comfort but this was annulled by the lack of information. Betty’s priority at that time was to find out about her husband’s situation.

### **Information lacks clarity**

Delia stated that she received no information about her husband at all whilst waiting in the relative’s room, she explained:

*“The next thing I know the nurse came in with a bag and she said ‘I’m sorry’ you know, and they asked me if Henry (referring to her husband) had anything wrong with his heart or anything and I said ‘no’ ... and said she was sorry and gave me this bag (a bag containing husband’s belongings) ...pause ...She told me he’d gone and she said there’s the phone if you want to notify anybody and I was in a state I couldn’t use the phone so Tom (referring to her gardener who had brought Delia to A&E) did it ... erm, that’s the part that upset me”*

This nurse did not explain to Delia that her husband had died. Once Delia realised this she became very upset. Delia found it distressing initially not knowing her husband had died, accompanied by a lack of clarity, sensitivity and comfort, and further accompanied by a lack of assistance in contacting her relatives. Delia reflected:

*“but they could have come and said well there’re trying to revive him and stayed with me and explained what they were doing, that would have been nice ... (pause) ...”*

The literature reveals that many individuals who are suddenly bereaved state that hospital staff informed them of the death in ways that were inexpert and uncaring (Spalls & Callis, 1997; Wright, 1996) and that this had a detrimental effect on their grieving and made the impact of the death more devastating for them.

### **Facts not explained**

Fran and her family were equally distressed by the lack of information. Fran explained:

*"I think what I'm trying to say is nobody had prepared us for the fact that after an hour, and I know it was only a short time, the prognosis was that my Mum was going to die."*

This lack of information was compounded by insensitivity around the news of her death being broken. Fran continued:

*"We were dumbfounded ... because we just didn't know ... it all seemed to happen so quickly because Mum was right one minute and 2 hours later you're being told 'there's no point there's nothing we can do she might as well be dead', which I ... I know it's a shock ... it's a shock. I know all about this but I just found the way it was told to me so heartless and I didn't want somebody to hold my hand or ... I just wanted someone to sit down and say look this is what has happened, you've got this big blood vessel your Mum's has got to the end of its life ... if someone had told me gently what had happened I could have understood it much more than just to be told 'her aorta's burst and there's no point' ... what does that mean!"*

Fran and her family did not receive accurate and timely information about her mother's condition and the information that was given was not presented in a clear and sensitive manner. This experience was etched in her memory and remained with her and dominated much of the conversation in the interview. Fran continued:

*"But it's like being in hell because you don't know what's happening the person you want to be with is ... (tearful)... you want to go and talk to them cause then when I realised that Mum was so poorly I wanted to go and speak to her but there was no point, that's what he said, there's no point ... (referring to the surgeon who spoke to Fran and family)"*

A doctor is usually nominated to deliver the news of the death to the relatives; however, the literature suggests that the bereaved are more concerned about the nature of the communication than the person's position. The bereaved would prefer that the professional giving this information had time to answer questions and appeared to care (Vanezis & McGee, 1999). There is also evidence that the family and friends of the deceased person appreciate staff appearing concerned (Marrow, 1996) as it demonstrates they care.

### **No nurse**

The participants had no nurse allocated to them. Delia explained:

*"I didn't want to be on my own ... I would have liked a nurse to have sat with me till my family came, it would have been a big comfort to me just to talk."*

Louise was collected from reception and taken to the family room and no information was given:

*"They just took us down to the room and just put us in the room"*

The participants attributed this lack of information as contributing to their experience of a "bad sudden death" experience in A&E. This lack of information is multi-factorial; there was a lack of a reception and the receptionists were not ready or prepared for the relatives. Once the relatives had registered the details they were left alone contributing to a sense of abandonment and isolation; this sense of abandonment was heightened as there was no allocated A&E nurse. When information was given to the relatives it lacked clarity and the facts were not explained, and then the news of death was delivered in an uncaring manner.

### **Lack of facilities**

One of the participants experienced a problem with the facilities. Betty stated:

*"When we went into the room of course we then had to telephone relatives ... there was no phone there and my daughter, who's only 22 in shock ... had to go out into the corridor to get through to switchboard to make a phone call ... You're standing there and there's all these old dears and people you know stood behind you ... that was very stressful and I really didn't like that."*

This problem highlighted the need for privacy at such a sensitive time, but this was not afforded to Betty and her family. The importance of providing a room with appropriate facilities to provide privacy for the relatives in A&E is emphasised in the literature (see BAEM & RCN, 1995).

### **Not seen by a doctor**

Following the death only some of the participants spoke to a doctor; although, as Fran reported, the news of the death was not always conveyed well. However, some

relatives did not have the opportunity to see and talk to doctor but would have liked to do so. Betty stated:

*“One of the things we didn’t get ... we were never seen by a doctor, no one actually explained to us a part from sister that he had died.”*

Betty needed to know more about what had happened in A&E and about the medical interventions given. Delia had a similar experience:

*“It was a nurse ... it was a nurse and she brought the belongings out in a bag you know ... and I didn’t see anybody else at all ... no one ... we saw no medical staff at all after that.”*

### **No access to the resuscitation room**

Some of the participants were not offered access to the resuscitation room during the resuscitation attempt or at the point of death of their relative. In her account Delia builds on the theme of “not knowing”:

*“Because you know I don’t know what they did to him (referring to husband) in there ... If they had told me he had arrived and they were working on him... But they didn’t and I was in the dark completely until they came in and told me that he’d gone.”*

Delia continued:

*“If I could’ve seen what they were doing, perhaps it would have upset me, if I’d seen what they were doing to him. If a nurse could have come and said well their trying to resuscitate him or whatever I would have known that ... you know ... It would have been nice to know what they were doing to him cause he was still my husband.”*

Fran was equally distressed at the lack of opportunity to be with her mother and said:

*“No ... (tearful)... even though she was so poorly ... even though she was not conscious ... if somebody could have said ‘look she’s still alive .... You can go in you can hold her hand or you could... you can just’ ... my son, her grandchild ... he adored his grandma and for somebody at that time he was only 14 he ... It was like somebody had dropped a bomb on him and I think if he could just have seen Mum just whilst she was still alive and felt her whilst she was still warm ... you know, we knew she was going to die we knew she had only minutes left if we could just have been given those few little minutes I think we would have all ... Ahh ... I think we would have all felt slightly better because at the time one minute I saw Mum in the ambulance and the next time I saw her she was dead ... (Crying)... ”*

Not being with a relative at end of life was in these accounts distressing for the participants and seen as a preventable omission of their need to demonstrate care for their relative. On arrival at A&E, efforts may still be being made to resuscitate the patient. A programme of care that offers family members the opportunity to remain present during the resuscitation of a relative, supported by an experienced trained nurse assigned to them solely for this purpose may be beneficial (RCN, 2002). In this situation, it is critical that relatives do not feel excluded from the proceedings. Studies indicate that relatives feel less helpless and isolated if they are informed honestly and frequently of the patient's condition (Vanezis & McGee, 1999). If the bereaved feel left out or uninformed, it may lead to feelings of anger (Cooke, 1993; Wright, 1999) that can continue during the ensuing grieving process.

### **Breaking the news**

The participants had the news of the death broken to them in a manner that was perceived as poorly articulated and lacking any indication that the nurse cared for them. This created memories for all these participants that evoked an emotional response in the retelling. Grace's husband collapsed at his allotment away from home. Despite extensive resuscitation attempts in A&E he died before Grace could reach him. She explained how the news of his death was broken to her in a telephone conversation:

*"I rang the A&E department but Alf (her husband) had not arrived yet. A Sister rang back to say what type of car did he drive, and what watch was he wearing, then the Sister told me over the phone that Alf had died. I was very distressed and crying as I was at home alone."*

Grace continued:

*"It was difficult to hear that news over the phone."*

In this situation the relative would be invited to attend A&E and upon arrival information about the events leading up to the death would be given followed by the fact that death had occurred. Wherever possible, bad news should not be given in a telephone conversation; a face-to-face situation is the preferred method (Kent &

McDowell, 2004). Louise and Olwyn had the news of the death delivered in response to a question. The explanation given to Olwyn was delivered by a nurse using medical terminology which she did not understand. Olwyn said:

*“He just said that he’d (referring to her husband) been brought in and that they’d, erm, he’d had a cardiac arrest. He didn’t he say he’d had a heart attack. He said he’d had a cardiac arrest and that they’d tried to save him. (Tearful voice)”*

Fran experienced a similar situation and recalled a distressing incident with the surgeon who had been involved with the resuscitation of her mother. The way the news was delivered still engendered anger. Fran said:

*“It makes me angry now to think about it ... it makes me very angry and I’m sorry ... he was unfeeling, he was cold, I didn’t know what had happened to my Mum, he came in he was obviously very, very senior to all the others and ... this gentleman, I use the word loosely, came in and was very, very, very off hand and at this point he said ‘your Mother’s still alive’, which of course ... (pause) ... ‘thank God’ you think, ‘she’s still alive but she’s burst her Aorta’, which to a non-medical person I didn’t know what that meant I had no idea that that was as serious as it actually was ... and he more or less said there’s no point hanging on to her, she’ll die ... she’s dead, she’s more or less dead and I said to him ‘is she still alive?’ and he said ‘she’s still alive but she’s almost ...’, to the effect that she’s as good as dead and it was how ... it was the most awful thing ... I know he’s got a job to do and I know delivering bad news to people is ... must be awful, but there wasn’t one ounce of ... it didn’t help us at all, I didn’t really understand she’d actually died till he actually left the room...”*

The way in which information about the death was relayed and delivered appeared to stay with the participants long after they left the A&E department. A lack of clarity or simple explanation when the news of death is broken seems to contribute to confusion and misunderstanding, compounding an already difficult and emotion-laden situation. Zalenski et al (2006) suggests that competent and empathic death disclosure by hospital staff may help to maintain the continued wellbeing of the bereaved.

## **Spending time with the deceased**

Some participants were given the opportunity to spend time with the deceased whereas others had to ask to see their relative. None of the relatives were given information about what to expect. Louise's brother had been severely disfigured in a road accident but they were not informed of this; she recalled:

*"Then he (referring her Dad) ran away as soon as he saw him."*

Fran reported feeling disturbed by her Mother's appearance which related to a lack of preparation:

*"But still at this point nobody had explained what had happened and of course when I went into see Mum ... (pause) her stomach had swollen completely ... Which of course we were unprepared for, I mean obviously she had the sheet over her. Emm ... but we were unprepared for that and if somebody had just said look you know this is what's happened your Mum ... your Mum's stomach ... Because she looked completely disfigured she was lying flat and there was this huge mound."*

Grace described feeling rushed by the staff:

*"I wanted time alone with my husband and I wanted to stay longer, but felt they (referring to nursing staff) wanted us to go because they needed the space. I didn't want Alf to go to the mortuary at all, it was really upsetting to think of him going there."*

The absence of preparation by the staff seems to have contributed to increased distress for the participants as changes in physical appearance were not discussed. Before relatives view the body the nurse should prepare them for what the deceased person will look like (Davies, 1997; Wright, 1996). This is especially important if the person has undergone physical change due to injury. Equally important is time to spend with the deceased in order to say goodbye in unhurried or unrushed manner.

## **Information and leaving A&E**

Some participants were given written and verbal instructions about what to do following the death. Olwyn received a bereavement booklet but reflected:

*"It explained what I had to do ... (reflective pause) it didn't explain why he died."*

Olwyn wanted information about why her husband had died, which at that time was not immediately available. No written or verbal instructions were made available to other participants. The participants relied on other family members, friends or undertakers to direct them about what to do after the death. Grace stated:

*“We left the department and had no information about what to do next. I got advice from a neighbour about a funeral director.”*

Clear information regarding what to do following a sudden death must be communicated both verbally and in writing to the bereaved. Family members should be consulted regarding specific requirements after a death, particularly to ensure that all interventions are spiritually and culturally acceptable in order to avoid causing offence (Sewell, 2002). Accommodating and fulfilling cultural or religious rituals indicates respect for patients, their relatives and friends (Chaplin, 2003), and will facilitate grieving.

This lack of care and support for the bereaved, at a critical time, such as after a sudden death, contributed to long-lasting negative impressions about the care received in A&E and culminated in a “bad sudden death” experience.

### **The impact of sudden death**

Three main themes emerged from the data regarding the impact of sudden death: a sense of shock, the physical and emotional impacts, and the personal impact.

#### **Sudden death – a sense of shock**

The critical injury or illness and subsequent death of their relatives were sudden and unexpected events for all the participants. For the participants, the experience of sudden death resulted in the life they had previously known, understood and experienced being abruptly changed or “broken” as one participant described it. A sense of shock was described by all participants in response to sudden death. This state of shock related to a sense of feeling numb, and had an impact on the participants physically, emotionally and psychologically. Nigel said:

*“Cause I was in a state of shock.”*

This shock was experienced at the time of death and persisted thereafter. Eva refers to shock in the present tense after her husband’s death:

*“Sometimes I just feel so shocked.”*

This sense of shock stayed with the relatives and was compounded by how suddenly the patient’s condition deteriorated prior to the death. The participants emphasised two main contributors compounding the sense of shock as the suddenness and unexpectedness of the death. Edward explained:

*“She just collapsed ... it was just as sudden as that you see ... it was very, very sudden very, very quick ... I still can’t believe how quickly it happened, neither can anyone else.”*

This led to confusion and a lack of understanding, especially when an explanation about the cause of death was not immediately available. Alan said:

*“And, err, I, as I say it was so unexpected it’s not as though she’d been knocked down or in an accident you know she just collapsed which we couldn’t understand like at first (pause).”*

The sudden death situation provoked the relatives to question why it had happened and all found it difficult to comprehend. Delia recalled:

*“like my Dad died of cancer and I knew he was going to die, I say you could accept it more although it’s still a shock you know...but like with Henry (referring to her husband), anybody with a sudden death like that, one minute you’re talking to them planning your holidays and the next minute he’s gone you know he’s not there anymore ... it’s hard.”*

The lack of opportunity to say goodbye contributed to this sense of sudden loss. As Betty described:

*“And you don’t have time to say goodbye to them ... it was unexpected, it was sudden ... life is cruel”*

Accompanying this sense of shock was a sense of injustice. All the participants commented on how healthy their relative had looked or seemed immediately prior to the death. This was especially the case for patients who had long-term health problems. Nigel stated:

*“Cause we’d commented on that afternoon on how well she’d looked on that day ... Yes she’d had her hair done, err, and she didn’t look tired and she looked ... she looked ... she looked really smashing, whereas some days she looked really tired, drawn you know ... but she looked really well, she looked years younger ... much like she used to look.”*

This prompted a futile search for meaning as to why this happened. Delia

questioned:

*“I did actually ask why, and why did they (referring to medical staff) think it happened.”*

All participants experienced an initial sense of shock at the time of the sudden death. As the interviews progressed it became evident that this sense of shock persisted long after the participants left A&E. The suddenness and unexpectedness of the event, the rapid demise of the deceased, the confusion and sense of injustice about the death and the inability to say goodbye all compounded this sense of shock. This left the participants wondering why this had happened and prompted a search for meaning.

## **Sudden death – the physical and emotional impact**

### **The physical impact**

The participants experienced specific physical and emotional responses at the time of the sudden death. All described in great detail their acute grief reactions, such as disbelief, numbness, feeling stunned or being devastated, and these were evident immediately after the death and continued indefinitely thereafter. The literature suggests such feelings and emotions are commonly associated with death but are more pronounced in sudden death (Clements et al, 2003; Kaltman & Bonanno, 2003; Parkes, 2008). The different physical and emotional responses were not experienced in any fixed order by the participants, nor were they only experienced once; they re-occurred several times and varied in their intensity and duration.

