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Title: End-of-Life Care in a Hospital Setting: An Ethnographic Study

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Thesis Abstract

The UK is renowned for excellence in end-of-life care. Yet research findings, concerns in the media and formal complaints to the NHS have highlighted problems with end-of-life care on hospital wards leading to calls for better and more compassionate care. This thesis critically analyses the practice of end-of-life care on hospital wards. Data are presented from an ethnographic study.

Data collection comprised non-participant observation of 280 hours on two acute hospital wards and 36 semi-structured interviews with sixteen staff members, eleven relatives and nine patients thought to be deteriorating and approaching the end-of-life. Data were analysed using a constructivist grounded theory approach drawing on symbolic interactionism. The data are presented through three overarching themes: Care, Decision-Making and Language and Meaning.

This thesis provides an in-depth account of the practice of end-of-life care on hospital wards from the perspectives of patients, relatives and healthcare professionals. The concept of 'care' is constituted by many different components: physical and metaphysical, objective and subjective. Relationships are the medium by which care is delivered and are a key component of care itself. What it means to care well when making decisions and communicating at end-of-life is unpacked, revealing the importance of ongoing dialogue to enable a shared understanding between patients, relatives and healthcare professionals.

This thesis encompasses both practical and philosophical approaches to provide a unique perspective on end-of-life care. It highlights current challenges in the provision of end-of-life care on hospital wards and considers how these can be better understood to deliver optimal care. If end-of-life care in hospitals is to be improved, strategies must consider the views of all those directly involved, the current reality of end-of-life care provision, as well as the different components of care and the varied levels at which they operate.

For Mum and Dad

Acknowledgements

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Chapter 1 Thesis Introduction and Outline

1.1 Introduction

How patients are cared for on hospital wards as they approach the end-of-life is a current topic of debate and discussion in the UK. Internationally the UK is renowned for its provision of excellent end-of-life care (The Economist Intelligence Unit, 2015). In recent years however, accounts from relatives, articles in the national media and independent reviews of hospital care have highlighted concerns about the provision of end-of-life care on hospital wards (Devlin, 2009 ; Office for National Statistics, 2014; PHSO, 2015; Royal College of Physicians, 2016). The discovery of conditions of 'appalling suffering' at the Mid Staffordshire NHS Foundation Trust by the Francis Inquiry further highlighted failings in hospital care (Francis, 2013). Concern in the national press about the Liverpool Care Pathway (LCP) grew to such an extent that in 2013 it prompted an independent review of the document which led to subsequent withdrawal and new guidance on the practice of end-of-life care. Furthermore, concerns about decision-making relevant to end-of-life care have led to two Court of Appeal cases resulting in new legal precedents related to resuscitation decisions. However, much of the commentary about end-of-life care has come from stories and anecdotes in the press and national reports. Systematic research investigating the experiences of people directly involved in end-of-life care and how such practice occurs on a daily basis in light of the recent changes in policy remains unexplored. This thesis addresses this gap in the literature by investigating the reality of end-of-life care on hospital wards from the perspectives of patients thought to be approaching end-of-life, their relatives and the staff involved in caring for them.   It unpacks the concept of 'care' through three themes: Care, Decision-Making and Language and Meaning. Here I state the aims and objectives of this research before presenting an outline of this thesis.

1.2   Thesis Aims and Objectives

Aims:

• To explore end-of-life care in a hospital setting.

Objectives:

• To observe and describe how end-of-life care and decision-making happen in practice.

• To explore the perspectives of patients approaching end-of-life, and the family members and/or close friends of patients approaching end-of-life in order to uncover their underlying values[1].

• To explore the perspectives of healthcare professionals providing end-of-life care in order to uncover their underlying values.

• To identify areas of ethical difficulty within end-of-life care practice.

1.3   Thesis Overview

This chapter is followed by two background chapters. Their purpose is to set the scene for this research by describing the history of end-of-life care in the UK and relevant current developments in policy and practice.

Chapter Two provides the historical context of end-of-life care and demonstrates how the care of dying patients on hospital wards has changed over time. Chapter Three describes recent high profile events in the UK related to the care of dying patients on hospital wards. These include the Francis Inquiry, the independent review of the LCP, new recommendations for practice following the withdrawal of the LCP, and two prominent legal cases relating to the practice of making do-not-attempt-

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[1] It is important to define what is meant by the term 'values'. The Oxford Dictionary of Philosophy defines 'value' as: '*To acknowledge some feature of things as a value is to take it into account in decision making, or in other words to be inclined to advance it as a consideration in influencing choice and guiding oneself and others*' (Blackburn, 2008). Values have also been described as 'deeply-held views' about the world which can function as principles (George *et al.*, 2015). Throughout this thesis, the term 'value' refers to views which are deeply-held and influence the ways in which individuals and organisations act and make decisions.

cardiopulmonary resuscitation (DNACPR) decisions. Relevant policy concerned with decision-making and care at end-of-life is also discussed.

Chapter Four provides a critical review of the literature and discusses what the literature has revealed about the practice of end-of-life care on acute general hospital wards from the perspectives of patients, relatives and staff. It focuses on the concepts of care, decision-making and communication with relation to philosophy and ethics and investigates how these concepts have been previously described, conceptualised and understood in practice.

Following the literature review, Chapter Five sets out the research methodology and methods. It outlines the theoretical perspectives underpinning this research study, examines the inherent assumptions of this approach and considers the quality and value of this type of research work. It describes the research setting in detail and explains how the study was conducted and the methods employed in data analysis.

Chapters Six, Seven and Eight are the three results chapters, which set out the main findings of this research according to three key themes: Care; Decision-Making; Language and Meaning. Chapter Six explores the concept of care as experienced by patients, relatives and staff members. The aim of this chapter is to consider what it means to care well for these patients and their relatives on hospital wards. Chapter Seven explores the practice of decision-making. It considers how information is provided to patients and relatives and how decisions are made when patients are approaching the end-of-life on hospital wards. The aim of Chapter Seven is to better understand what it means to 'care well' when making decisions at the end-of-life and where the challenges in practice lie. Chapter Eight explores end-of-life communication through analysis of the concepts 'language' and 'meaning'. It examines the use of language and how it is interpreted to form meaning through the analysis of examples of interactions between patients and staff, relatives and staff, and between staff members. The aim of Chapter Eight is to consider what it means to 'care well' when communicating (through the use of language and the formation of meaning) at the end-of-life.

In Chapter Nine, the concept of 'care' is further unpacked through discussion of the main findings of this research in light of the wider literature. The discussion of the data builds on the literature by applying both practical and philosophical approaches to the data. In

Chapter Ten recommendations for practice, policy and future research are presented. Chapter Eleven summarises and presents final conclusions for this thesis.

Chapter 2   The History of End-of-Life Care in UK Hospitals

A specific focus on end-of-life care within hospitals has been a relatively recent development in the UK. It was not until the 1960s that end-of-life care began to be prioritised within medicine (Clark and Seymour, 1999; Ten Have, 2002; Lewis, 2007). This chapter outlines the historical, social and cultural contexts of modern-day end-of-life care in UK hospitals in order to better understand current practice.

2.1   The History of End-of-Life Care in UK Hospitals

The history of hospitals can be traced back to Greco-Roman times when Christian hospitals founded on the values of charity and philanthropy were established to offer charitable aid and healthcare to those in need (Ferngren, 2009; Risse and Balboni, 2012).   In medieval England the term 'hospital' referred to many different types of institutions: leper houses, poorhouses, hospices for poor travellers, and centres for the sick poor (Lewis, 2007). Within institutions caring for the sick poor care was provided by lay people rather than trained physicians or surgeons (Lewis, 2007). During the English Reformation in the 1500s all church property in England including the hospitals was seized by the crown. However, certain hospital buildings were later given to the City of London and funded by local parishes, and later by taxes, to provide a form of welfare for the poor (Clark and Seymour, 1999; Lewis, 2007). In the seventeenth and eighteenth centuries the population expanded and new hospitals were built. The first public hospital, the Westminster Hospital, was established in 1720 by a Christian charitable society (Lewis, 2007). Increasing numbers of public hospitals were built to treat the sick though they excluded certain types of patients such as people with mental illness, TB, small pox and the dying (Clark and Seymour, 1999). By the late nineteenth century specialist surgical treatment for cancer was advancing and cancer hospitals were established across England. The Brompton Hospital was established in 1841 and the Royal Marsden Hospital in 1851 (Clark and Seymour, 1999; Lewis, 2007). Due to the lack of space within cancer hospitals plans were made to build special homes for the dying. In the 1850s and 1860s both the *British Medical Journal* and the *Lancet*

highlighted the needs of terminally ill patients and the lack of provision for the care of the dying (Lewis, 2007). However, the dominant focus of medical research on finding a cure for cancer meant that the funds were never made available for special homes for the dying and the provision of end-of-life care (Clark and Seymour, 1999; Lewis, 2007).

In Britain in the late nineteenth and early twentieth centuries the advance of scientific medicine was accompanied by a decline in the role of organised religion in the social processes of dying and death (Lewis, 2007). It was at this time that Christians from different denominational backgrounds were active in setting up homes for the care of the dying. These homes included St Joseph's Hospice, opened in 1905 in Hackney, East London (Clark and Seymour, 1999). While such hospices and hospitals provided physical healthcare they also recognised and prioritised spiritual care for the soul (Clark and Seymour, 1999; Lewis, 2007).

At this time medical theory was moving away from a holistic conception of illness to one of localised pathology within the physical body, and hospitals became increasingly important as centres for medical education and research (Lewis, 2007; Bishop, 2011). The scientific revolution of the seventeenth century had a profound impact on the practice of medicine, whereby the materialistic idea that all nature is composed of matter and under the control of universal laws of mechanics, meant that nature could be seen as a machine. It followed that human bodies could also be seen as machines (Lewis, 2007; Bishop, 2011). Bishop argues: '*Mechanical thinking has been elevated to the arbiter of all knowing. People who are dying look like broken machines; if we replace the broken or dead bits with other machines, then human life – now defined as human function – will have been restored*' (Bishop, 2011, p. 108). As a result, the relationship between the patient and physician changed and rather than relying on conversation with the patient alongside physical examination, contact with the patient became less direct as a result of new technology and medical expertise. The patient's views came to be perceived as unreliable. For knowledge to be of value it had to be standardised and reproducible; scientific observation and the treatment of disease were given priority over the care of a patient as a human being (Lock, 1995; Lewis, 2007).