The main overt expression of grief noted by the participants was crying. Eva said:

*“I just cried and cried.”*

Alan too said:

*"I had my cries."*

The immediate impact of the sudden death left the participants feeling numb. Jane stated:

*"I ... I was numb ... I was numb."*

First hand experience of sudden death was aptly explained by Edward:

*"Well I was totally stunned emm ... because it had happened so quickly."*

Other participants had similar experiences. Fran said:

*"We were dumbfounded."*

Grace said:

*"I felt numb."*

The participants therefore experienced some initial physical reactions to the death, such as crying, being upset or feeling numb. The literature highlights that this is associated with both expected and sudden death (Kent & McDowell, 2004; Stayt, 2007). Delia recounted her difficulties sleeping due to a preoccupation with the death of her husband:

*"At the beginning it was very, very hard and I thought I was going mad you know cause I kept ... that Wednesday kept, just kept going, just like a tape it goes through your head all the time. It's eased up a lot now but as soon as I got in bed at night that Wednesday would replay itself over and over again."*

Maureen had similar problems and said:

*"I may as well not have gone to bed at night because I just couldn't go to sleep..."*

Jane had difficulty in working:

*"I can't get back into me work. Er, I am working but... very half-heartedly. I don't seem to have any motivation somehow."*

Nigel also experienced difficulties in returning to work:

*"I decided I wasn't going to go back to work because I wasn't in the right frame of mind"*

Being unable to sleep, eat or work were experienced as longer-term physical reactions to the death. Both the immediate and long-term physical reactions to sudden death as experienced by the participants are congruent with the literature (see Ferrell & Coyle, 2006).

### **The emotional impact**

The emotional responses experienced by the participants have been grouped together into denial, anger, sadness and guilt. The experience of denial, anger or guilt following death and sudden death is well-documented in the literature - see for example Kubler-Ross (1969) and Wright (1996).

### **Denial**

Associated with this sense of shock was disbelief or denial. Delia stated:

*"I was in denial."*

Associated with denial was a sense of disbelief. Eva stated:

*"But you know, it's hard to believe it's ... it's hard to believe he's gone like."*

Maureen reflected:

*"I can hardly believe he's gone."*

### **Anger**

The participants talked about feeling angry at the sudden death. Often this experience was pre-empted by frustration and despair that manifested itself in anger. The following comments reflected this:

Eva: *"I just felt angry why should it have happened"*

Betty *"Life is cruel it was so totally, totally unexpected and shouldn't have happened."*

Fran: *"Because I did feel angry, very angry for a long time afterwards."*

Participants described venting their anger at others. Grace stated:

*"I go to church every Sunday. I did feel angry with God and didn't want to go again after Alf's death (referring to death of her husband), but Alf would not have wanted this"*

Alan was angry with a difficult patient who was in the next resuscitation bed to his wife:

*“Some guy who’d done something to his neck, I think he was on drugs the way he was behaving, he would not let the Sister put a collar on him (Alan went over to the patient) ... ‘why don’t you let them get on with what they’re doing otherwise you can get out!’ ... I said ‘I’ve got a wife dying ... and you’re refusing treatment’ I said ... then I said ‘God take this man instead of my wife’ ... I was really mad.”*

Some participants felt angry with either medical staff or their General Practitioner because their relative had either seen them on the day they died or close to it. Eva stated:

*“Err, and then I was angry in one way because, I was a bit angry because I thought well he’s seen the doctor, the doctors seen him and she was quite pleased that he was doing well.” (Eva and her husband had seen the GP on same day he died)*

Some participants experienced personal frustration, particularly when they were not present at the time of death. Olwyn said:

*“What hurts most is ‘cause I wasn’t with him.”*

Some participants reported feeling frustrated at health professionals who they felt did not provide enough information or explain properly what to expect after the death in terms of an emotional response. Betty said:

*“I feel all around there is very, very little help. You’re shoved out of the hospital door more or less splash! ... You may be able to swim you may not and this is ... emm... err ... very critical but I’m very disappointed that something that is happening to an awful lot of people not just ... you know I’m lucky that I do have a certain amount of support but I’ve found it very difficult to cope and because ... You need ... I think you need a person ... (tearful) ... (pause) ... It’s the face to face help that you need.”*

The review of the bereavement literature reveals that those deaths that are sudden are more likely to create exaggerated and potentially complicated grief responses (Currier et al, 2006). These deaths are perceived by relatives as untimely and unfair, often intensifying the feelings of disbelief, shock, and anger (De Ranieri et al, 2002). The participants acknowledged that their feelings of anger and frustration had reduced over time, but these feelings and others did re-surface when they reflected upon their losses.

## **Sadness and guilt**

All participants experienced great sadness at the loss of their relative. There was an overriding feeling that if they could have done more or acted differently their relative would have survived. Eva had tried to resuscitate her husband:

*“I’m constantly saying to myself was there ‘ought else I could have done and I’m facing it all the time and then I say to myself you’ve got to stop thinking that way because I know there wasn’t and I know I’d done all I could you know but a sense of blame or what I don’t know.”*

Some participants felt guilty. Louise stated:

*“I felt guilty... (pause) (referring to death of her brother)”*

The relatives experienced guilt, either for not being present when their relative died, or for not doing enough or simply because they died. Some participants experienced a feeling of total devastation at the loss of their relative. Grace stated she felt:

*“Devastated about his death (referring to death of her husband)”*

The participants talked about feelings of despair and desperation in the months following the death. The unexpected and unanticipated nature of the death was a continual difficulty for the participants and compounded the sense of sadness and guilt. The lack of opportunity to say goodbye, or to be with their relative at the time of the death left the participants with a deep sense of loss. They experienced a yearning for their relative and missed them intensely. Both Fran and Kate reflected:

Fran: *“I think it’s now that I miss her more emm (Referring to her mother)”*

Kate: *“I mean I still miss him (referring to the death of her father)”*

Alan felt:

*“Inside you’re broken (tearful pause)”*

All the participants related to this sense of brokenness, but some participants talked about a sense of relief related to the fact that their relative did not appear to be in pain. Edward stated:

*“She wasn’t in any pain of any sort.”*

Olwyn said:

*“The consolation is that he didn’t know ... he wasn’t in any pain (referring to her husband).”*

Nigel stated:

*“And err the comforting thing for me was that she died in my arms.”*

All participants experienced physical and emotional responses as a result of the sudden and unexpected deaths of their relatives. The words used by participants to describe their initial reactions to the death were “shock” and “numbness”. The initial sense of shock was an overwhelming reaction to the loss. A number of other feelings and emotions were expressed as a result of this sudden event. Louise’s comments sum up the situation most aptly:

*“I’ve gone through every possible emotion you can possibly think of, emm, its heart rending ...just they’re not here anymore and it’s very, very hard to accept that.”*

After leaving A&E and as their bereavement experience progressed, not all participants continued to express their feelings openly. Some participants alluded to a private grief.

Jane stated:

*“I do my grieving when am on me own. You know ... (pause) ... I’ve done plenty when I’ve been on me own.”*

Alan shared:

*“I tried to act normal and even now I try to act okay and happy-go-lucky, but inside you’re broken (tearful) ... (pause).”*

Other participants also hid overt expressions of grief from those around them. They did this in an attempt to look normal to the outside world and so not cause concern to family and friends. It appeared that the participants did not want to seem to be taking longer than expected to deal with their grief. As discussed in the literature review, theorists such as Freud (1957) or Linderman (1944) have advanced an argument that grieving and mourning are resolved within a specific time frame. Such marginalization of bereavement reflects a discourse in which the primary goal of grief work is the severing of ties with the deceased in order to be able to reinvest in new attachments. This means letting go of the

deceased and moving on in order to return to normal functioning. Departure from these activities may lead to the assumption that the mourning behaviour or length of mourning was an indication of abnormal grief. Clearly the social norms and expectations regarding grief and resolution in British society resonate with such theorists.

The physical and emotional responses experienced by the participants in the first part of the study are congruent with the existing research and literature as reported on in Chapter Two. The experience of sudden and unexpected death has proven to be a significant event in the lives of the participants. The initial reaction to such a death was shock, accompanied by a plethora of other physical and emotional responses which varied in intensity, frequency and duration.

### **Sudden death – the personal impact**

The participants described the immediate personal impact they experienced following the sudden death, irrespective of the nature of their relationships with the deceased. For all the participants there was an abrupt and dramatic change in their life following sudden death. Some relatives had difficulty in coping with the enormity of the situation, as Maureen explained:

*“I can hardly believe he’s gone ... my life has changed completely (very tearful and crying) ... It is not the life I used to lead ... (pause)”*

The chaos following the death led to a sense of a loss of control and participants reported functioning in an automatic way. Kate and Olwyn said:

*Kate: “I don’t know whether you’re in shock or what or whether you just do things automatically.”*

*Olwyn: “I think I went into automatic mode.”*

Other participants experienced a state of helplessness and other relatives stepped in.

Isobel said:

*“They sorted everything out. (Referring to older sister and aunt)”*

Participants felt unable to carry on with their normal activities such as cooking or cleaning. Jane explained:

*“The children worked on a rota. It was their idea. It wasn’t me ...”*

The sudden unanticipated death of a relative resulted in some of the participants experiencing the feeling that they had lost control. Their previous abilities were temporarily suspended. The initial impact of the death and associated sense of shock and numbness rendered the participants incapable of conducting themselves as they had previously done. This state of helplessness following a sudden death is well documented in the literature (Ferrell & Coyle, 2006). This temporary inability to function and loss of control was particularly evident in the period between the sudden death and the time of the funeral, and the participants noted that other relatives and friends helped with practical activities at this time. The funeral was a significant event for all participants. Participants were involved in the funeral, but mostly the arrangements were made by other family members and the funeral directors. The funeral marked the opportunity to celebrate the life of the deceased and at the same time to say goodbye. Grace remembered:

*“At the funeral his walking friends carried the coffin ... and I had cards galore from all over the country.”*

Helen explained:

*“Yes ... friends came to the funeral, you know my closest friends, which I thought was good of them cause they didn’t know him very well (referring to her father) ... a contingent of them came in oh and I thought that was very nice of them to do that”*

Maureen was pleased at the response to her husband’s funeral:

*“And even people have said to me if you have to say something about a funeral David’s funeral (referring to her husband) was the best one they’d ever been to ... It was marvellous the church was standing room only, they were outside stood and emm it was marvellous.”*

Olwyn reflected:

*“The day of the funeral, erm, it was, it was funny really, erm, it was great. I can’t say great really ... The church was packed, absolutely packed.”*

The funeral was an important event for all the participants. It was viewed as a testimony to the deceased reflecting the love, friendship and esteem that people held

for them. All participants found the period immediately after the funeral a particularly difficult time. Edward explained:

*“Emm, and it’s not until the funerals over. You’ve got to keep going, you know, and an awful lot of people are up at the service, see them all and so on and emm and you’ve got to keep going and the danger spot is immediately afterwards.”*

After the funeral the support from family and friends started to decrease and at this point the participants felt that they needed to get back to as normal a life as possible, somehow trying to accommodate the reality of their loss into their lives. Many of the participants returned home after stopping with relatives prior to the funeral. On returning home for the first time the sense of loss was heightened. This sense of loss was accompanied by a profound feeling of loneliness. The reality of the situation became more evident on returning to an empty house. Edward stated:

*“Yes so I suppose the worst thing after, other than the actual death, on that day was coming back to the house ... to an empty house yes.”*

A sense of ongoing loss and sadness pervaded the participants’ life. Helen said:

*“I still miss him terribly (referring to loss of her father)”*

It is without doubt that the sense of loss experienced by the participants is a phenomenon that is difficult and challenging, but not uncommon, for suddenly bereaved relatives as reflected in the literature (see Martin & Doka, 2000; Parkes, 2008).

Grief was conceptualised by the participants as a journey. Eva stated:

*“I know I’m going to get there.”*

Along this journey, significant events were noted by the relatives; the suddenness and unexpectedness nature of the death, the funeral or coming back to an empty house. These difficulties were highlighted by the participants and were mapped out as steps on this journey. At some point, although at a different time for each, the participants felt the need to try and resume their normal a life without the deceased. Edward talked about picking up the threads:

*“But it’s inevitable it’s got to happen ... You’ve got to reach that point ... I’ve got to pick up the threads get back into my own activities.”*

The participants talked about getting on with life and learning to cope without their loved one, but at the same time living with the memories of the deceased. This resonates with the work of Klass et al (1996) who did not see bereavement or grieving as ever fully resolved or culminating in closure or recovery; rather, the work of grieving and mourning is to maintain the presence of the deceased in the web of family and social relationships by establishing a continuing role for them within the lives of the bereaved.

The impact of sudden death for the participants was shocking and the suddenness and unexpectedness compounded this sense of shock. Confusion and chaos following the death led to a futile search for meaning in an attempt to understand what had happened and why. The physical and emotional impact of sudden death was manifested by various overt expressions of grief, such as crying, and various emotions, such as anger, disbelief and frustration. The immediate personal impact from the sudden death was a feeling of a loss of control and a suspension of any sense of normality for the participants. A sense of ongoing loss and sadness pervaded the participants’ life.

### **Living with the trauma of sudden death**

#### **The reality of sudden death**

Living with the reality of sudden death was a difficult experience for all participants. They encountered different challenges and described how difficult living with the reality of death had been, irrespective of the nature of the relationship with the deceased. Maureen said:

*“My life has changed completely (very tearful) ... It is not the life I used to lead.”*

Alan explained:

*"I tried to act normal and even now I try to act okay and happy go lucky but inside you're broken (tearful) ... (pause) ... Yes, but I say underneath ... (tearful) ... you get upset ... err ... you're lonely... you're all right during the day but when you come home to an empty house ... There's nothing there."*

Eva said:

*"I just cry and cry and cry and I just ... she says (referring to a friend) it's just part of the healing process ... I know I will get over it but at the moment I just ... I just cry and think I can't face any more."*

Nigel explained:

*"Certain things still get ... still upset me ... Err I was watching a film, Driving Miss Daisy, and at the end err the chap starts feeding her and I got upset about that because I used to do that (tearful voice) ... yes and it just triggered it off and I had to get up and ... I was in tears cause it had just sparked it off and that was months after so ... it's still there you know."*

Sudden death created a void in the participants' lives that they recognised could not be filled. The emptiness created by this void penetrated all aspects of their life. Some tried to mask this emptiness by hiding their emotions from family and friend in order to portray an image that they were coping. The literature review acknowledges coming to terms with the reality of death as one of the most painful and difficult parts of the bereavement trajectory (Parkes, 2008). All participants described feeling lonely, alone or socially isolated, especially when they returned to an empty house or at night time.

### **Moving on with life**

The participants described how they were starting to move on with their lives. They explained how the memories of their relatives helped spur them on. Eva explained:

*"It's really hard ... I'm crying and laughing and crying at the same time you know, but its things like that that you can remember. There's things like your memories that they can never take away from you can they? ... You know you can stick hold of them no matter what happens you've always got your memories you know."*

Alan stated:

*"You've got to get on with life haven't you?"*

Olwyn made changes to help her move on:

*“Erm, I got another car...Erm, and I’ve changed my job. I’ve gone self-employed to spend more time at home.”*

The participants described how they felt the initial impact of the death, immediately after a period of shock, and then described the ways in which they began to rebuild their lives. The participants discussed ways in which their life continued following the sudden death and about moving on and getting on with life. The participants reflected on finding and creating a new story in which the deceased were still important parts of their lives, but one where grief was no longer the central controlling force in their lives. The participants discussed their memories and events in their lives which were important ties with the deceased. The literature suggests that the bereaved often feel a bond with the deceased that can continue for decades (Klass et al, 1996). This continuing sense of connection does not necessarily indicate a poor adjustment to the loss; rather, the memory may bring a sense of comfort to the bereaved (Carnelly et al, 2006) and help the bereaved to move on.

### **Sources of support**

Adjusting to life and moving on without their relatives raised numerous challenges for the participants. Three main sources of support were highlighted as beneficial: family and friends, and professional and voluntary support.

### **Friends and family**

The participants experienced a close and loving relationship with their nearest relatives following sudden death. Although two participants described some strains within the family network related to prior family difficulties, they still experienced support from family members following the sudden death. The support of family and friends was one of the most significant for the respondents. Alan said:

*“Yes, they said ‘we’ll sort out everything out Dad’ you know.”*

Fran explained:

*“My Mum was very religious so she had a strong network of friends from the Church ... people are constantly saying you know ‘we’re really sorry to hear about your Mum she was a very very well loved*

*lady'. There were loads of cards and people calling emm ... you know it shocked a lot of people so that kind of momentum kept us going through Christmas..."*

Jane reflected:

*"Me daughter was a brick."*

Eva said:

*"Friends and neighbours around here have been so good you know and they always ask if I'm okay or if I need anything doing, you know, they've been marvellous."*

The support from family and friends was significant for the participants. Although the relatives offering the support may have been grieving themselves, they provided love and comfort to the participants as well as helping to alleviate isolation and loneliness.