Despite far-reaching advances in medical diagnosis and treatment, there has been ongoing and powerful critique of the reductionism and dualism within modern medicine

(Illich, 1995; Lock, 1995; Illich, 2003; Lewis, 2007; Bishop, 2011). Reductionism is an understanding of nature which views things (including human beings) as simply the sum of their different parts and the interaction between component parts. Dualism is the idea that the mental and the physical or mind and body are separate and different things. These approaches have been blamed for modern medicine's focus on cure and lack of care and compassion for the dying and those with incurable conditions in need of palliation. Widespread societal changes were also occurring during the eighteenth and nineteenth centuries: Enlightenment ideas led to new challenges to traditional social hierarchy, and the rights of the individual and the value of ordinary rational people were acclaimed (Gracia, 2002; Lewis, 2007). Institutions such as poorhouses and asylums were built to manage problems traditionally seen as the responsibility of communities and local church parishes (Lewis, 2007). Long-held Christian beliefs about life and death were being superseded in society by scientific and naturalistic worldviews (Lewis, 2007). As the population aged and chronic diseases increased, old age came to be viewed increasingly negatively within a modern society which valued productivity, efficiency and independence (Gracia, 2002). '*Modern liberal capitalist society's faith in material progress has, as Christianity's hold on our hearts and minds receded, turned health into a form of secular salvation and the physical (and mental) decline that aging brings about into something culturally unacceptable*' (Lewis, 2007, p. 70).

2.1.1 Hospitals within the NHS

In the post-World War II period many advances were being made in the treatment of cancer however doctors had few treatments to offer patients diagnosed with advanced cancers (Seymour *et al.*, 2005a). In these situations it was often suggested that there was nothing more to be done (Clark, 2014). Seymour et al. (2005) document the history of cancer pain management during this period and explain that many doctors were reluctant to use opioid analgesia to treat pain because of the risk of causing side effects such as hallucinations. Medicine had traditionally taught that pain reveals illness and to suppress pain was regarded as a dangerous thing to do (Gracia, 2002). Furthermore some feared accidentally hastening the death of the patient and it was also practically difficult to administer regular medication to dying patients at home (Seymour *et al.*, 2005a). Consequently cancer patients suffered unrelieved pain for weeks and months before death (Seymour *et al.*, 2005a).

In 1948 when the NHS was formed, the goals of healthcare provision remained the treatment of acute illness and the rehabilitation of armed forces personnel (Clark and Seymour, 1999). Hospitals were viewed as central to the provision of healthcare. Early on in the NHS a culture of research was promoted and developed (Lewis, 2007). At this time the demographics of the UK were changing. Due to the development of medical treatments the mortality from infectious diseases was reduced and the fall in death rates along with a rising birth rate led to an expanding and ageing population. By 1951 more than 10% of the population was over 65 years compared to less than 5% in 1901 (Clark and Seymour, 1999). As people lived longer the prevalence of chronic diseases such as cancer and heart disease increased. Disease and death were increasingly viewed as medical problems and the number of deaths occurring in hospital increased. While in 1900 most people died in their own homes (Department of Health, 2008a), by 1956 forty percent of deaths occurred in hospital (Clark and Seymour, 1999).

In 1957-8 a former UK army doctor carried out a survey of terminal care for 'persons with a restricted expectation of life' (Glyn Hughes, 1960, p. 9). The survey included every medical officer in the councils around Britain, senior administrators responsible for hospital services, voluntary and religious organisations, social services, nursing bodies and over six hundred family doctors (Glyn Hughes, 1960). While Hughes believed that every patient should have the opportunity to die in their own home he recognised that many, due to the nature of their illness, would require hospital care. He was critical of the lack of trained nurses in many nursing homes and homes for the dying. Hughes advocated for beds for the dying within acute hospitals and for better relationships between hospitals and homes for the dying (Glyn Hughes, 1960; Lewis, 2007).

2.2   Technology versus Care

Interest was growing in the subject of end-of-life care and in 1957 the British Medical Association devoted a plenary session of their conference to the subject of care of the dying (Lewis, 2007). Articles focusing on care of the dying and the need for better services to support their care were being published in medical journals (Leak, 1948; Grant, 1957; Hinton, 1964; Wilkes, 1965). Concern about the need to improve care of

dying patients was present in the UK and in the U.S.A. And while the focus in the UK tended to be on the lack of services and 'neglect' of patients, in the United States there was an increasingly negative reaction to the use of futile medical treatments for dying patients (Clark, 2002).

From the end of World War II fears about the 'dehumanization' of medicine led to widespread concerns about the adequacy of professional morality in medical practice (Ten Have, 1994; Pellegrino, 1999). Illich wrote scathingly about the impact of the 'medicalisation' of death and dying on society (Illich, 1995; Illich, 2003). Researchers began to investigate the social meaning of death and dying: in 1965 Glaser and Strauss challenged medically accepted views about truth-telling for patients with terminal prognoses in their study 'Awareness of Dying' (Glaser and Strauss, 2005); Sudnow described the behaviour of healthcare professionals as they treated dying patients in hospital (Sudnow, 1967); Kübler-Ross categorised different emotional reactions to the experience of dying (Kübler-Ross, 1989). In an attempt to balance the rise of science and technology that was beginning to dominate medical education new courses in social sciences and the humanities were added to medical school curricula in the U.S.A. throughout the 1960s. Their aim was to develop '*scientifically competent yet humanistically responsive physicians'* (Fox, 1999; Pellegrino, 1999, p. 75). Academic institutes such as the Hastings Centre and the Kennedy Institute were established for the purpose of encouraging greater discussion of issues in bioethics, the medical humanities and the philosophy of medicine (Lewis, 2007). In 1971 Engle published his biopsychosocial model of disease and argued that illness resulted from inter-related environmental, social, psychological and biological variables and not simply the physical (Engel, 1977). He sought to broaden the traditional reductionistic view of medicine in which biological factors were given priority and to develop a scientific and rational approach to patient behaviour and psychology such that patient's verbal accounts could be given appropriate consideration (Lock, 1995). However, his theory has been criticised for not going far enough and for failing to recognise and challenge the implicit values within medicine (Lock, 1995). In the UK, Archibald Cochrane argued that the NHS resources were being allocated disproportionately with an over-emphasis on cure rather than care (Lewis, 2007). Thomas Mckeown contended that NHS provision had become 'lopsided' prioritising specialist services in hospitals at the expense of other key