### **Professional support**

Professional support was sought, or expected, from the family General Practitioner (GP) or Practice Nurse (PN). The participants had different experiences of professional support. Alan stated:

*"Yes but I went to see her (referring to GP). I made an appointment just to tell her what had happened to my wife."*

Some participants found their GP's to be extremely helpful and supportive. Delia stated:

*"And my GP ... he phoned first to see did I want him to come round and talk to me ... err well, he said he'd explain once he knew the post mortem, he said 'I'll talk to you I'll explain everything to you', which he did, he was wonderful..."*

Other participants had no support from their GP and felt disappointed. Edward reflected:

*"I think the offer might have helped quite honestly, yes the offer would have been quite good I think ... And, emm, I'm sure that I know they're very busy, but if there had been some sort of approach even if ... well it's difficult for him to phone I suppose, well I don't know something might have been nice."*

## Voluntary support

There were a number of different responses regarding voluntary support after sudden death. Some relatives actively sought help, whereas others they did not need help as they had adequate help from families and friends. Some participants wanted help but found it difficult to access such help. Betty explained:

*“Yes I’m finding it and have found it very difficult to get help. There is very, very little and it’s very disappointing ... I’ve obviously had people around me to help me and support me. I eventually managed to get through to Cruse and emm ... the waiting list for Cruse is anything between 10 weeks to 6 months. Now in 10 weeks to 6 months you could really be in a state..”*

There was a lack of knowledge about voluntary support and how to access this support. Grace stated:

*“I did not realise there was anyone to contact.”*

Some voluntary support came from the church. Two participants were regular church attendees and experienced great comfort and support from the church. Maureen stated:

*“The Church was marvellous ... absolutely marvellous.”*

One participant who was not religious found an unexpected source of support from a church visitor. Jane stated:

*“A lady came round (referring to a church visitor) about a month later to see me, and she came on the twelve months, just before Christmas ... Well, I’m not that way inclined really, erm, with religion, you know ... I don’t make a habit of going to church although I come from a church family. Erm, she was very nice and I thought it was very kind of her to do that. I mean, she didn’t have to you know.”*

Family and friends were the main source of informal support whereas GPs were the main source of formal support during the initial months of grieving. The grief reaction showed some gradual improvement over time, but no endpoint in grief reaction was seen – consistent with suggestions of other research, such as Klass et al (1999), that there is no specific endpoint in grief.

## **Discussion from the analysis of the findings – Part I**

In the discussion arising from the findings, a number of salient points are raised regarding the experience of sudden and unexpected death.

### **“The experience of shock”**

The participants all experienced shock as a result of sudden death. This experience was traumatic and disabling for all the participants. Despite this heightened state, the participants were able to vividly describe and remember the events of the day. The participants gave graphic accounts of their feelings, particularly about an overriding sense of shock. A plethora of physical and emotional reactions compounded the experience of shock. The participants reflected on this sense of shock and numbness which pervaded all aspects of their life, rendering them somewhat incapable and inert. This response is congruent with existing literature and research (see Bonnano & Kaltman, 2001; Ferrell & Coyle, 2006; Parkes, 2008; Wright, 1996). The initial reaction to both death and sudden death is well documented and often leaves the bereaved with an overwhelming sense of shock, numbness and loss (Kubler-Ross, 1969). However, in sudden death this sense of shock is often more pronounced (Clements et al, 2003; Parkes, 2008).

### **“Looked after”**

The participants in this study who had a “good sudden death” experience felt a sense of being “looked after” by the staff in A&E, and in particular by the A&E nurse. The participants reported that being “looked after” helped not only throughout their stay in A&E but also left a lasting impression after leaving A&E. The A&E nurse, although completely unknown to the participants, was there to help and assist them in A&E. This nurse performed several vital functions: timely communication, facilitating privacy, giving information, giving patient status reports and helping with phone calls or making tea. In contrast, the participants who had a “bad sudden death” experience commented on the absence of an A&E nurse, had no initial reception, experienced a

lack of privacy, received minimal or no information about their relatives and had little practical help offered. This consequently left them with a sense of abandonment and not feeling “looked after” at this critical time. The literature suggests that relatives need help and support during this critical period. The demonstration of concern and support by health care professionals has been shown to influence relatives’ perceptions of the care that their loved one received prior to sudden death (Jurkovich et al, 2000; Kirchoff et al, 2002; Li et al, 2002). Experiences around the time of death and afterwards can also influence grieving and the longer-term health of bereaved (DoH, 2005). Amid a busy and sometimes chaotic A&E it is easy to see how family members may be overlooked by a sense of clinical urgency regarding the needs of patient. However, Malone (1993) warns that failure to maintain a holistic approach in sudden death and to exclude the needs of the relatives reduces sudden death and dying to merely a clinical event as opposed to a profoundly human event that touches the lives of others.

### **“Presence”**

The “presence” of the A&E nurse was important but in a different way from the “looked after” theme. The “presence” of the nurse in this theme transcends the actions in the “looked after” theme, which was about helping and communicating. In this theme, the act of being present was more meaningful and facilitated exchange between the bereaved and the nurse, even though no conversation may have been forthcoming. The “presence” of the nurse signalled a level of connectedness with the relatives whereby rapport and trust developed. Finfgeld-Connett (2006) described “presence” as an interpersonal process that is characterised by sensitivity, holism, intimacy, vulnerability and adaptation to unique circumstances. Similarly, Benner’s (1984) work emphasised the humanistic qualities of “presence”. Caring for bereaved relatives involves more than simply providing practical help; although important, it involved being “present” at a time of crisis and need. A&E nurses were “present” with

the bereaved as they experienced a profound change through sudden death, which led to a period of questioning and searching for meaning. The “presence” of the A&E nurse at this time had a positive outcome for the relatives. Conversely, the participants who had no nurse present reported a sense of abandonment, felt unsupported and less cared for during their time in A&E.

### **“Knowing”**

The participants talked about “knowing” that something was seriously wrong without being told. The actions of A&E staff inadvertently engendered this belief. When being met at reception or in the ambulance bay, the participants were ushered to the family room. Although this permitted private one-to-one communication, in the main this signalled something was wrong to the participants. When the disclosure of the death took place, some participants knew what was about to be said before being informed by observing the non-verbal cues of the staff, such as their facial expressions or lack of eye contact.

### **“Broken and bereft”**

In both the immediate and ensuing months after the sudden death a sense of brokenness remained with the participants. One of the participants described feeling “broken”. This was a feeling that all the participants identified with. Associated with this was a feeling of being “bereft”, which manifested itself in an overwhelming sense of loss. When someone has died, their death is often described as a loss; this notion of loss is widely documented in the literature (Corr et al, 2009; Parkes, 2008; Stroebe et al, 1996). The loss and sadness pervaded all aspects of the participants’ lives to such an extent they felt “broken” and “bereft”.

### **“Surviving”**

The emotions stimulated by the sudden death varied greatly for participants, ranging from profound distress to inertia. Many participants felt overwhelmed by the things

that needed to be done, such as activities of daily living, shopping or cooking. Participants relied on others, such as friends and family, to help deal with issues. The loss of emotional energy and motivation was a common theme for the bereaved in the early months following the sudden death. However, the participants described their “survival” techniques, such as the ways in which they sought help and support from family, friends, professional and voluntary sources, they used to get through. Support such as from family and friends were deemed invaluable. Coping strategies, such as taking up old hobbies, reading or watching television, kept the participants going through some of their darkest times.

## **Conclusion**

The experiences of the participants have been reported extensively and comprehensively with numerous quotations from the interviews used to support the analysis and to convey as accurately as possible their accounts. The findings and analysis give insight into the lived experiences of sudden and unexpected death. Appropriate care and concern, alongside privacy, communication and the information given to participants at the time of sudden death had a lasting positive impact for the participants. The interviews document that positive memories of the care received whilst in the A&E department remain positive. Contrastingly, negative memories remain negative, despite the passage of time. Time does not appear to change the impact of initial care and its effect on subsequent grief. A&E nurses contributed to the bereaved overall experience in A&E, and participants identified individual nurses and doctors and whether their communication was seen as good or bad. The impact of initial care for the participants appears to impact on subsequent grief. What the participants experienced remained with them as they left A&E and was still memorable in the ensuing interviews. Analysis of the relative’s interviews led to a comprehensive understanding of the experience of sudden death and its impact in the lives of the bereaved.

## **Reflections of the researcher**

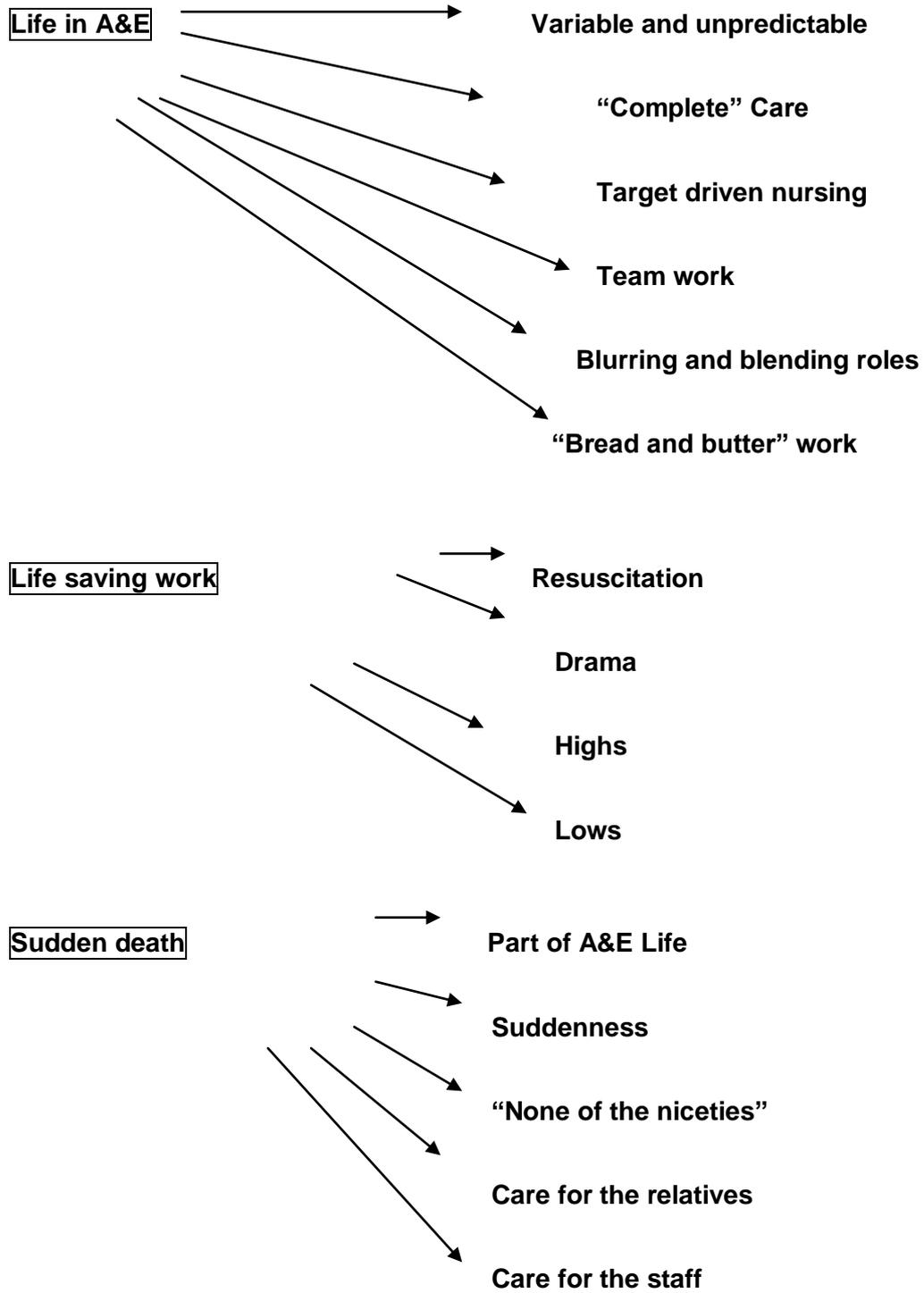
The experiences of the participants in part I of the study prompted further personal reflection for the researcher. Speaking to the relatives and exploring their experiences of sudden death only revealed part of the situation. The relatives' interviews, as intended, revealed their experiences of sudden death and highlighted many different things. Listening to positive, or "good sudden death", experiences in A&E was encouraging. Conversely, it was difficult to hear about less positive or "bad sudden death" experiences. The assumption of the researcher was that *all* suddenly bereaved relatives would receive the highest standard of care possible at this difficult time. This period of reflection became the catalyst for part II of the study, which focused on the experience of sudden death from the perspective of A&E nurses and how they perceived their role in this. The next chapter presents the findings from the narrative interviews with A&E nurses.

## **Chapter Five: Findings and discussion from the nurses' stories: *"I shocked her and she survived"***

### **Introduction**

In the second part of the study, the experience of A&E nursing and sudden death from the perspective of A&E nurses was explored using narrative interviews. Analysis of the data gathered from the nurse interviews followed a template approach as described by King (2004) and discussed in Chapter Three. Twelve A&E nurses participated in the narrative interviews and this chapter presents the findings. A conceptual map presenting all the themes that were forthcoming from the template analysis of the data is given in Figure 5.1.

Figure 5.1 Thematic map for part II



## **Part II: Reflections of the interview process**

In the second part of the study, the experience of sudden death from the perspective of A&E nurses was explored using narrative interviews. Twelve A&E nurses participated in the narrative interviews. The participants were encouraged to tell their story and all the participants provided rich descriptions of their experiences A&E nursing and about sudden and unexpected death. The interviews took place in a private area away from the A&E department at a time and date that was convenient to the participants. The nurse interviews were longer given the narrative nature and lasted between two and three hours. The interviews followed a similar pattern commencing with general discussion of how the participant was feeling or general discussion about the day which was intended to help participant relax and become less conscious of the tape recorder. The interview naturally progressed into talking about their experiences of A&E nursing and sudden death. At the end of the interview the tape recorder was switched off and a period of de-briefing took place to ensure the participant's well-being following the interview. At the end of the interview the researcher ensured the participants had the appropriate contact details if any follow up was required.

All the narrative interviews were analysed and no data was left un-coded. As intended, the narratives generated much data about, for example, the A&E nurses' backgrounds, entry to nursing, experience of A&E nursing, experience of sudden death and future plans. As stipulated earlier, the main aims for part II of the study concerned the nurses' experiences of A&E nursing and their experiences of sudden and unexpected death in the A&E department. Therefore, the findings pertinent to these aims have been presented in the chapter. The first section of the analysis focuses on the stories about life in A&E, detailing the reality of working in A&E; this is important as it explains the context in which sudden death takes place.

## Life in A&E

### Variable and unpredictable environment

The nurses talked about working in a variable and unpredictable environment. Sandy stated:

*"I think it's the not knowing what's coming through the doors really, it's just so different, nothing is routine, and you get a variety of everything."*

Mandy concurred:

*"There's such a variety of things to see when you're working here ... err, I just love A&E nursing there's such a lot of different specialities and different things to see."*

For the A&E nurses, working in an unpredictable and variable environment was a source of enjoyment and satisfaction. The challenge and ability to meet the needs of different patients and to be flexible enough to do this on a daily basis is seen as being fundamental to the A&E nurses role. However, this variability also presented challenges. For Maria and Lynne the variable nature of A&E nursing presents a dichotomy. Maria stated:

*"I enjoy the variety, you know, patients with all sorts of problems not just one speciality. Sometimes I feel it's ... you know, like jack of all trades, where we have to know bits but we don't have a full understanding of one particular thing."*

Maria enjoyed the variety but felt frustrated at not having the depth of knowledge in one specific speciality. Lynne felt frustrated regarding the unpredictable workload and stated:

*"unstructured, very random, unpredictable, ermm (long reflective pause) ermm, that's part of the reason why I like working here, because of that unpredictability, but that also causes problems in itself, it's a very unpredictable workload (long reflective pause) ... when it's demanding you don't feel like you can give adequate care for patients and that's one of the stressful things working in A&E."*

Lynne enjoyed the unpredictable nature of A&E work but at the same time found it challenging and stressful in getting the balance right and being able to provide adequate care for patients when the department was busy. Lynne raised an important issue about adequate levels of care when there are large volumes of patient's attending A&E. The variable and unpredictable nature of the A&E workload is well documented in the literature (Bache, 2001; Dolan & Holt, 2007); the demand-led nature of the work presents challenges when trying to accommodate an unexpected influx of patients.