health issues such as elderly care and mental illness (Lewis, 2007, p. 61). Both Cochrane and McKeown '*wanted greater policy emphasis on what they saw as a neglected medical tradition, the physician's caring function*' (Lewis, 2007, p. 61). There were calls for physicians to rediscover the 'lost art of caring' (Callahan, 2001).

Technological advances in medicine led to new complex moral issues for not only physicians but patients and society as a whole (Ten Have, 1994). The scope of traditional medical ethics grew, expanding to include healthcare ethics, and gradually became incorporated under the new title 'bioethics' (Ten Have, 1994). In the late 1970s Beauchamp and Childress published 'The Principles of Biomedical Ethics' and outlined their principle-based approach to medical ethics (Beauchamp and Childress, 2001). It provided an ordered and clear framework for managing moral dilemmas in medicine and healthcare and was embraced widely by physicians (Pellegrino, 1999). Many proponents of bioethics had become critical of traditional modes of moral reasoning, such as consequentialist utilitarianism and Kantian deontology, and instead favoured newer models of moral reasoning such as the principlism championed by Beauchamp and Childress, narrative ethics and a modern approach to casuistry (Arras, 1991; Arras, 2013).

In the 1970s and 1980s, in contrast to a principle-based morality, another alternative approach to ethics was emerging which came to be known as the 'ethics of care'. This approach grew out of feminist ethics as well as theology and moral philosophy. The proponents of an ethics of care were deeply critical of the modern focus on individualism and instead emphasised the inherent inter-connectedness and dependency of all human beings (van Heijst, 2011). The ethics of care focuses on responsibility and relationships rather than rights and rules, it perceives ethics in concrete circumstances of life rather than in the abstract, and it is expressed as an activity rather than a set of principles (Tronto, 1993; Klaver *et al.*, 2013).

By the 1990s sociologists began to study the new discipline of bioethics and to focus specifically on moral problems in medicine (De Vries, 2010). Chambliss conducted an ethnography in various hospital settings in the United States (Chambliss, 1996). His analysis challenged the nature of what is deemed an ethical problem and how ethical problems are defined within healthcare (Chambliss, 1996). In an ethnography of

hospital life Kaufman highlighted that the implicit values inherent within hospitals work to shape and determine death and dying (Kaufman, 2006). It was during the mid to late twentieth century when interest in the care of the dying was growing, and new perspectives on ethical approaches to medicine and healthcare were being advanced, that a new approach to end-of-life care was first developed in the UK.

2.3 The Hospice Movement and Palliative Care in the UK

Cicely Saunders is often regarded as the founder of palliative care in the UK. In 1967 she founded St Christopher's Hospice, the first modern hospice for dying patients in London (Clark, 1999b). Saunders had a multi-disciplinary background having trained in nursing and social work before becoming a doctor. During her medical training and career as a doctor she worked with dying patients at St Joseph's Hospice in East London and conducted systematic research into patients' needs and response to treatment (Clark and Seymour, 1999; Saunders, 2000). She also published extensively on topics such as the potential for special homes for the dying, nursing care for dying, the terminal stages of disease and the need for good physical, psychological and spiritual care (Clark, 1998; Clark, 1999a).

Saunders' approach to the care of dying patients was radically different to that which she had encountered in the NHS in the 1950s and 1960s. She argued that patients with pain due to advanced cancer could receive good pain relief through the competent prescription of regular strong pain killers (Saunders and Baines, 1983). She also maintained that pain at the end-of-life was more than the result of physical disease and was linked to the emotional, social and spiritual dimensions of the patient (Saunders and Baines, 1983; Saunders, 2000). This idea became known as the concept of 'total pain' (Clark, 1998). Her approach emphasised the importance of listening to the patient's story and trying to understand their experience (Clark, 2014). Saunders described her own philosophy of end-of-life care as being '*concerned with the nature of man, with living and dying, and with the whole man – body, mind and spirit – part of some family unit, with physical, practical needs for us to tackle with maximum competence*' (Saunders, 1978, p. 193). The essential elements to her approach included care for the

patient and their family, expert symptom control, a holistic approach and skilled care provided by a multi-disciplinary team (Saunders, 1978).

Saunders used the name 'terminal care' and 'hospice care' to describe her work. Her ideas spread across the Atlantic and around the world. And in 1975 the term 'palliative care' was first used when a specialist unit for end-of-life care was opened in the Royal Victoria Hospital, Montreal (Gracia, 2002). This new terminology for an end-of-life care service in a hospital marked a change in thinking - hospice care did not have to be limited to a hospice building - and it led the way for the development of palliative care work in a variety of care settings (Gracia, 2002).