### **“Complete” care**

The episodic nature of A&E work represents a level of completeness in patient care. Often this care has an immediate impact for the patients; as a consequence the staff receive instant feedback from short, time-limited interventions. Jean explained:

*“I love seeing them from start to finish.”*

Di concurred:

*“It's lovely when if everything's sorted, if they only need suturing or a broken arm or whatever, they go out and everybody's smiling.”*

There is completeness in the patient's care from initial assessment through to eventual discharge. The nurses describe a sense of satisfaction with the results of their care and the immediacy of the impact is the basis for their satisfaction.

### **Target-driven nursing**

The participants reported that major changes had taken place in A&E following reforms within the NHS service. *Reforming Emergency Care* (DoH, 2001a) was published to drive changes in emergency care and set out an ambitious programme of reform. However, the four hour target prompted much discussion about how A&E nursing had become target driven as opposed to patient driven. Di said:

*“Like the four hour waits is an issue, it is an issue and everyone's sort of target nursing now and you know where you used to have time to talk to that little old lady who'd not seen anybody for 2 days because she'd been stuck in her house, it's the housekeeper who sort of goes*

*and has a chat because the nursing staff don't always have time ...which is sad really cause you're not nursing are you're just target nursing."*

Jean concurred:

*"Emmmmm, there's very much an onus on the person in charge to look at the four hour bed waits, as they call them, but it's four hour waits for anyone who comes through the doors of A&E, be it waiting for a bed to go elsewhere or waiting for treatment and going home from A&E, it's four hours is the cut-off point."*

It is without doubt that these targets and reforms have been effective in reducing waiting times in A&E (HCC, 2006). In England at the beginning of 2003, almost a quarter of patients spent more than four hours in A&E. In April 2004 95% of patients in A&E, left the department within four hours and this rose to 98% in April 2005 (HCC, 2006). Responding to the reforms in A&E resulted in target driven nursing.

### **Teamwork**

Another aspect of A&E nursing centred round teamwork, camaraderie and sense of allegiance. Mandy said:

*"But we do work quite well together ... we do work well together as a team."*

Di reflected:

*"You do form really good friendships."*

Teamwork forms a fundamental aspect of A&E work and the literature highlights that the success of a patient's care relies on the A&E team working seamlessly and cohesively together (Bache, 2001). A&E nursing is not practiced in isolation and the nurses recognised the importance of working together as a team.

### **Blurring and blending of roles**

There was a mixed response from the nurses regarding the changing nature of nurses' and doctors' roles. Jenny noted that the medical profession has become more supportive than it used to be:

*“A lot more support from senior doctors...”*

As A&E as a specialty has developed, it has necessitated more support for the development of the service by the introduction of specialist A&E consultants, Emergency nurse practitioners (ENP) and role expansion for A&E nurses. Karen talked about the demarcation between doctors and nurses becoming less obvious and about a blending of the roles:

*“...and the demarcation between doctors and nurses is also getting ... its closing up that gap ... but A&E it's a very good mix between doctors and nurses, there's a lot of cooperation isn't there ... well in A&E we all help each other because you have to and everybody's doing lots of mixed things and it's not just this is what the doctor does, this is what the nurse does, now they've become a bit blended.”*

Karen suggested there has been a gradual blurring of the roles between nurses and doctors in A&E and, as such, the territory between the professions has become less clearly defined or demarcated. The role of the ENP has evolved to a point where nurses assume responsibility for autonomous practice in areas that were traditionally the work of doctors. However, Jean highlighted that in A&E changes in the nurse's role and collaboration may not be readily accepted. Jean stated:

*“Even our own doctors haven't accepted it ... Because it's their domain, it is just historic, it is just purely historic...but I think the majority of the old school feel that we should stay at being nurses and not take on extended roles.”*

Jean continued:

*“I think the younger doctors see it as a means to them being freed up to do other things, we take on the roles of phlebotomy, cannulation, doing ECGs, putting the pots on, suturing, even seeing patients, and being autonomous from start to finish, we're doing what they see as the little jobs and it leaves them free to do the bigger jobs of diagnosing more difficult, multi-diagnosis type patients, cause obviously we're not in that league...we're still seen as the underlings.”*

This is an interesting insight into how the A&E nurse's perceive doctors' views on the work of A&E nurses. Jean states that part of role expansion for nurses has incorporated taking on traditional doctor's roles, such as cannulation. Jean suggests that nurses are merely expanding their skills by adopting discarded medical roles

and, as a consequence, nurses remain in a subservient position to doctors. Public awareness has similarly altered in respect to the role that nurses play in the provision of care, Jenny stated:

*“They used to hold these doctors up to be something ... well they did have a lot of respect for doctors, whether they were good doctors or bad doctors, if they were called a doctor then they accepted everything...They just saw nurses as they were in those days and, emm (long reflective pause) ... emm, nurses were there to carry out doctors instructions whereas now that’s changed a lot and the more they’ve had involvement the more they accept it.”*

The public image of nursing is changing (Masters, 2005; Takase et al, 2006). Lynne suggested this:

*“I think the public’s more aware now that we’re not just doctors’ handmaidens and that, we are a profession and I think we view nurses as nurses”*

The literature highlights an ongoing debate regarding the blurring of professional boundaries (Callaghan, 2007; Nixon, 2008; Norris & Melby, 2006; Tye & Ross, 2000).

The government advocated collaborative practice in many of the reforms set out to transform emergency care (DoH, 2000). Central to collaborative practice is an ethos of breaking down the traditional boundaries between professions, thus developing a more flexible workforce. This has come to fruition to a certain degree in A&E with a blurring of the roles between nurses and doctors.

### **“Bread and Butter” work**

The participants made reference to the often mundane nature of A&E work. The phrase the “bread and butter” of A&E work was coined by Chloe who equated this aspect of A&E work with the minor cases that present in A&E. Chloe said:

*“I do think your bread and butter is your minor work emm ... you’ve got a variety ... you’ve got everything under the sun ... I still appreciate that your minor stuff’s your bread and butter.”*

Alongside this was a depth of knowledge about minor injuries. Laura said:

*“And with minor injuries, you know what they need sometimes more than the doctors...cause that is more sort of nurse led errmm and wound closures and things like that, you’ve got a lot more experience.”*

Laura suggested that A&E nurses have a deeper knowledge and experience in how to care and treat for these types of patients compared to doctors. Sandy agreed that the majority of the A&E workload does not revolve around major cases and trauma but on minor cases:

*“But I do think sometimes that when staff come to A&E some just think oh it’s trauma and accidents, but it’s not like that, it’s not like that at all, the majority of our patients are not trauma, you know a lot are minor injuries.”*

This reflects the misconceptions that exist about the nature of the A&E work. In contrast to widespread perceptions, few patients attending A&E have life-threatening injuries. Major trauma equates to less than 0.2 per cent of the total A&E activity in England (NAO, 2010). However, over 50 per cent of patients attending A&E have less serious conditions, such as minor injuries and illnesses (DoH, 2009). Sandy highlighted how the media and television dramas such as Casualty and ER perpetuate the misconceptions about A&E work. Sandy stated:

*“And I think some staff see these programmes on television like casualty, trauma, and A&E isn’t just about that the adrenalin rush but there’s a lot more to A&E than trauma and resus... so it’s a mixture.”*

The participants categorised the minor illness and injury cases as the “bread and butter” of A&E work, an essential and fundamental aspect of the A&E workload. This type of work was not viewed negatively; on the contrary, all the staff reported enjoying working with patients with minor injuries. This appears to contrast to the drama associated with other aspects of A&E work, such as major trauma, that appeared to be one of the main incentives for some participants choosing A&E nursing.

### **Life saving work**

#### **Resuscitation**

Working with critically-ill and injured patients in the resuscitation room formed a significant part of the nurse’s workload in A&E. This was a sharp contrast to the

“bread and butter” work, and the narratives exposed the essential nature of resuscitation work. Maria reflected on her first experience of major Trauma:

*“mmm, we had a trauma ... a young lad from an RTA...it all came together on that particular day, you know, with a road traffic bleeding into his abdomen err listening and checking for pneumothorax... And, you know, checking airway ... I mean I’ll always remember that ... he did survive ‘cause he went to theatre and he did survive and knowing ...knowing that, that we played a part and we helped, that was enough for us and that that made a big impression.”*

Maria talked about another significant resuscitation event when she looked after a patient who had serious head injuries:

*“He’d been assaulted the day before ... err I just I wasn’t happy with him ... and you know how you get the niggles at the back of your head ... he deteriorated, we (referring to another A&E nurse) were just talking to him and then all of a sudden I looked at him ... and the next thing he fitted so we whipped him into resus and got everybody there err and he ended up being transferred to Intensive Care at another hospital, and I rang them up the next day and he was awake and they had vented him and he was fine ... and that was an achievement.”*

Mandy also reflected on working in resuscitation and stated:

*“It is nice to work in an area where you can make such a difference... and we all work together and like you’re saving people ... and it is really exciting.”*

For A&E nurses, being involved in saving life work was important. The nurses all recalled various stories that involved caring for patients who had been severely injured through major trauma or had a life-threatening illness. Initially, the outcome appeared grave for these patients, but with resuscitation efforts and specialised skills the patients had survived. Being part of this resuscitation work left a big impression on the nurses and formed an important part of their role. This led to a sense of achievement that was not equalled by any other activity in A&E. This seems in keeping with one of the primary aims in the A&E philosophy: the preservation of life (Dolan & Holt 2007; Timmermans, 1998; Walker, 2008). The intention is that all patients who attend A&E will survive, and advanced life support and extensive resuscitation measures are employed in an effort to prevent death. In the event of a

patient being critically ill or injured, the focus in A&E often involves dramatic life-saving interventions through active resuscitation.

## **Dramas**

The issue of drama associated with A&E nursing centres especially on the work in the resuscitation room when caring for critically-ill and injured patients. The main role discussed was that of a life saver; when a patient comes into A&E with either a major life-threatening illness or injury the A&E team work together to try and save the patient's life. For the participants being involved in a successful resuscitation or a life saving event was a positive experience. Mandy said:

*"You're saving people really aren't you? ...we do all we can to try and do that job and save people."*

Chloe reflected on her feelings following a successful resuscitation event and said:

*"And you think 'oh wow' you know – there's still nowhere else that matches it. So, you look at each other and you smile and you think 'whew', you don't get that on a ward (pause) no you definitely don't get that on a ward."*

Chloe talked about feeling elated when the situation turns out well. In sharp contrast, Jenny who has been in A&E for a long time, and felt that the drama of the resuscitation

*"Had lost its attraction for her."*

She explained:

*"I think, maybe like a lot of new nurses, I used to prefer err the trauma ... the major trauma, the big things, you know? I don't know ... the adrenaline rush thing (shaking head), the longer I've been here ... I don't get that same rush with these things, I prefer the things that ... I much prefer to manage minor injuries or patients that I can ... maybe with being an ENP as well, you see things through from the beginning."*

For Jenny the drama involved in a life-saving role had become less significant in her role as A&E nurse, in contrast the completeness of care was more satisfying.

The main area regarding drama in A&E relates to the work done in the resuscitation room where the life-saving work takes place. A&E nurses are involved in dramatic

events which may lead to a patient's life being saved. This situation was noted as one of the most positive experiences for the participants.

## **Highs**

Some of the common themes raised by A&E staff associated with the “highs” of working in A&E have already been mentioned in respect of the variety and the unpredictable nature of A&E work.

With regard to patients with major life threatening illnesses and injuries there is a similar “high” noted regarding immediacy when an intervention makes a difference; the ultimate “high” being when a patient's life is saved. Maria explained:

*“It was quite a high, ermm ... that you know that ... err, well, that he didn't die with us, you know he could have done”*

A similarly exhilarating experience occurred for Gary when he saved the life of a patient. Gary reflected:

*“Emmm ...she'd (referring to a patient) had hiccups for a while and, and two doctors had seen her and a Consultant had seen her and sent this lady home, and as I was helping her get dressed she arrested, emm so dragged her into exam 1 from exam 2, put cardiac monitoring on and she was in VF and I defibbed her and she survived and ... I did the right thing, I shocked her and she survived and she's alive today, and I, err, I just had, err, I had just ... I felt a skip in me step, sort of, you know? I did feel ... quite proud actually, but I just felt I really, really done something worthwhile.”*

This had obviously been a positive experience for Gary – which is echoed in his enthusiasm and the urgency in his voice when telling this story in the interview. For Gary, the issue was a matter of life or death and his role was as a life saver. As he reflected on his actions in the story, the dramatic nature of his work shone through. Learning what to do in such situations brings meaning and direction to a difficult event, the emphasis being on life saving as a fundamental part of A&E work (Timmermans, 1998). Being prepared and rehearsed for emergency situations means staff are suitably equipped to deal with any form of emergency. Chloe described how good it feels when someone's life is saved:

*“We’ve got them back and you know then that’s good and it’s a good feeling.”*

The ultimate “high” for the A&E nurses was to save life. Part of this involved teamwork. For example, Laura described caring for a critically-ill patient in the resuscitation room:

*“Erm, we just, we just worked alongside each other. We hardly spoke to each other because we just knew what each other was doing, and it just went, it went really smoothly. And that way we had a really good, we had one of the consultants and two really good anaesthetists (laughs.) Erm, and it just went so smoothly really. Every, everything was just sort of done ... in a logical sequence. Erm and there was no shouting and no one getting stressed. But everything was just calming and it just went so smoothly really.”*

This episode was denoted as a high because each nurse and doctor worked together, pre-empting the actions of the other. This resonates with a good sudden death where the event is calm and controlled, not chaotic or stressful. As Laura reflected on this resuscitation situation it was obvious from the satisfaction in her voice that this was deemed a positive situation for her.

Chloe said:

*“On a good day in A&E everything hopefully goes smoothly; as well as providing care you’ve got time to talk to your patient – I don’t mean idle chatter, but I mean talk to your patient to get to know them to try and make their experience a little better. If you’ve sorted out their pain and made them comfortable and they’ve not got anybody with them I do think if you’ve got some time to spend with them it just makes them feel like a person rather than an object on a trolley in a cubicle waiting to be moved along what they see as a conveyor belt at the beginning of their episode in an NHS hospital ... you’re interacting with your patient, you’re being human, you’re trying to be genuine ... And I think they remember you for that.”*

On initial analysis it would appear that for A&E nurses the ultimate “high” relates to saving the life of a patient; however, as their stories developed it emerged that other significant “highs” result from having the time to care for patients, providing a high standard of care, paying attention to detail, talking to patients and relieving pain or suffering, which left the nurses feeling satisfied with outcome for the patient and family.

## Lows

One of “lows” that the participants reported concerned not having the enough time or staff to provide optimum care for patients. This caused the participants to feel guilty and stressed. Laura stated:

*“Errmm, not enough staff to give full nursing care to a lot of patients that’s waiting in A&E.”*

Katherine said:

*“And you know patients aren’t being looked after, they’re not getting their obs done, continuing care that’s just slipped by.”*

The participants reported that an inability to provide optimum care to their patients at critical times produced feelings of guilt and stress and were classed as significant lows.

When a patient died in A&E as a result of sudden death this was also considered a “low”. Chloe reflected on a failed resuscitation attempt one New Year’s Eve:

*“I’ve got to say the most difficult incident I’ve had to deal with was New Year’s Eve, and it wasn’t my first dealings with somebody coming in as a trauma but it was my first dealing with feeling helpless no matter what you did ... it was a bit like a TV programme ... ER, no matter what you did you were fighting a losing battle ... the doctors were there and the trauma team were there ... despite so many units of blood, more units than you can imagine putting into a person, you started to lose that person and you knew ... you felt helpless and all the medical staff did as well and I think the ... because the doctors had given it their all, everybody had given it there all ... well, we all actually cried while this young man was dying ... you just knew that you were fighting a losing battle ... and it’s the first time I’ve ever cried, not that I don’t care, I normally keep my emotions under check in front of relatives, but it’s the first time...”*

Chloe stated that this was the most difficult incident she had had to deal with; what she found difficult were her feelings of helplessness in the apparent imminent loss of her patient. Twice she used the war metaphor of “fighting a losing battle”, reflecting the lengths the A&E team and Chloe were going to in attempting to save this young man’s life. His death was the ultimate “low” for Chloe. Other participants reported similar feelings of helplessness and inadequacy concerning sudden death. In a comparative study of death anxiety in hospice and emergency nurses by Payne et al

(1998) hospice nurses had lower death anxiety than A&E nurses. Unlike the hospice nurses, A & E nurses when confronted with death were unable to discuss problems with colleagues, avoided thinking about death and showed a greater fear of death than hospice nurses; the A&E nurses reported that some of their most difficult times were spent with bereaved relatives. Scott (2007) suggests that sudden death is one of the most daunting aspects of emergency care. Scott (2007) continues that caring for the relatives is undeniably difficult and it is not unusual for A&E practitioners to wish to avoid this situation. The next section details the work of A&E nurses and their involvement with sudden death.