From the 1960s onward, there was rapid growth and expansion of palliative care services in the UK and palliative care gradually spread into community care settings and hospitals (Clark and Seymour, 1999). The first UK specialist palliative care hospital team began work 1976 at St Thomas's Hospital. It was a multi-disciplinary team that included doctors, nurses, a social worker, chaplain and a secretary (Clark and Seymour, 1999). In 1987 Cicely Saunders' approach to dying patients was formally recognised as a medical specialty by the Royal College of Physicians termed Palliative Medicine (Gracia, 2002). Today there are over 250 hospitals in the UK with specialist palliative care teams or specialist palliative care nurses (Higginson, 1997). Historically palliative care developed in response to the needs of patients dying from cancer. However, there has been growing evidence and awareness that palliative care should be available to all patients approaching end-of-life and not simply to cancer patients (Higginson, 1997). Studies have shown that between 23-35% of hospital inpatient populations have palliative care needs (Gott *et al.*, 2001; To *et al.*, 2011). Over time the scope of palliative care has widened to include patients with life-limiting non-cancer diagnoses such as end-stage organ failure, neurodegenerative conditions and advanced dementia (NCPC, 2012).

2.3.1 End-Life Care Terminology

Due to the gradual development of end-of-life care over time and spread to different settings and countries, the terms referring to such care are many and varied. This has meant that the terminology used at end-of-life is often unclear. Terms such as hospice care, supportive care, end-of-life care, terminal care, specialist palliative care and

generalist palliative care have all been used yet are often poorly defined (NCPC, 2012). Terminal care refers to the care of patients with incurable conditions which are no longer amenable to curative treatment; death is certain and will usually occur within days to months (Higginson, 1997). Hospice care can refer to both a philosophy and a physical location of care. It was the philosophy outlined by Cicely Saunders when she established St Christopher's hospice and is in effect the same as palliative care today. The term palliative care has been defined by many organisations but the definition from the World Health Organisation (WHO) remains widely quoted and used (See Figure 1).

Figure 1: WHO Definition of Palliative Care

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

• Provides relief from pain and other distressing symptoms;

• Affirms life and regards dying as a normal process;

• Intends neither to hasten or postpone death;

• Integrates the psychological and spiritual aspects of patient care;

• Offers a support system to help patients live as actively as possible until death;

• Offers a support system to help the family cope during the patients illness and in their own bereavement;

• Uses a team approach to address the needs of patients and their families, including bereavement counselling if indicated;

• Will enhance quality of life and may also positively influence the course of illness;

• Is applicable early in the course of illness in conjunction with other therapies that are intended to prolong life such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

(World Health Organization http://www.who.int/cancer/palliative/definition/en/, 2015)

General palliative care is the care provided to patients by healthcare professionals as part of routine clinical care from the time of their diagnosis until death, whereas specialist palliative care refers to the care provided by healthcare professionals who

specialise in the principles and approach of palliative care (Higginson, 1997). The National Council for Palliative Care (NCPC) defines end-of-life care as: '*Care which helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support'* (NCPC, 2012, p. 27). Today, the terms 'palliative care' and 'end-of-life care' are often used interchangeably though some propose the latter is used to refer more specifically to care in the last days of a terminal condition (The Economist Intelligence Unit, 2015). In contrast, the General Medical Council (GMC) defines patients who are approaching the end-of-life as those who are likely to die in the next twelve months (GMC, 2010). For the purpose of this thesis I have chosen to use the description of end-of-life care defined by the British Medical Association (BMA) (See Figure 2). I will therefore use the term 'end-of-life' to refer to patients thought to be likely to die in the next twelve months as well as those thought to be more imminently dying.

Figure 2: BMA Definition of End-of-Life Care

End-of-Life care: refers to the total care of a person with an advanced incurable illness and does not just equate with dying. The end-of-life care phase may last for days, weeks, months or even longer. It is defined as care that helps those with advanced progressive, incurable illness to live as well as possible until they die. It includes the prevention and relief of suffering through the assessment and treatment of pain and other problems, whether physical, psychological or spiritual.

(Campbell *et al.*, 2016)

2.4   The Development of End-of-Life Care Policy

Though health authorities in England were required to ensure palliative care provision for all patients from 1987, services have often been found to be variable (Higginson, 1997; Seymour *et al.*, 2002). In a review of local authority Health Improvement Plans in England, Seymour et al. found that progress in ensuring adequate palliative care

provision was often minimal. Furthermore, where palliative care services were available they were often focused on the needs of cancer patients. Instead, palliative care for non-cancer patients approaching end-of-life was viewed as an 'optional extra' (Seymour *et al.*, 2002).

In 2008, just after the 60th birthday of the NHS, the UK government published their End of Life Care Strategy and pledged their commitment to improving end-of-life care (Department of Health, 2008a). The then Secretary of State for Health described it as '*the first comprehensive framework aimed at promoting high quality care across the country for all adults approaching the end of life'* (Department of Health, 2008a, p. 7). The report set out key areas for improvement with related planned actions and recommendations for ensuring high quality care at the end-of-life. They include: raising the profile of end-of-life care and changing societal attitudes to death and dying, training of health and social care staff in the provision of end-of-life care, coordination and integration of care across health and social care sectors, emphasis on the importance of involving family and friends in end-of-life decision making, and the use of tools to improve end-of-life care such as the Liverpool Care Pathway (LCP) (Department of Health, 2008a). The initial strategy was followed by annual reports to gauge the progress being made.

The Strategy led to the establishment of the Dying Matters Coalition, an organisation which works to change societal attitudes to death and dying, to the National End of Life Care Intelligence Network which provides analysis of routine data to improve the quality of end of life care, and to the first national survey of end of life care from the perspective of bereaved relatives (VOICES) (Department of Health, 2015). In doing so the End of Life Care Strategy set the scene for the provision of high quality end-of-life care in all settings throughout England.