## **Sudden Death**

### **Part of A&E**

The nurses talked about their involvement in sudden and unexpected death in A&E.

The first point raised was that sudden death was an accepted part of A&E work.

Jenny stated:

*“You accept that bereavement and death in A&E are part of A&E and that’ll never change.”*

Katherine reflected:

*“I think in A&E most deaths are sudden aren’t they? Because obviously of the nature of the department. It’s not like they’re on a ward and they’re poorly and you’re looking after them, you build up a relationship with the family as well as that person. But in A&E you’re not privy to that because of accidents and how they happen so you have to build up a relationship quickly if you can.”*

Associated with sudden death being an accepted part of A&E work was the consensus that it was also part of the A&E nurse’s role. Karen said:

*“But I think bereavement care by A&E nurses is an important role.”*

Jenny felt that for the continuity of care at the time of death, the A&E nurse should care for the relatives and stated:

*“I think it’s important that continuity.”*

Mandy stated:

*“So we do take bereavement care very seriously, and I do think it’s important because I always like to think ... I think it’s important that we as A&E nurses do it because obviously we’ve got knowledge ... we know what’s happened to somebody, what treatment we’ve given them and why we’ve given them that treatment ... and I think you’ve got to be there for them (referring to bereaved relatives) ... looking out for them at that time ... you need a nurse looking after them ... it has always been one of the A&E staff ... we’ve never had anybody from outside or anything. ... (Long reflective pause).”*

## **Suddenness**

The nurses acknowledge that the suddenness of the death is particularly difficult to deal with, as Katherine reflected:

*“And she came in conscious and talking, she was poorly, err, and, emm, and she just deteriorated while she was in resus and she arrested a total of three times and we got her back three times, errmm and I think it was the fact that I knew her and I was talking to her ... (softer, broken voice) and then at the end of that she died (pause) the three nurses and the doctor that was in there were just crying, it was awful, it was really bad.”*

Chloe reiterated this:

*“I mean people die on wards that I’ve worked on ... but it weren’t like in as emotionally charged up circumstances like some of the deaths I’ve seen whilst I’ve been in A&E... in A&E they come in, you’ve never met them before and they’ve died before you’ve had chance to form a nurse-patient relationship...you’ve got a shorter time span to get to know the relatives and to judge how they might be feeling about losing someone ... (long pause).”*

Lynne stated:

*“Ermm, it’s not nice ... it’s not ideal is it? ... It’s not ideal when anybody dies, you know? But I should think that with the rapidity often you know one minute the patient’s alive, they’re at home, you know? Leading their day-to-day normal life, and then the next minute they’re coming in and they’re either dying or they’re dead, err, that’s what makes it difficult you know? ... It’s so sudden and unexpected they’ve got no warning, no hope, no time ... no chance (pause) to say goodbye properly, you know? No chance to prepare themselves for it ... it’s just so sudden ... I think that’s the worst ... (reflective pause).”*

As discussed in Chapter Two death is not an uncommon event in the A&E department. The rapid demise of the patient, despite resuscitative efforts and the suddenness of the death was challenging for the A&E nurses.

### **“None of the niceties”**

In Chapter Two, the characteristics of a good death were analysed. The analysis demonstrated that a death in A&E was not one immediately associated with the qualities ascribed to a ‘good death’. Lynne explained:

*“It’s not a nice environment is it ... you know, there’s none of the niceties is there? It’s not like on the ward is it? ... like a long stay elderly ward ... in a private room and it’s nice and quiet and their family have had chance to see them and say goodbye and err you just think well ... it’s a nicer atmosphere ... it’s just not a nice environment, it’s not very dignified and then the relatives are in here and we don’t have that much time to spend with them although we should have ... but it is really difficult in our environment to deal with it properly ... to deal with it nicely ... respectfully ... I think we do ... we do our best, but I don’t think we ever ... it’s never nice though.”*

However, in contrast Lynne also said:

*“Sometimes I think it’s a comfort to them when they’ve been fine and dandy one day, oh it sounds awful this, but then they just drop down dead and they’ve had no pain, no suffering, and sometimes that is a comfort to them, although it is difficult for them because they don’t have time to prepare and they don’t feel like they’ve had time to say goodbye properly ... but sometimes I do think that is a comfort sometimes ... (long reflective pause).”*

Despite the sudden death being, by its very nature, very difficult to accept and experience, the fact that it is sudden means that, through the apparent lack of prolonged suffering, there is no pain involved. This could be seen as a source of comfort to suddenly bereaved relatives.

### **Care of relatives**

The nurses talked about the care of relatives in A&E and said they assumed a caring role when able. The next section highlights the main forms of care in A&E for suddenly bereaved relatives.

### **Initial reception**

Initial reception by an A&E nurse who was allocated to care for the relatives was important. Karen stated:

*“when they first come in I take them into the room (referring to relative’s room) ... or sit them down and explain that ... or find out what they understand about what’s gone on and explain that the patient’s extremely poorly and that the doctor’s trying to save their life and then I say I’m going to go and see what’s happening and then I’ll come back and tell you what’s happening so I’ll go out and just check how the resus is going ... and I always believe it’s better to ... to paint a really black, black picture to that minute that you tell them they have died, errm, because it’s easier for them to start accepting and thinking that that’s what you’re going to tell them and it’s better to say well ‘no, we’ve brought them round’, that doesn’t matter, it’s better for them to be prepared for us to say ‘no, they’ve died’ because that’s a far bigger shock isn’t it.”*

### **Witnessing resuscitation**

Witnessing the resuscitation event was offered to relatives. Mandy stated:

*“If you’re looking after the relatives ... you know, if somebody’s in resus, or if somebody’s in paediatric resus or main resus we always ask the relatives if they want to be present to be with them and we always explain what’s happening to them. You explain to them what’s actually happening to their relative, so they’re not too shocked ... when they come in here and see people being resuscitated or whatever, cardiac massage or whatever, and we explain what they might see when they come in, but if they don’t want to come in then they don’t have to.”*

Katherine felt that it is relatives’ rights to be present in the resuscitation event; she said:

*“My personal thoughts are that people should be given that choice and it’s their right to be there and they’ve been there through their life, so why have we got the right to say they can’t be there at the end...”*

Despite the controversial nature of the family presence in the resuscitation room (Helmer et al, 2000; Ong et al, 2004 Yanturali et al, 2005) A&E nurses facilitated this for relatives who wanted to be present during the active resuscitation.

### **Facilities**

The participants discussed the importance of having a relatives’ room and a separate viewing room in close proximity to the resuscitation room. Di discussed the struggle she had in both getting and setting up these facilities:

*“We’ve just recently done out our bereavement room because it was a rather grisly, grey, horrible room ... but it was a very dowdy room and obviously we went into all the research and had a look to see*

*what sort of things they said it should be like ...and it's lovely, its' very, very tasteful and its unassuming and we're happy with it."*

The literature suggests that the viewing environment is important because this will be one of the last times the relative may see the deceased and so should be a calm and ambient setting (Brooker & Nicol, 2003). The relatives' room is the place where the relatives are taken on arrival to A&E, it is where they wait to hear news about their loved one, and is often associated by some relatives with death or bad news, as Lynne experienced:

*"I fetched them round into here (the relatives' room) and they said 'oh what's happened to him' ... but because I fetched them into this room they assumed he'd never breath again and they associated this room with bereavement and death."*

This may relate to the influence of the media where the relatives' room is portrayed as an area used to break bad news.

### **How you tell them matters**

An important point raised by the nurses was how the news of death was broken to the relatives, as this could have a lasting positive or negative impact on the relatives and their bereavement journey. At the same time the nurses felt it was important for the relatives to feel the nurses cared about them at the time of sudden death.

Katherine stated:

*"For those relatives to know that you care and it's just really things like what you're saying to them, because they'll remember what you're going to say to them maybe not there and then or over the next day, but a week down the line they'll remember what you've said so you've got to be very careful. I think what you say and your mannerisms, tone of voice everything really and facial expressions, I think you've got to be so careful."*

Chloe added a personal reflection:

*"Cause how you've dealt with them will stop with them for the rest of their lives. I mean I remember leaving the ward when my Dad had died and how that nurse dealt with me and my Mum, I've never forgotten it so and that was good thoughts, even though my Dad had died I was sad because my Dad had died but it was good thoughts because I remember the nurse, I remember her face, I remember her name and I remember the care she gave (long reflective pause) ... (silence)."*

Sandy suggested that A&E nurses are best placed to tell the family about the death:

*“I think nurses are better at dealing with bereaved relatives than doctors”*

Karen makes the point that clarity in the message is important and states:

*“I’ve learnt it’s important to say the word ‘dead’ or ‘died’, not to say ‘lost them’ because they don’t understand it. I always say ... I always say ‘they’ve died’ because ermm cause if you say things like ermm ‘we’ve lost them’ or ‘they’ve gone’, anything like that you find that they don’t understand (long reflective pause).”*

Zalenski et al (2006) suggests that competent and empathic death disclosure by hospital staff may help to maintain the continued wellbeing of the bereaved. A&E nurses were anxious to undertake this role in such a way that brought clarity to the situation but at the same time showed they cared.

### **Seeing the body**

Viewing the body at the time of death was important, even when the patient may be disfigured after trauma. Karen said:

*“I always think that to see the body sometimes helps ... helps the grieving process ... I do tend to encourage people to go in and see the body ... (long pause) ... I always have an arm out, I hate when they have them ... people have them cocooned, I always like an arm out for them to touch ... I always use the lighting, I like it when there’s low lighting in and I never like there to be any visible signs of trauma on them, such as blood or ... some people just leave blood on their hands or whatever, or sometimes blood coming through the venflon site and I don’t like that, I just like them to look as peaceful as much like their sleeping.”*

Lynne stated:

*“When it’s trauma or whatever and they look really awful and it’s difficult to know what to say to family. Some people are actively encouraging them to go in and see them you know but they’re in a really bad way ... badly injured, but then again I think, you know ... it’s always a dilemma, should they really see them when they look awful? But what happens if they don’t see them? ....”*

The A&E nurses highlighted the importance of the careful preparation of the body for the bereaved relatives to view. However, when the body was badly injured or disfigured a dilemma arose about whether the relatives should view the deceased or not. The literature (Chapple & Ziebland, 2010; Wright, 1996) suggests where the

patient is badly injured or disfigured, the way a person imagines the patient might look in these circumstances is usually worse than the reality.

### **Time to say goodbye**

The nurses all felt it was important for the bereaved relatives to have time to spend with the deceased and say goodbye. Karen stated:

*"I'm always happy for them (referring to bereaved relatives) to stay as long as they want."*

Jean stated:

*"It's a special time just as giving birth is a special time ... and they need time to do what they need to do."*

Mandy says:

*"The relatives to sit with their relatives for as long as they want, they don't have to feel that they're being rushed off or anything, errmmm."*

Despite working in a busy and demanding environment the A&E nurse facilitated time for the bereaved to spend with their deceased relative.

### **Follow up**

Although there was no formal follow-up procedure in A&E, the staff felt that this would be helpful for both the relatives and staff. Jenny stated:

*"I think it would be nice if someone from A&E could follow them up to see if they are coping or not and if they're not then ... then maybe give them further advice"*

Katherine suggests:

*"What I do is write my name and department phone number in the back of the bereavement booklet, and then if they do want to contact you for anything or to ask any questions, even if it's a week or a month down the line, like if they've got a question in their head then you can say 'feel free and phone me and I'll try and answer that question for you if I can' for them."*

Parris et al (2008) conducted a retrospective study into a follow-up service offered to bereaved relatives after a sudden death in A&E. The study concluded that a follow-up program was helpful to the relatives as it provided information about the cause of

death and clarified where possible any unanswered questions about the sudden death.

## **Care of Staff**

### **Feelings about death**

During the interviews the participants talked about their own fear and concerns about death and dying. Katherine reflected:

*“When I first started my training I had a fear of death (reflective pause)”*

Katherine continued by talking about her feelings associated with sudden death:

*“And he’d (referring to a patient) been hit by a four tonner, a big truck, and, you know, looking at him he had no injuries ... and I’m fine while I’m working and doing. It’s when I stop ... I can remember this doctor saying ‘what a waste, a young fit man’ (reflective pause) and that (referring to death of this patient) really, really hurt.”*

Katherine’s stories of her involvement in sudden death in A&E show that they affected her personally. These events remained with her. Gary concurred:

*“I mean death obviously, its not, its not, its not so much the death it’s the families, it’s the dealing with the families err and I find that a problem.”*

Sandy explained:

*“You have to still get on with the work and things it doesn’t stop you thinking about it and still being upset.”*

### **Difficulty caring for relatives**

The difficulties and challenges encountered by the nurses in caring for relatives were highlighted. Katherine talked about the reaction of the relatives at the time of a sudden death:

*“then the next thing we knew it was resus’ doors being thrown open and it was Dad running in saying ‘she’s not dead, tell me she’s not dead’ and he was just inconsolable and he just scooped her up and he and you know he was just walking round with her and I thought that was just awful (pause).”*

The other participants found caring for relatives to be similarly challenging and at times very difficult. Gary related his experiences of sudden death to things he has found personally challenging. On breaking the news to some relatives about their father's death Gary felt as though:

*"their world had collapsed and ... that was awful because I was having, obviously I was having to, I know I wasn't making their world collapse, but by me letting them know ... that's when their world collapsed ... and that was really hard."*

Gary immediately followed this up with a story of a young man in his twenties who died suddenly. Gary explained that he found it difficult caring for the young man's mother because she was so upset in the circumstances. Gary explained:

*"we did have a young, a young gentleman, mid-twenties, and he died at my age ... and that was sad again, the, the family thing, what made it worse was the fact that that this lad knew and the morning, that morning, he was a little bit better and he was saying he loved his Mum and that if anything did happen he did love her and stuff, and this is her telling me this after I'd told her and that's, that's upsetting is, is the dealing with the relatives."*

Mandy reflected:

*"Another area that challenges me ... well ... there's lots of things that challenge me, but another area is people dying ... that's always quite challenging ... a lot of little things ... you know when they upset you, like when children die ... that's quite challenging to deal with ... obviously, dealing with the baby or the child at the time... you tend to just get on with things and you focus on what you're doing and you just get it done, and then obviously afterwards you reflect really, but then afterwards you've obviously got to deal with the relatives which is quite challenging sometimes, errmmm, and you get upset ... I get upset, but if you didn't get upset you're not normal ... I find that really challenging sometimes (reflective pause)."*

### **Returning to the norm**

The participants discussed how difficult it was to care for suddenly-bereaved relatives and then return to other patients in A&E. Lynne stated:

*"I think you learn to deal with doing this job ... I think it's all that ... you have a professional face, errmm ... (long reflective pause) ... sometimes you deal with a death and then you're going in and putting steri-strips on somebody and I think if it's something straightforward like that it's ... when you've dealt with the relatives it is highly emotional and everything and you need a couple of minutes to gather your thoughts and then you can go out and deal with just routine"*

*things that's manageable really, but sometimes, when you've to deal with a ... someone who's complaining about how long they've been waiting, you know sometimes you feel like saying 'come with me mate, I'll show you what it's been about', but you can't can you? But I'd love to."*

### **Getting it right**

Di stressed throughout her interview the importance of getting "it right" with reference to caring for bereaved relatives. Di said:

*"You know you only get the one chance to do it right, you know that loved one only dies the once as a sudden death."*

Gary often feels concerned about saying the right thing, Gary reflected:

*"I hope I always say the right thing, but there's always a part of me that thinks have I said the wrong thing."*

Gary was concerned about saying the right thing. In reflecting on getting it right, some staff felt that asking relatives later on if things could be improved may give valuable insight. Chloe stated:

*"Or maybe if, you know, I don't know, if maybe we could offer, you know, a few months down the line, contact the relatives and ask them how they thought their bereavement or their circumstances were handled, you know, how can you make improvements on losing somebody? But if you would have liked ... you know what they would have liked at that particular time, you know, as a way of improving our skills and services to them as well, you know (long reflective pause)."*

Jenny concurs:

*"I think that's a good point, when they could give you a little bit of feedback, you know, 'is there anything we could have done differently for you when you were here or when you left?' Because at the time they don't know what they want, but maybe having thought about it they could come up with something like 'I wish they'd done this' or 'I wish they done the other but' or 'I wish somebody would have told me this cause'. I didn't think we'll ever get any better on it unless we get feedback from them patients or relatives, but I do think we give them information out, errm, in most cases."*

### **Identifying with the relatives**

Chloe continued to talk about an incident on New Years Eve when she was caring for a young man from a road traffic accident who was dying in the resuscitation room.