Since the 2008 Strategy was released most NHS Trusts throughout England have developed local strategies for implementation (Campbell *et al.*, 2016). In 2015 it was shown that spending on end-of-life care by Clinical Commissioning Groups (CCGs) in England ranged from between £15 and £10,504 per patient with palliative care needs (Campbell *et al.*, 2016). While 78% of CCGs were found to commission 24/7 specialist palliative care advice services, only 29% of CCGs knew how many people in their region

had palliative care needs (Campbell *et al.*, 2016). Differences in NHS provision of end-of-life care services compared to voluntary sector provision also add to the variation seen across the country. While national recommendations for end-of-life care exist there is no national service specification or funding mechanism. Such recommendations are sufficiently vague that interpretation and implementation may vary widely. Therefore, end-of-life care continues to be an area of concern and debate in social and political life in the UK. However, since 2008 several key documents have been published which demonstrate the progress made in improving end-of-life care. These include the NICE Quality Standard for End of Life Care (National Institute for Health and Care Excellence, 2011), the Independent Review of Palliative Care Funding (Hughes-Hallett *et al.*, 2011), *One Chance to Get it Right,* the system-wide response to the independent review of the LCP (LACDP, 2014b)(this will be discussed in greater detail in Chapter Three), and the *Review of Choice in End of Life Care* (The Choice in End of Life Care Programme Board, 2015). In 2015 the *Ambitions for Palliative and End of Life Care* was published (National Palliative and End of Life Care Partnership, 2015). Developed by a partnership of national statutory and voluntary organisations, the report sets out a vision to improve end-of-life care which aims to make palliative and end-of-life care a priority at a local level across England. It sets out six 'ambitions' or key principles for how end-of-life care should be delivered. The ambitions include: 1. each person is seen as an individual, 2. each person gets fair access to care, 3. Maximising comfort and wellbeing, 4. Care is coordinated, 5. All staff are prepared to care, 6. Each community is prepared to help (National Palliative and End of Life Care Partnership, 2015). For each of these ambitions the report sets out what is already known about the current situation and identifies the action needed in order to achieve the ambition.

In 2016 the government published their official response to the 2015 *Review of Choice in End of Life Care*, in the following report: 'Our Commitment to you for end of life care: the Government Response to the Review of Choice in End of Life Care' (Department of Health, 2016). Their response outlines the actions taken by the government, which are led by organisations across the healthcare system, to realise the ambition for all people to have high quality and person-centred care at end-of-life. The report summarises seven actions that will be taken by the government which include: developing more personalised care, improving the quality of care across different settings, encouraging

innovation in the delivery of high quality care, providing national leadership and support for local healthcare leaders, ensuring that healthcare professionals receive training to be able to provide high quality end of life care, promising to increase partnership working and accountability and transparency to ensure that needed improvements are made (Department of Health, 2016). These recent governmental strategies and national ambitions provide the political background and context within which this research study took place.

2.5   Conclusion

In this chapter I have outlined the history of end-of-life care in the UK. I have documented developments in hospital medicine alongside the social and cultural changes of the times in order to highlight the extent to which end-of-life care is situated in social, cultural, demographic, economic and political contexts (Lewis, 2007). By highlighting the many and varied past influences on the development of care of the dying I have set the scene for the practice of end-of-life care today. In the next chapter I consider recent events which have influenced the provision of current end-of-life care in UK hospitals.

Chapter 3   End-of-Life Care Policy

In this chapter I outline recent and significant events in the UK which have influenced end-of-life care policy and the practice of end-of-life care within hospitals. These events include: the Francis Inquiry and Report, the Liverpool Care Pathway (LCP) and two prominent legal cases relating to decision-making about resuscitation. I then discuss relevant policy concerned with decision-making and care at the end-of-life.

3.1   The Francis Report

Between 2005 and 2008 conditions of 'appalling suffering' were found to have occurred for patients treated in the Mid Staffordshire NHS Foundation Trust (Francis, 2013). Following this discovery, Robert Francis QC was commissioned by the then Secretary of State for Health to chair an inquiry into the events which had occurred in Mid Staffordshire. The purpose of the Inquiry was: to provide an opportunity for those affected to share their experiences, to investigate how such 'appalling suffering' had been able to flourish for so long, and to provide recommendations for future healthcare practice. In 2013 the Report of the Mid Staffordshire NHS Trust Public Inquiry (which became known as the Francis Report) was published. The inquiry highlighted an organisational culture that tolerated poor standards of care and a disengagement by those with management and leadership responsibilities (Francis, 2013).

In response to the findings the Francis Report listed 290 recommendations which relate to many aspects of healthcare (Francis, 2013). Several of the recommendations relate to all NHS staff. For example Francis highlights that all NHS staff members must abide by the core principles and values that guide the NHS. However, though all NHS staff are referred to in many of the recommendations, there is also a section of recommendations (no. 185-213) focusing on nursing. In this section Francis highlights the need for increased training for nurses on compassionate care and suggests aptitude tests for caring when recruiting new nurses. There is a section of recommendations on medical training and education (no. 152-172) but none of these recommendations are about compassionate care. The nursing-specific recommendations appear to suggest certain perspectives on 'care' and what is required to ensure it is provided to a high standard on

hospital wards. This raises some key issues. First, the recommendations imply that it is simply nurses (as opposed to all healthcare professionals) who need more training in 'caring'. Second, the idea of introducing aptitude tests for caring suggests that care has an essence, an intrinsic quality, which can be tested for. Third, these recommendations suggest that compassionate care is not distributed. That is, it is not distributed between healthcare professionals (as described in my first point), but also that it is not distributed between organisational levels (individual, ward, hospital, Trust, regional and national levels). Fourth, they do not take into account the ways that care must vary and adapt depending on the situation in question. For example, care may involve doing something (an intervention, for example) to a patient, but it may also involve the way that staff care when they spend time with a patient. Following its publication the Francis report has stimulated debate and discussion about the need for high quality care in hospitals and how this can be ensured (Lobl, 2013; Paley, 2014). It has also prompted action in the form of strategic plans from NHS organisations and government relating to how they will act to ensure good care (Department of Health, 2013b; The Royal College of Physicians, 2013; NICE, 2015b). The Francis Report has had widespread influence throughout the NHS and continues to be a point of reference for policy planning and service implementation (Keogh, 2013; National Advisory Group on the Safety of Patients in England, 2013; Cummings, 2014).

3.2   Calls for Compassionate Care

In 2012, following the discovery of the failures in care at the Mid-Staffordshire NHS Foundation Trust, the report 'Compassion in Practice' was launched by the Chief Nursing Officer for England (Department of Health, 2012). It described the vision and strategy for nursing, midwifery and care staff. The report called for person-centred care and highlighted six fundamental values known as the 6Cs: care, compassion, competence, communication, courage and commitment. In 2013 the importance of compassionate care was further emphasised on social media through the work of doctor, campaigner, and cancer patient Dr Kate Granger. Following her experiences as a patient receiving care in hospital she was struck by the importance of common courtesy and human connection during interactions between patients and healthcare professionals. She launched the '#hello my name is' campaign, encouraging healthcare professionals to

introduce themselves to patients. She won the support of thousands of healthcare professionals, politicians, celebrities and raised thousands of pounds for cancer care charities before her death in 2016 (BBC News, 2016). The need for compassionate and person-centred care continues to be the topic of discussion and debate in the literature and media in the UK (Hordern, 2013; Borgstrom and Walter, 2015; Hardy, 2015). While the Francis Report, Compassion in Practice and Kate Granger's campaign referred to the importance of high quality healthcare in general, I will now consider a recent area of healthcare policy which was specifically related to end-of-life care, the Liverpool Care Pathway (LCP).

3.3   The Liverpool Care Pathway (LCP)

The LCP was developed in the 1990s with the aim of transferring the hospice model of excellent end-of-life care to all care settings (Ellershaw, 2003). It provided guidance for staff caring for dying patients about the aspects of care considered to be important for end-of-life care, such as symptom control, spiritual care needs, and the importance of informing and involving those close to the patient. It was used widely in UK hospital wards, nursing homes, hospices, and in peoples' own homes, and was recommended as a best practice model for care of dying patients by the National Institute for Clinical Excellence (NICE)[2], the 2008 End of Life care Strategy, and by the European Association for Palliative Care (NICE, 2004; Department of Health, 2008a; EAPC, 2010). The LCP underwent regular updates and additions over the course of a decade and new versions were published in line with then current recommendations. However, it is not clear whether or not new versions were updated locally. Furthermore, the LCP was criticised due to concerns over lack of proper evaluation or evidence for its benefit (Shah *et al.*, 2005; Shipman *et al.*, 2008; Phillips *et al.*, 2011). Ethical concerns were raised that it was being used to shorten the lives of dying patients and that it failed to address concerns around the withdrawal of artificial hydration or the use of sedative medications (Craig, 2008; Devlin, 2009). These concerns as well as reports of poor practice led to several articles in the national press during 2012 (Bingham, 2012;

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[2] NICE has been re-named and now stands for National Institute for Health and Care Excellence

Doughty, 2012; Hickman, 2012; Phillips, 2012). In response to these concerns the Secretary of State for Health called for an independent review of the use and experience of the LCP in England.

In 2013 the review panel, led by Baroness Neuberger, published their report (Department of Health, 2013a). Though the panel found no evidence that the LCP had caused harm it raised concerns that in many cases the LCP was not being applied appropriately. Contrary to the intentions of the LCP and guidance from the GMC about the importance of informing relatives about diagnosis, prognosis, the uncertainties of end-of-life, and involving them in decisions, the panel found that some relatives were not given the opportunity to be involved in decisions made about their loved one's care, nor informed that their loved one was dying. Evidence showed that on occasion staff used conversations about placing a DNAR form as a proxy for agreement to start the LCP. The panel found that accounts from relatives and carers focused mainly on issues related to the withdrawal of hydration and nutrition at end-of-life. It argued that patients should always be supported with food and fluid unless there is a strong reason not to do so and that this should be clear to staff, patients and relatives. The panel members highlighted misunderstandings about whether commencing the LCP was a treatment decision requiring the patient's consent or a 'best interests' decision to be made by healthcare professionals. They maintained that the LCP was not a single medical procedure and there was no legal obligation for doctors to seek consent. However, because many sections of the LCP did concern treatment they proposed that explanations and discussions with patients and families were required. Finally, the panel recommended the withdrawal of the LCP and replacement over the next 6-12 months with an individual end-of-life care plan for each patient. Furthermore, they called for the Government to make improved quality for the dying a priority for NHS England (Department of Health, 2013a).