Chloe felt helpless as the resuscitation attempts were failing and this young man

died. Chloe identified with this young man as he was only a year and a half older than her own son:

*“and all the way home I couldn’t stop thinking about this young man and his parents ... as I say, everybody is supposed to be happy New Year’s Eve and here you are, you know, you’ve got 2 grieving relatives that, err, they’ve just lost a son, who’s a year and a half older than my own son so ... as I say ... that morning when I got in both of mine were fast asleep ... I didn’t wake them up but I went and looked at them, you know, there but for the grace of God (long reflective pause).”*

Gary also identified with the relatives; Gary’s first story was about a man in his 40s who collapsed and died. In this story Gary found it challenging to deal with this situation because the man had three sons, Gary stated:

*“He’d got three young sons, and I’ve got two brothers and they were all about, the eldest was about my age and the middle and the youngest were my brothers.”*

Gary identified himself with the family. Katherine had similar feelings:

*“But you feel that loss for them and I tend to go home and have a cry, and yeah, if it’s a child, yeah definitely, and just think what if that were mine or what if that were my Mum and how I would react? And I don’t know if that is right or wrong, but you just think life’s so precious..”*

Jenny reflected:

*“And I think if you can relate it to yourself, like if I have anybody in that’s my son’s age it’s ... (pause) you tend to think about ‘if’, if you were in that person’s position and that’s what others have said, ‘well that’s what age my Dad was’, or ‘my son’s that age’ or ‘my child’s that age’ ... I think if you can relate it to yourself it’s in some ways a little bit more difficult.”*

### **Seeing the pain**

The nurses found dealing with bereaved relatives difficult as they witnessed firsthand the pain evoked through a sudden death. Katherine stated:

*“I thought you shouldn’t cry, but now I can’t help it in some situations when they’re saying certain things and they’re bartering with all the ‘if only’s’ and ‘it should have been me’ and I think those are awful and that upsets me, yeah definitely.... (Long reflective pause ended this conversation)”*

Chloe said:

*“You just know what they’re going to have to go through (pause), and to me once ... to me life is precious, once they’ve died that’s it they’ve gone (pause) somebody has lost somebody and they never get that back (long reflective pause) ...(silence).”*

Jenny reflected:

*“I find it more distressing to deal with the relatives, that’s the part of it that upsets me personally more than the patient that’s died ... (pause) especially if there’re children involved, ermm, but it’s part of your job and you just get on with it. It’s their distress that distresses you ... err you’re upset for the one who’s died, you feel sorry for what’s happened, but it’s the distress of the relatives you’ve got with you that causes you to get upset. They’re the ones you cry with, they’re the ones you’re trying to console.”*

### **Preparation of staff**

The consensus amongst the nurses was that dealing with sudden death was difficult and challenging, both personally and professionally. But if staff could feel more prepared, this may help in the situation. Jenny suggested that nurses could be prepared via shadowing more experienced nurses:

*“I know some nurses do struggle with it. I know one or two, err, don’t like to go in and I think that’s more junior nurses and I think that’s our fault, senior nurses fault, I think we should take them in with us and give them a lot more support early on so they are confident when they actually have to go in on their own. (Pause)”*

Mandy concurred:

*“If its somebody junior then we would let them watch someone else before we let them do it.”*

Karen felt that experience helps in the preparation for caring for relatives:

*“I’m not scared of dealing with bereaved relatives, I think my previous experience of caring for the bereaved has helped because in my previous job I was dealing with bereaved relatives more, probably 2 times a week, and it is less now in A&E. My previous experience has helped.”*

Karen continued that having more knowledge about the subject helps prepare you too:

*“I think at first when you deal with relatives you’re scared because you lack the knowledge about what to do – you’re inexperienced. You don’t know whether to cry with them or not, whether the relatives should view or not, whether to be silent or to speak. You want to make sure you give the right information and say the right thing. I*

*would hate to think I'd said something that was wrong and that's all the relatives could remember afterwards. (Pause)*"

Chloe talks about personal preparation for the worst outcome and states:

*"(Pause) ... when I say you've got to get hardened to it I don't mean to say you've got to be uncaring, but you've got to get used to situations where when the phone call comes you've got to, at the back of your mind, depending on what they say on the phone call, you know that maybe the outcome for that patient is not very good, before they've got there even, though you're going to give it your best, you know the outcome not going to be successful so I think you've got to prepare yourself for that."*

The literature highlights the importance of staff preparation when caring for suddenly bereaved relatives (Brysiewicz, 2008; Garrett & Chan, 2004; Wisten & Zingmark, 2007). The A&E nurses highlighted the difficulties associated with caring for suddenly bereaved relatives and commented on their lack of preparation.

### **Effect on staff**

The nurses talked about the impact of caring for the relatives had on them. Jenny reflected:

*"It drains you, sometimes you do feel emotionally drained."*

Mandy states:

*"Little things that tend to upset me, like I once had to look after a child who'd died of asthma and I was fine until his Mum picked him up and cuddled him (broken voice) ... and then I just had to go out ... Like I once looked after, eerr, an old lady whose son-in-law had been driving and was blinded by the sun and crashed into the back of a truck, and he had injuries as well but it had gone into his mother-in-law's head and she just had ... she just had an untreatable brain injury, and while he was waiting for his wife, which it was obviously her mother, and he just said can I ... can you bring her in here and so we pushed the trolley in next to him and he just like held her hand and he said I'm really sorry ... (reflective pause)."*

Jean has felt devastated and, at times, like a failure:

*"It's devastating ... but where it's a traumatic accident an RTA, event, incident, whatever causes them to come to A&E, but they've been living life ... that sudden death, errmmm ... you do feel like you've failed because whatever, you know when you've had a prolonged resus and you seem to be winning and you've got them out of cardiac arrest situation, and you've got them ... coming round sometimes, and then they suddenly go off again ... that's hard because you do*

*feel like you've failed ... and we've had some prolonged resuses here ... errrrmm prolonged resuses of drowning and things like that, errr, when you're really willing things to happen because you know through media, things that have been published that you can go on for a long time that you can get these people back, the relatives have got that hope, you've got that hope and in the end when the decisions made and you stop, it's failure ... it's, it's despair, it's, it's just your whole shift's a nightmare"*

Despite acknowledging the effect of sudden death on staff members there was consensus amongst the nurses that little was done to help or support each other at this time. Katherine stated:

*"On the whole we're pretty bad at that really, at supporting each other."*

Lynne stated:

*"We are poor at debriefing."*

Mandy explained that support does happen informally:

*"We normally chat informally really..."*

Chloe stated:

*"I've yet to see like a debrief ... but I think it would be good if, you know, they had a facility where even if it's just at the end of the shift somebody just said do you want to talk about what's happened today. (Long reflective pause) ... silence. You're going through a whole range of emotions and everything and, err, people have got to understand you know, it's not easy working in A&E some days ... because we are supposed to be a caring profession but yet we don't seem able to care for us as people (long reflective pause)."*

This is interesting as is in contrast to the team spirit and camaraderie alluded to earlier in this chapter when the staff talked about their experiences of A&E nursing.

Yet at the time of sudden death this appears to be lacking.

Many of the stories the nurses shared about sudden death were difficult and traumatic experiences. The nurses identified with the both the personal and professional challenges when dealing with sudden death. This manifested itself in them dealing with their own emotions regarding the sudden death as well as those of the relatives.

## **Discussion from the analysis of the findings – Part II**

### **Life in A&E: context of sudden death**

The nurses discussed the essential nature of A&E nursing and work. Life in A&E was described as variable and unpredictable, often pressurised and sometimes chaotic if a number of patients arrived in A&E within a short period of time. The nature of the work was described as being challenging and stressful. An added pressure was that of targets in which, ideally, all the patients had to be seen treated, admitted or discharged within a four hour target time, which was often difficult to achieve. It is arguably understandable why the context in which sudden death takes place is not ideal. Similarly so for why the A&E environment may not be conducive to a good death experience. Other contributing factors are that, from the outset, the sudden and unexpected nature of the death makes it difficult. The circumstances of the death and, often, the nature of the patient's injuries are similarly not conducive to a good death. Therefore, sudden death and the care of bereaved relatives take place against a backdrop of a busy and pressurised environment with imposed four-hour targets. The care of suddenly-bereaved relatives is something which cannot be rushed and makes the practicalities of caring for suddenly-bereaved relatives even more challenging.

### **Life saving work: roles in the resuscitation room**

The work and events in the resuscitation room were described as being dramatic. Goffman's (1959) metaphor of a theatrical performance to explain the organization of everyday life and the techniques by which impressions are conveyed is one way in which sudden death in A&E may be considered. Goffman's (1959) approach to the study of social interaction is often called *dramaturgical*, meaning that he viewed social life as something like a staged drama. According to Goffman, everyone is always on stage consequently, causing everyone to be a performer. Our performances are labeled "fronts", which are the part of the individual's performance

that regularly functions in a general and fixed fashion to define the situation for those who observe the performance. Goffman infers from this that everyone has "masks" (fronts) which they use in their everyday lives. These fronts can take the form of assumed roles within a given society. Goffman identifies two stages on which people perform; a front stage and a back stage. Goffman suggested that the front stage is not a person's true self, but merely an actor using a front, and in the back stage the person is closer to their true self. Goffman (1959) refers to professionals giving and maintaining a convincing performance so that the audience can see that they are authentic, and talks about the professional (front) and private (back) face comparing them to the roles that actors play in dramas or situations.

In the narratives, the nurses talked about working in resuscitation and witnessing some catastrophic events that had left patients with life threatening injuries or illnesses. The nurses talked about their main role being that of life saver; this role was important to the A&E nurses, and when a patient's life was saved it was a significant event and had a lasting impression on them. If death was averted and the patient, even though critically ill or injured, left A&E to theatre or ITU it was seen as a success because the patient "didn't die with us". The drama of a resuscitation event could last from a few minutes up to hours, depending on the nature of the problems with the patient. Throughout it all the nurses displayed their professional face of a life saver, and being involved in much activity during the resuscitation event. This brings meaning to their role as A&E nurses and is important for them. It is a convincing role; A&E nurses have learned what is expected of themselves in the resuscitation room and give a credible performance. The nurses had learnt the *script* involving resuscitation and, to some extent, they had internalised it. However, in sharp contrast to this role of life saver was the role that involved caring for the relatives. This was a very different role – here, when a patient dies, the main role for the nurse was that of "death teller"; as the patient had not survived it was the opposite of the life-saving role. In this role the professional face was maintained to some extent, but sometimes

the back stage face was revealed when the nurses talked about seeing the pain of the bereaved relatives and sometimes crying with the relatives. There was no obvious *script* for this role. Due to the underlying philosophy of life saving and an expectation of cure, caring for suddenly-bereaved relatives is challenging because patients are not expected to die. Nurses in A&E have become accustomed to the norms and culture of A&E nursing and internalised the underlying norm of the life-saving role. This is then re-iterated and reinforced when they have worked in resuscitation and learnt the protocols and procedures involved in advanced life support and trauma resuscitation. Hence, caring for suddenly bereaved relatives creates a conflict for the A&E nurses because they are not anticipating this outcome, and in caring for the suddenly-bereaved relatives, the nurses are exposed to their pain. This may be extenuated when the sudden death in A&E is not one immediately associated with the qualities ascribed to a 'good death'.

## **Conclusion**

Nursing stories can provide a rich data source for nursing research, and are a valuable tool for enhancing clinical practice. The experiences of the A&E nurses have been reported extensively and comprehensively with numerous quotations from the interviews used to support the analysis and to convey as accurately as possible their accounts. The nurses reported on different aspects of A&E nursing such as the unpredictable and varied nature of the work, how different reforms have impacted on the work of A&E nurses and that working in a contemporary A&E environment is target-orientated as opposed to patient-focused. This often led to conflict for A&E nurses as they balanced the workload of a busy environment with the needs of the suddenly bereaved. Working with critically-ill and injured patients in the resuscitation room formed a significant part of the A&E nurse's workload and involved a life saving role. This role was a sharp contrast to the care of suddenly bereaved relatives who had experienced a sudden and unexpected loss.

## **Chapter Six – Synthesis, conclusion and recommendations**

### **Introduction**

This chapter presents the main conclusions from both parts I and II of this study. The approach throughout the research has been to be as open as possible in describing the processes by which its findings and conclusions were developed. This chapter concludes the research by considering the limitations and strengths of the study, implications for nursing practice in the A&E department, recommendations and further research opportunities. The final section contains an account of my personal reflections surrounding the research journey.

### **Good and Bad deaths – being present, life saver and death teller**

Unsurprisingly, in part I of this study the participants reported experiencing initial shock as a result of the sudden death. The participants explained that this sense of shock persisted long after they left A&E. In particular how the suddenness and unexpectedness of the event, the rapid demise of the deceased, the confusion and sense of injustice about the death and the inability to say goodbye all compounded this sense of shock. This appeared to leave the participants wondering why this had happened and prompted a search for meaning. This response is congruent with existing literature and research (see Clements et al, 2003; Kaltman & Bonanno, 2003; Ferrell & Coyle, 2006; Parkes, 2008).

Perhaps what was a more significant finding was the way in which people died, whether it is experienced irrespective of its suddenness as a good death experience or not, had profound implications for participants. The context for this study was A&E departments, an environment where the concept of a good death is not normally associated with death in A&E. For example Scott (2007) argues that death in A&E is stripped of the characteristics associated with a good death experience. In Chapter 2 the definition of a good death, and, conversely, a bad death was examined. The

participants who had a “good sudden death” experience felt a sense of being “looked after” by the staff in A&E, and in particular by the A&E nurse. Being “looked after” involved, for example, a nurse meeting the participants at the point of arrival in A&E, being informed in a timely manner about what was happening to their relative, and, or making them refreshments. The participants reported that being “looked after” helped them not just during their stay in A&E but also left a lasting impression of being cared for and cared about after leaving A&E. In contrast, the participants who experienced a “bad sudden death” commented on the absence of an A&E nurse, were not met by anyone on arrival in A&E, stated they experienced a lack of privacy, remember receiving minimal or no information about their relatives and had little practical help offered. This consequently left them with feelings such as a sense of abandonment and not feeling “looked after” at this critical time. A&E environments are, as discussed earlier, busy, sometimes chaotic, and it is easy to see how family members may feel overlooked particularly when the focus of care is the patient; this is all compounded by clinical urgency.

The “presence” of the A&E nurse was also seen as important. This “being with” was described as different from the experience of being “looked after”. The “presence” of the nurse transcended the actions that were seen as caring by helping and communicating. The act of being present was more meaningful and facilitated exchange between the bereaved and the nurse. Often this was without conversation. It was an unspoken way of being with another. The “presence” of the nurse signalled a level of connectedness with the relatives whereby rapport and trust was developed. Caring for bereaved relatives involved more than simply providing practical help; although important. It also involved being present at a time of crisis and need. The “presence” of the A&E nurse at this time had a positive outcome for the relatives. Conversely, the participants who had no nurse present reported a sense of abandonment, felt unsupported and less cared for during their time in A&E.

In both the immediate and ensuing months after the sudden death a sense of brokenness remained with the participants, which manifested itself in an overwhelming sense of loss. The loss and sadness pervaded all aspects of the participants' lives to such an extent they felt "broken" and "bereft". However, the participants shared their "survival" techniques. These included ways in which they sought help and support from family, friends, professional and voluntary sources, all used to assist them through their loss.

In part II the nurses discussed the essential nature of A&E nursing and work. Life in A&E was described as variable and unpredictable, often pressurised and again from their perspective sometimes recognised as chaotic. The nature of the work was described as being challenging and stressful. An added pressure was that of targets in which, ideally, all the patients had to be seen treated, admitted or discharged within a four hour period. It is understandable why the context and setting in which sudden death occurred, as discussed in this study, is not ideal. Also the sudden and unexpected nature of the death, the circumstances of the death and, often, the nature of the patient's injuries are similarly not conducive to a good death. Therefore, sudden death and the care of bereaved relatives take place against this backdrop. The work and events in the resuscitation room were described as dramatic.

In the narratives, the nurses talked about working in the resuscitation area and witnessing patients with life threatening injuries or illnesses. The nurse's explained that their primary role in this context was that of "life saver"; a role seen as important to the A&E nurses. When a patient's life was saved it was seen as a significant event, almost heroic, and had a lasting impression on them. If death was averted and the patient, even though critically ill or injured, left A&E to theatre or ITU it was seen as a success because the patient "didn't die with us". The actual drama of a resuscitation event could last from a few minutes up to hours, depending on the nature of the problems that the patient presented. Throughout these events the role of "life saver" took precedence. In sharp contrast to the role of life saver was another

role, one that involved caring for the relatives following a sudden death. This very different role was perceived by the nurse participants as emotionally draining. When a patient died, the main role for the nurse was that of “death teller”. Due to the underpinning purpose of A & E care is that of life saving, and an expectation of cure. Caring for suddenly-bereaved relatives was perceived as challenging because patients who die represent failure of their efforts. Nurses in A&E become accustomed to the norms and culture of A&E nursing and appear to have internalised the underlying norm of the life-saving role. This role of “life saver” is regularly reinforced when they work in resuscitation and symbolically through the protocols and procedures that frame advanced life support and trauma resuscitation. Hence, caring for suddenly bereaved relatives creates a role conflict for the A&E nurses because death as an outcome is a failure. When caring for the suddenly-bereaved relatives, the nurses are exposed to the double burden of relatives’ loss and personal feelings of failure.

### **Limitations**

A number of writers, such as Rubin and Rubin (1995), warn about the intensive nature of qualitative research, which makes a relatively small sample size a practical necessity. Being a qualitative study, this research was limited to a small number of participants. Quantitative researchers may deem this to be a small sample and the degree to which they judge this research to be representative would be called into question. However, the intention of the research was not to be representative; rather, the aim was to understand and describe the phenomenon of sudden death from the perspective of those who have experienced it.

Another concern was related to the sensitive nature of topic under investigation in the study, namely sudden death. Both the relative and nurse participants were being asked to talk about emotive experiences related to sudden death. Given the depth and detail of data obtained from the participants, it became clear that the topic did not

deter the participants. Similarly, being a lone researcher investigating sudden death and hearing stories from the participants about sudden death was at times very distressing, difficult and challenging. However help and support from the University supervision team was always available if needed.

In part I, semi-structured interviews were employed to gather information from the bereaved relatives, perhaps limiting the answers to the questions asked. In reality, the participant's responses went beyond what was being asked of them and provided rich descriptions of their experiences of sudden death. In part II, the exclusion of D grade staff nurses (equivalent to Band 5 post AFC) may be seen as a limitation. At this level, these junior nurses were not generally as experienced in issues related to sudden and unexpected death. However, it must be acknowledged that their thoughts may have highlighted a different perspective on the training, preparation and education about sudden death.

### **Strengths**

The qualitative nature of the study enabled a depth and richness to the research that could not have been achieved by other methods. The selection of the participants via purposive sampling assisted in attaining this depth and richness in the data that may not have been achieved with participants who had not had experience of the phenomenon under investigation. That said, it is without doubt that the major strength of this study has been the commitment of the respondents who participated in it. All the participants, be it relatives or nurses, are the people who made this study possible by making themselves available for interview and by being willing to discuss highly personal and emotive issues. It is only through the commitment of the participants that this work has come to fruition, and I am forever indebted to them for their help, commitment and support.

### **Implications for practice**

As revealed in the literature review, sudden death is a uniquely individual experience hence there is great variation in how people react when they are suddenly bereaved. Also, the literature suggests that a sudden death is more difficult to cope with than an anticipated or expected death. A&E nurses need to be aware that grief reactions can be more pronounced and prolonged following sudden bereavement. A lack of knowledge or insensitivity on the part of those supporting bereaved relatives can make sudden death more difficult. A&E nurses need to ensure that they support and facilitate the grieving process through the provision of appropriate care for those who are suddenly bereaved.

### **Recommendations**

This study recommends that *all* A&E nursing staff should be prepared for the arrival of suddenly bereaved relatives. This involves training, preparation and education about all aspects of sudden and unexpected death. In particular an induction programme should be implemented for new staff to A&E to enhance awareness of their role in sudden death. A&E nurses need to have bereavement-based knowledge and clear protocols to implement after a sudden death. That said regular education sessions should be available to all staff in A&E involved with supporting bereaved relatives. These recommendations should be supported by a robust Bereavement Policy that incorporates local and national recommendations.

### **Implications for future research**

This study has built on existing understandings of A&E nursing and sudden death and challenged aspects of existing conceptual frameworks concerning death and dying. The implications for further research incorporate the development of a national A&E framework for sudden death. This framework should embrace existing good

practice regarding sudden and unexpected death, providing the opportunity for change and a strategy for moving towards national consistency.

### **Reflection on the researcher's personal journey**

I am conscious as I write up this research study of the ways that I have developed as a person, nurse and researcher. I have been engaged in writing, reflecting and thinking, as well as conducting interviews, amongst many other activities. Throughout the research process I have presented myself in an open and honest manner.

Reflecting on the process I am reminded of the many different relationships that have been established throughout this study. I am constantly touched by the experiences of the relatives and stories from the nurses. It was my privilege to come into contact with them and to get to know them, and without that this research would not have been possible. In particular, the relatives who had such tragic experiences of sudden and unexpected death were an example to me in dealing with these difficult circumstances. I am aware of the different dilemmas concerning sensitive research and always ensured that my work was carried out in a sound ethical manner. I have been committed to researching with integrity and honouring the commitments I made with regard to the research. To this end I know at the conclusion of this journey that this research has been conducted in an honest and trustworthy manner that is fitting to the trust placed in me by the participants.

### **Conclusion**

Part I explored the impact of sudden death on the lives of the bereaved, and semi-structured interviews were employed to explore the personal impacts and experiences of loss. The participants detailed how the initial shock surrounding the sudden death permeated all aspects of their life. A comprehensive understanding of the experience of sudden death and its impact on the lives of the bereaved was forthcoming. As a consequence, this study has increased awareness about the

needs of the bereaved after a sudden death. Through exploring sudden death from the perspectives of the bereaved, it became evident that A&E nursing staff need to be aware of their actions at the time of a sudden death and the impact they may have on the bereaved, not only in A&E, but also in the ensuing bereavement period.

In part II the experience of sudden death from the perspective of A&E nurses was explored using narrative interviews. The narratives revealed that working in a contemporary A&E environment is unpredictable and target-orientated as opposed to patient-focused. This often led to conflict for A&E nurses as they balanced the workload of a busy environment with the needs of the suddenly bereaved. The results of this study reinforce the need for continuing education regarding all aspect of sudden death in the A&E environment. It is hoped that A&E nurses who care for suddenly-bereaved relatives on a daily basis may gain greater insight and understanding into the way people live with sudden death in order to provide appropriate support at this critical time.

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## Appendices

## **Appendix 1 – Permission letters for the study**

The permission letter from the part I is included in this appendix.

The permission letter from part II had been archived and is no longer available.

Hence other supporting documentation has been included.



14 December 2000

Dear Mrs Newton

**Sudden death in the Accident and Emergency Department (A&E): its impact on family members.** [REDACTED] LREC Ref: SOU/00/029.  
**Ethics Committee Reference Number: CEN/00/247/CA**

Thank you for submitting the above study for review by the [REDACTED] Research Ethics Committee. I have taken Chairman's action to approve the study under reciprocal arrangements with [REDACTED] LREC. This decision will be reported to the Committee for ratification at the meeting on 22 January 2001. The study should be started within three years of the date on which LREC approval is given.

All documentation forwarded to [REDACTED] LREC were reviewed and you have confirmed that signatories provided on your form are employed/based at [REDACTED] NHS Trust.

Would you please note that granting of ethical clearance does not confer management approval for the study. This can only be given by your employing authority. If the study is to take place in the [REDACTED] NHS Trust and you have not already done so, you must contact the Trust's Research and Development Office in order to gain approval from the Trust. (Contact Dr [REDACTED])

Insurance cover is required for investigators who hold a substantive or honorary appointment with the [REDACTED] and are involved in research studies on volunteers. If a project has been approved by an LREC, it only needs to be reported to the Senate Ethics Committee, in order that cover can be provided. (Please contact: [REDACTED] Secretary, Committee on the Ethics of Research on Human Beings. Telephone: [REDACTED]) If you hold an appointment in another university, you should contact that university to clarify the position concerning research studies and insurance cover.

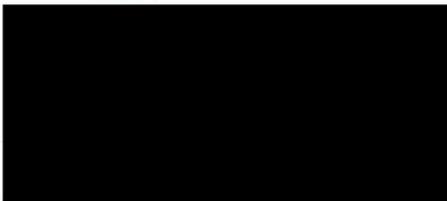
Chair: [REDACTED]  
Chief Executive: [REDACTED]

You must notify any serious unexpected adverse events to the Ethics Committee. If any significant protocol amendments are proposed you must obtain prior approval from the Ethics Committee.

The Ethics Committee is required to monitor the progress of research studies and I will therefore be writing in about a year's time to ask you to complete a short review form.

**Finally, please ensure that you quote the Ethics Committee reference number given at the top of this letter in any future correspondence.**

Yours sincerely,



[REDACTED]

Our Ref: JS/sa

29 April 2004

[REDACTED]

[REDACTED]

Dear [REDACTED]

**SUDDEN DEATH IN THE A&E DEPARTMENT - AN EXPLORATION OF A&E NURSING STAFF EXPERIENCES. R&D REF - 03/255**

I am writing to ask whether you would support a research project involving nursing staff in A&E at [REDACTED]

Sharon Newton, a Sister in A&E, is interviewing nurses about their experience of sudden death in A&E departments for her PhD. The project was approved by the Trust in February 2003, and planned to involve nurses at [REDACTED] hospitals. Sharon has now approached R&D for permission to extend the project to involve nurses at [REDACTED]

Sharon will seek to recruit a further 6 nurses, and the in depth interviews will last for approximately an hour each. Matron [REDACTED] is aware of, and supports, the project.

I enclose a copy of the nurse information leaflet, which provides a brief summary of the study. If you would like further information, please contact me directly.

If you feel able to support this project, please let me know as soon as possible, and I will approve the extension to the study.

Yours sincerely

[REDACTED]

**HEAD OF RESEARCH & EFFECTIVENESS**

Enc.

cc Mrs S A Newton, A&E Dept., [REDACTED]

---

**DIRECTORATE OF NURSING AND PRACTICE DEVELOPMENT**

**Director of Nursing**

## **Appendix 2 - Invitation and information leaflet for relatives about the study**

Dear

We are continually trying to improve the quality of care offered to families who have suffered a sudden death. In order to do this we need feedback from those receiving this care i.e. you. I appreciate this is a very sensitive area, but it is an important area to know more about, so that we can do it better.

I am writing to you to invite you to take part in a research study concerning your recent bereavement.

A detailed information sheet is attached for you to read which gives an explanation of what the research involves. Please read this carefully before you decide whether to take part.

There is no obligation to take part. Should you decide that you wish to be interviewed and then change your mind this will not cause any inconvenience.

If you would like to participate, please fill in the consent form and return it in the stamped addressed envelope and you will be contacted by Mrs Newton at a later date.

Please do not hesitate to contact me or my secretary if you have any questions or concerns arising from this request.

Yours sincerely

(Name of A&E Consultant)

**Title**

Sudden death in the Accident and Emergency department: its impact on family members.

**Invitation:**

My name is Sharon Newton and I am a Senior Nurse working in the Accident and Emergency Department at W----- Hospital (Phone number -----).

I was sorry to hear about your recent bereavement after your relative was admitted to the A&E department and died. The following letter invites you to take part in a research study based on improving services available to newly-bereaved families following sudden death. Before you decide to take part in the study it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends, family or your GP if you wish. Please do not hesitate to contact me if there is anything that is not clear, or if you would like more information, and take time to decide whether or not you wish to take part.

**Purpose of study:**

The purpose of the study is to investigate the services provided for families who have had bereavement due to unexpected death. The aim of the study is to find out how improvements in the service can be provided to people like you who have experienced a sudden bereavement. This letter is being sent to relatives who have had a recent bereavement. Those who agree to participate become involved in a short interview in their own home. I will also be talking to other families, about 20 in total.

**Participation:**

The decision to become involved is yours although you may wish to discuss the information in this letter with your family or friends. If you decide to take part you will be given this information sheet to keep and be asked to sign a consent form. Having decided to take part you are still free to withdraw at any time and without giving a

reason. The following part of the letter may help you to answer some of the questions you have about the research.

**What happens if you take part?**

Once you have signed the consent form, you will receive a phone call to arrange a convenient time to carry out the interview.

The study involves you participating in an interview in which a tape recorder will be used to record your answers. The interview will last about 30-40 minutes and can take place in your own home or at a location convenient to yourself, such as the hospital. During the interview you will be asked to talk about your personal experiences and invited to answer questions about the time in hospital. There are no right or wrong answers to the questions; it is what you felt that is important. The interview is concerned with your personal experiences. Below please find some of the types of questions you would be asked:

- 1) "How you have coped since losing a close family member?"
- 2) "Is there any special form of help you would have liked to have had?"
- 3) "How your life has changed since the death?"

The tape recording of the interview will be listened to and you will be sent a written copy.

**Some things you may wish to consider about of taking part:**

As a result of taking part you may at some point in the interview feel sad or upset; should this happen, the interviewer will stop asking questions until you feel more comfortable and able to continue. Should you feel at any time unable to continue the interview then the interview would be abandoned.

Many people do find it helps to talk to someone about their bereavement experiences. It is hoped that the interview will be beneficial to you. What you say and have experienced will help improve the service provided to others, as well as enhancing the good areas.

**About the interviewer:**

The interviewer is a qualified nurse with many years of experience of working with bereaved people who have experienced sudden loss. She has also received special training in conducting interviews.

**Confidentiality:**

All information which is collected about you or your relative during the course of the research will be kept strictly confidential. Any information about you which leaves the hospital will have your name and address removed so that you cannot be recognised from it.

**Results of the study:**

The results of the study will be used in the research project. A copy of this will be kept in the A&E department at W----- hospital. At a later stage the results may be published in a nursing journal. If you would like a copy of the results they can be forwarded to you upon request.

**Review of the study:**

This study has been reviewed by S----- M----- Local Research Ethics Committee who have agreed that it may go ahead and by a lecturer and Professor at the University of M-----.

**Contact person for further information:**

Sharon Newton, A&E department W----- Hospital, -----, -----,  
telephone -----.

Thank you for taking the time to read this and for taking part.

**Consent form**

(19<sup>th</sup> January 2000 version no.1)

Patient Identification Number:

**Title of Project: Bereavement Care following sudden death**

Name of Researcher: Sharon Newton

**Please initial box**

- 1. I confirm that I have read and understand the information sheet dated..... for the above study and have had the opportunity to ask questions.
  
- 2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.
  
- 3. I agree to take part in the above study.

Name of Relative

Date

Signature

Researcher

Date

Signature

1 for relative; 1 for researcher;

### **Appendix 3 - Interview guide for semi-structured interviews**

N.B. biographical data will be obtained and verified prior to interview commencing.

1. What are your memories of the day ..... died?
2. Can you recall the events in the A&E department?
3. Who was it that cared or looked after for you? Was there a nurse involved?
4. What did the nurse do?
5. Is there one incident that stands out?
6. Did you receive any information before you left the department?
7. Did you get a booklet, leaflet or any written information from any member of staff?
8. What was the most/least helpful thing that happened?
9. How did you obtain the death certificate and register the death?
10. Did anyone offer to visit you at home or help from the hospital?
11. Was there anything you would like to have changed about your bereavement care?
12. If yes to no.11 what would you have liked to have changed?
13. Have you been contacted or visited by anyone, such as social worker or GP, since ----- (name of deceased) ----- death about the death?
14. Have you ever thought about getting in contact with someone for help?
15. Would you know who to contact?
16. Would a visit from a bereavement worker have helped at all?
17. Would you like to say anything at all about the experience?
18. Would you like to ask me about anything that happened or how you feel now?

These questions act as prompts aimed at promoting a more detailed discussion

#### Appendix 4 - Relative Cameos

Participant	Cameo
Alan	Alan is in his seventies and was married to his wife for 50 years. They live in a small house on a large council estate. Alan is retired and despite being in poor health he had looked after his wife for the past 17 years. His wife was disabled with severe rheumatoid arthritis and Alan was her main carer. They had two sons who were a very close family.
Betty	Betty and her husband were in their early 50s. They live in a large detached house in a quiet residential area and both were in full-time employment. They have two children, a son and a daughter. Their son lived away from home before his father's death and their daughter was still at home, but moved away from home 6 months after the death of their father to commence her university course. Betty and her husband had a loving and happy marriage for many years and both enjoyed a close relationship with their children. Betty and her husband were in very good health. Her husband had had previous minor heart problems and still went training regularly.
Eva	Eva and her husband had been married 39 years, Eva was devoted to her husband and they enjoyed a very happy marriage. They have three daughters who are all married and independent from the family home. Eva and her husband live on a council estate, and had lived in the same house all their married life. Eva's husband had several different jobs. Eva's husband had several major health problems which began in 1986. Despite these major problems he survived but was forced into taking early retirement on health grounds.
Delia	Delia had been married to her husband for 46 years. They had a very close relationship although, due to his mental health problems, there were difficulties. She had looked after him for several years when his health failed. They lived together in a large semi-detached house in a quiet suburb. All her family had left home and were married themselves. She and her husband were both retired.
Edward	Edward had been married to his wife for 43 years; they had three children, two sons and a daughter, and a total of nine grandchildren. Although the children lived away from the local area they visited each other regularly and were a close-knit family. Edward lost his wife, who had been relatively well, unexpectedly just after the Millennium.
Fran	Fran lost her mother suddenly and unexpectedly. Fran's mother had sold her house and moved in with them and had been living with them for six months. Her mother had been relatively well most of her life. Fran was married and had a son and daughter who both lived at home.
Grace	Grace was married to her husband for 39 years it would have been there 40 <sup>th</sup> wedding anniversary the next year. Her husband was 68 years old when he died. He was retired. Grace was also retired. They had one daughter who was married and one grandchild.

Helen	Helen lost her father through a sudden death, he was 87 years old. He collapsed suddenly and died in A&E. Her father was retired and lived in a residential home near to his family. Helen is employed and married and has two sons and a step-daughter.
Isobel	Isobel lost her father who was aged 48 when he died. Isobel was aged 25 when her father died. Her father was employed, as is Isobel. Her father lived with his girlfriend and youngest son, and Isobel lived five minutes away in her own flat.
Jane	Jane lost her husband. He had retired at the age of 65 due to ill health and had been unwell for five years. Despite this, Jane states he was a very active person and still managed independently at home. They had a daughter and a son and grandchildren. They had been married for forty years. Jane worked from home.
Kate	Kate lost her mother through sudden death. Her mother retired after working till the age of 62. The family originally immigrated to Australia in 1970, but returned to the UK in 1979 due the ill health of Kate's father. Kate's brother remained in Australia and she returned with her family to the UK. Kate was employed and lived alone.
Louise	Louise lost her brother through a road traffic accident. Louise had previously lost her mother and this left her and her father. They had no other relatives, just close friends. Her brother was employed and Louise also worked.
Maureen	Maureen lost her husband through sudden and unexpected death. He was 65 when he died and he was retired. Maureen has three children, a daughter and two sons. Maureen and her husband had been married for forty years but had known each other since being small children.
Nigel and his wife Nicola	Nigel lost his mother from a sudden and unexpected death. His mother was aged 82 when she died and had been a widow for 15 years. She had three sons and one daughter. Nigel was her main carer as the rest of the family lived away. Nigel was employed and lived at home with his wife and family.
Olwyn and her mother Olga	Olwyn lost her husband via a sudden and unexpected death. Her husband had retired. He had been in relatively good health. Olwyn was self employed. Olwyn and her husband had only been married 11 weeks prior to his death, but had been together for 6 years in total.

## **Appendix 5 – A worked example of the data analysis**

The following examples explain how the semi-structured interviews were analysed.

### **1. Conducted interviews**

The interviews were conducted in the participant's home and tape recorded.

Immediately after the interview, hand written notes were made about the interview.

This included information about how the interview had flowed, any initial impressions or comments about the participant's sudden death experience.

### **2. Listened to the interviews**

The interviews were listened to several times. This enabled the researcher to become familiar with what was being said by the participant and facilitated a clearer understanding of their sudden death experience. This included listening to the tone of the conversation, noting the emotions and non-verbal expressions and highlighted some particularly notable times for the relatives.

### **3. Transcribed the interviews using pseudonyms**

All the tape-recorded interviews were transcribed verbatim by the researcher. This ensured that all transcripts were true to their original sources. The transcription took place as soon as possible after each interview while it was still fresh in the researcher's mind. A copy of the transcript was sent to the relative for verification purposes, i.e. to check that the content of the interview was a true account of what had been discussed. Another copy of the transcript was kept for analysis. All transcripts and tapes were kept in a safe and secure place that was only accessible to the researcher, as specified in the Local Research Ethics Committee (LREC) application.

### **4. Line by line numbering of transcripts**

Each line of the transcript was numbered which helped in the analysis and coding so that each part of the transcript that was used could be traced back to its original location in the whole transcript. The following is an example of the line by line numbering in Betty's transcript.

**219 BETTY:** Its young it was unexpected it was sudden it was out of the blue for someone  
220 who was fit a flea as happy as Larry- life is crap as the Dr put it, life is cruel it was so  
221 totally, totally unexpected and shouldn't have happened. But I've been lucky particularly  
222 the first few weeks that....but people drift on but you know that....but I had people  
223 around me particularly the children but anyone who is left on their own and is not able  
224 to.....think that where do I go what do I where do I start which I didn't know I would find  
225 it devastating. Its absolutely devastating when you've got to go down to the DSSS and  
226 they.....that is dreadful because you're in a state of shock you have to go down you have  
227 to do something about it and there's no information no nothing and I got to the stage  
228 when I said to the lady I think I'll sit there and you sit here because they know absolutely  
229 nothing about bereavement. If you were going in there to make a claim you know the  
230 first thing she says to you is was your husband on benefit and you say no he was  
231 working and then she says to you which benefit did he receive and you know  
232 that.....you're in a state of shock, you don't know what to do and you've got to go down  
233 there and you've probably never been through the doors before and you go and stand  
234 out...you know at first she wanted me to sit out and talk to her in the open I said sorry  
235 but can you find me a room. Then you have to stand whilst they open the door and  
236 every time you go through the doors locked behind you and if you're not of an entirely  
237 strong nature that's mad and then you get in and then they can't help you .....you ask  
238 them questions and they can't help you. And trying to find help is very, very difficult,  
239 there's nothing as I say its totally unfair if I abuse myself if I was a drug addict or an  
240 alcoholic or anything like that then there's help there, its there available. For a  
241 bereavement which must happen, I'm not the only one, is not easy to get hold of. I  
242 eventually managed to get through to Cruse and emm...the waiting list for Cruse is  
243 anything between 10 weeks to 6 months. Now in 10 weeks to 6 months you could really  
244 be in a state now I'm on the list through the GP and emm I'm still waiting and there's  
245 only one and she does not just do that practice she'll do everybody.

At the right hand side of the page a large margin was created so that hand written notes could be made to emphasise some of the emerging issues.

#### 5. Read and re-read transcripts

Once each of the interviews was transcribed and line by line numbered the transcript was read and re-read and some initial categories emerged and further handwritten notes were made in the margins.

#### 6. Open coding

The open coding involved sections of the transcript being highlighted with a coloured highlighter pen to emphasise the emerging categories. The next section is an example is from Fran's interview.

74 FRAN: The young Dr that came was very...he was good very nice ....(pause)... but the  
75 Senior Dr I'm sorry I'm going to have to say this.. the Dr who actually came..... was...how  
76 can I say it.....(reluctant pause)  
77 INT SHARON: Just say what you feel...  
78 FRAN: It makes me angry now to think about it.. it makes me very angry and I'm  
79 sorry....he was unfeeling he was cold I didn't know what had happened to my Mum he  
80 came in he was obviously very, very senior to all the others and .....we at this point had no  
81 idea what had happened to my Mum we'd had a message that she was holding her own  
82 that was what we'd been told which.... which of course you're desperate to believe that's  
83 what's going to happen and I know...I'm not I'm not saying... I think some of the nursing  
84 staff didn't really know but this.. this gentleman I use the word loosely came in and was  
85 very, very, very off hand and at this point he said your Mothers still alive which of  
86 course.....(pause)...thank God you think she's still alive but she's burst her Aorta which to  
87 a non medical person I didn't know what that meant I had no idea that that was as  
88 serious as it actually was ..... and they all looked at me and I said well what am I supposed  
89 to do thinking that there was some sort of decision that had to be made and he more or  
90 less said there's no point hanging on to her she'll die.. she's dead she's more or less dead  
91 and I said to him is she still alive and he said she's still alive but she's almost ... to the  
92 effect that she's as good as dead and it was how... it was the most awful thing .... It was so  
93 it.. was so it.. was with such .... I know he's got a job to do and I know delivering bad news  
94 to people is.. must be awful but there wasn't one ounce of... it didn't help us at all I didn't  
95 really understand she'd actually died till he actually left the room... (pause crying)....

The highlighted colours represented different aspects raised in the interview as follows

**Blue** – Feelings and emotions e.g. anger

**Green** – Breaking the news of death

**Pink** – Receiving and understanding information

**Teal** - clarity of the message

**Gray** – Unhelpful comments

**Red** - Participant

**Yellow** – Researcher

This process took place with all of the transcripts prior to the secondary coding.

## 7. Secondary coding

Following the open coding, the highlighted sections of the transcripts were cut up and grouped together in envelopes to create categories. This involved gathering sections of the transcripts that seemed to fit together and that seemed to capture the

substance of a topic. This served as the basis for the different themes that emerged from the analysis.

#### 8. Higher order coding

The main sections of the transcripts were then grouped together to form the themes.

The themes and sub-themes were presented as a thematic map. The findings that emerged from the analysis were classified under three main themes: the experience of sudden death, the impact of sudden death and living with the trauma of sudden death. Verbatim quotes and excerpts from the transcripts were used to support the themes.

## **Appendix 6 - Invitation and information leaflet for nurses about the study**

Dear

We are continually trying to improve the quality of care offered to families who have suffered a sudden death. In order to do this we need feedback from those involved in caring for relatives who have been suddenly bereaved. I appreciate this is a very sensitive area, but it is an important area to know more about so that we can do it better. I am writing to you to invite you to take part in a research study concerning sudden and unexpected death.

A detailed information sheet is attached for you to read which gives an explanation of what the research involves. Please read this carefully before you decide whether to take part.

There is no obligation to take part. Should you decide that you wish to be interviewed and then change your mind this will not cause any inconvenience.

If you would like to participate please fill in the consent form and return it in the stamped addressed envelope and you will be contacted to arrange a date for the interview.

Please do not hesitate to contact me if you have any questions or concerns arising from this request.

Yours sincerely

Sharon Newton

**Title:** An exploration of sudden death in Accident and Emergency

**Invitation:**

My name is Sharon Newton and I am a Senior Nurse working in the Accident and Emergency Department at ----- Hospital (Phone number -----).

The following letter invites you to take part in a research study aiming to improve the services available to newly-bereaved families following sudden death. Before you decide whether to take part in the study it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Please do not hesitate to contact me if there is anything that is not clear, or if you would like more information, and please take time to decide whether or not you wish to take part.

**Purpose of study:**

The purpose of this study is to investigate the services provided for families who have had bereavement due to unexpected death. The aim of the study is to find out how improvements in the service can be provided to people who have experienced a sudden bereavement. Those who agree to participate will be involved in a short interview at their convenience. Approximately 10-15 nurses will be participating.

**Participation:**

The decision to become involved is yours, although you may wish to discuss the information in this letter with other colleagues or friends. If you decide to take part you will be given this information sheet to keep and be asked to sign a consent form. Having decided to take part, you are still free to withdraw at any time and without giving a reason. The following part of the letter may help you to answer some of the questions you have about the research.

**What happens if you take part?**

The study involves you participating in an interview in which a tape recorder will be used to record your answers. The interview will last about 40-60 minutes and can take place in your own home or at the hospital. During the interview you will be asked

to talk about your involvement in working as a nurse in A&E and about your experiences of sudden death and care of the relatives.

**Some things you may wish to consider about of taking part:**

As a result of taking part you may at some point in the interview feel sad or upset. Should this happen, the interviewer will stop asking questions until you feel more comfortable and able to continue. Should you feel at any time unable to continue the interview then the interview would be abandoned.

**About the interviewer:**

The interviewer is a qualified nurse with many years of experience of working in A&E and with bereaved people who have experienced sudden loss.

**Confidentiality:**

All information which is collected about you and your experiences during the course of the research will be kept strictly confidential. Any information about you which leaves the hospital will have your name removed so that you cannot be recognised from it.

**Results of the study:**

The results of the study will be used in the research project. A copy of this will be kept in the A&E department at ----- hospital. At a later stage the results may be published in a nursing journal. If you would like, a copy of the results these can be forwarded to you upon request.

**Review of the study:**

This study has been reviewed by ----- Local Research Ethics Committee who have agreed that it may go ahead and by a lecturer and Professor at the University of -----.

**Contact person for further information:**

Sharon Newton, A&E department ----- Hospital, -----, -----, telephone -----.

Thank you for taking the time to read this and for taking part.

**Consent form**

(19<sup>th</sup> January 2000 version no.1)

Patient Identification Number:

**Title of Project: Bereavement Care following sudden death**

Name of Researcher: Sharon Newton

**Please initial box**

- I confirm that I have read and understand the information sheet dated.....for the above study and have had the opportunity to ask questions.
- I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason
- I agree to take part in the above study.

Name of Nurse

Date

Signature

Researcher

Date

Signature

1 for nurse; 1 for researcher.

## **Appendix 7 - Prompts for narrative interviews with nursing staff**

### **Pre interview**

Ensure that the respondent is comfortable and relaxed. Ask general questions to make sure they are happy with the room, if they want a drink etc. When they are ready, begin the interview proper.

### **Preamble**

Thank you for taking part in my study and helping me. I want to collect stories from A&E nurses about their working lives. This will feel less like an interview and more like a conversation. I will try to listen, but I usually get engrossed and chat where I feel it appropriate. You can talk about whatever you like, let your story go where you want to take it. This is about you and your story; it is very informal and unstructured. What you say and talk about will be kept confidential, but may not be totally anonymous as the stories you talk about will be unique to you and may appear in the final work and consequently may be recognised by yourself or others that know you very well. However, as the researcher I will endeavour to keep the work as anonymous as possible.

It would be great to start with your story about you as a nurse.....?

Prompts Tell me how you came to work in A&E?

Tell me more about working in A&E?

Discuss all aspects of A&E work

Discuss their like/dislikes

Discuss positive aspects and frustrations

Tell me about a time that has been really exciting in A&E?

Staff will discuss their experiences of when things go well

Staff may reflect on incidents when the outcome was positive

Tell me about a time that has been challenging and difficult in A&E?

Staff will discuss when things are not going well

Staff may recount incidents which have been difficult to deal with or stressful

Staff may discuss when a patient dies in A&E (cue to talk about bereavement)

Tell me what it's like when someone dies in A&E?

Where is your story going – have you any plans.....?

Thank you for your story, I have enjoyed (appreciated/etc) listening to your story(s)

can I just check a few details for my project

Other data:

Qualifications

Dates

Grade

Special qualifications

Other areas of work in or out of the NHS

Age (Range)

A&E history

Date began in A&E

Breaks in service/reasons

Number of years in A&E

A&E qualifications e.g. ENB 199

Thanks very much for your help, as well as having helped me personally with my research programme I am hoping that the things that I learn from this study will be used to help develop what we know about A&E nursing.