Following the independent review of the LCP, debate continued surrounding the report's conclusions and the decision to withdraw the LCP. Some authors questioned the rationale for withdrawing the LCP because of the small risk that it might be misused by those not properly trained to use it (Regnard, 2013; Wrigley, 2015). Regnard maintained that the panel had failed to demonstrate that the LCP itself was the cause of poor care and argued that withdrawing the LCP without a clear plan for its replacement

was a disservice to dying patients (Regnard, 2013). Poor decision-making was one concern highlighted by the review panel, yet Wrigley argues that this was not due to the LCP but to poor practice (Wrigley, 2015). Concerns were also raised that withdrawing the LCP would lead to a vacuum in end of life care and a reduction in compassionate end-of-life care (Kmietowicz, 2012). Yet following the many negative headlines and stories in the media it is questionable whether ongoing use of the LCP would have ever been accepted in practice, if it had not been withdrawn, or would have continued to spark concerns about end of life care. Following the withdrawal of the LCP a national coalition of twenty one national organisations was set up to determine how best to improve the care of dying people.

3.3.1   The Leadership Alliance for the Care of Dying People (LACDP)

The coalition was called the Leadership Alliance for the Care of Dying People (LACDP). In 2014 it published an approach to end-of-life care for healthcare professionals and organisations in England (LACDP, 2014b). The approach focused on five priorities of care:

1. The possibility that a person may die within the coming days and hours is recognised and communicated clearly, decisions about care are made in accordance with the person's needs and wishes, and these are reviewed and revised regularly.

2. Sensitive communication takes place between staff and the person who is dying and those important to them.

3. The dying person and those identified as important to them are involved in decisions about treatment and care.

4. The people important to the dying person are listened to and their needs are respected.

5. Care is tailored to the individual and delivered with compassion – with an individual care plan in place.

This approach to care was accompanied by specific guidance for healthcare professionals about how to enact this approach in practice (LACDP, 2014a). While each patient was to have a care plan made in line with their unique and individual needs,

healthcare organisations were also responsible for creating new documentation for staff members to record the care they provided. In the hospital where data collection took place for this research project, the paperwork was titled the Care of the Dying Patient document (CDP). It was a regional document introduced as a pilot in July 2014 just as data collection commenced on the wards. The document prompted staff to keep patients and relatives informed and involved in decisions about care at the end-of-life, to regularly review patients and consider their physical, psychological and spiritual needs and to record the care given. The document did not dictate how care should be given but was designed as a means of recording care as healthcare professionals work within national and local guidance on best practice at end-of-life.

The five priorities of care emphasises the importance of the care of the patient as well as those close to them. It respects both patient autonomy while recognising the interconnectedness of human beings. This means that healthcare professionals involve patients and/or those close to them - through regular communication, explanation, conversations about the goals and wishes of the patient – in decision-making about treatment and care. The approach affirms the importance of respecting the patient by listening to their wishes and concerns and then acting to ensure their individual needs are met in a compassionate way. It encourages staff to take an interest not simply in clinical issues and decisions but in the felt needs of the patient. The LACDP approach was followed by the publication of NICE guidelines for the 'care of dying adults in the last days of life' in December 2015, which provided an evidence‑based guideline for the clinical care of dying adults in the NHS (NICE, 2015a). It focused on the recognition of dying, communication and decision-making, clinically assisted hydration, medicines for managing difficult symptoms (such as pain, breathlessness, nausea and vomiting, anxiety, delirium, agitation, and noisy respiratory secretions) and their prescription for patients judged by the multi-disciplinary clinical team to be within a few (2 to 3) days of death (NICE, 2015a). In reality much of the 2015 NICE guidance had previously been described in the LCP however the NICE guidance did emphasise and clarify certain points (especially related to hydration and nutrition) more than certain versions of the LCP had.

In 2014 the Royal College of Physicians published the results of a national audit in the report, *End of Life Care Audit: Dying in Hospital* (Royal College of Physicians, 2014). This

audit used data collected in 2013 before the withdrawal of the LCP. In 2016 the results of a second audit were published based on data collected in 2015 (Royal College of Physicians, 2016). The 2016 audit built on recommendations made following the 2014 audit findings and it was also designed to ensure that the LACDP *five priorities of care* approach was being implemented and was monitored on a National level. The audit collected data on clinical and organisational practice for patients at end-of-life within acute hospitals in England. Despite fears that withdrawal of the LCP might lead to a deterioration in end of life care, the 2015 report showed improvement in many of the audit measures. Yet it also uncovered ongoing and unreasonably wide variations in end of life care practice between different hospitals (Royal College of Physicians, 2016). The report highlighted the need for national standards in end-of-life care which it was hoped the newly published 2015 NICE guidelines for the '*care of dying adults in the last days of life'* would provide (NICE, 2015a). As the independent review of the LCP highlighted, decision-making at end-of-life was often noted as an area of difficulty and cause for complaint. In the next section I focus on the specific practice of making decisions about resuscitation, an issue which has resulted in complaints and legal proceedings in the UK in recent years.

3.4 Resuscitation Decisions

In 2014 the Court of Appeal assessed a case regarding the practice of making Do Not Attempt Resuscitation (DNAR) decisions for patients with mental capacity. The following year, a further case, this time relating to a resuscitation decision for a patient who lacked mental capacity, was reviewed by the Court of Appeal. In this section I outline the background context to DNAR decisions before discussing the details of these cases and the possible impact of the judgements on end-of-life care practice today.

3.4.1 The History of DNAR Decisions

Cardio-pulmonary resuscitation (CPR) was first introduced to medical practice in the 1960s (Kouwenhoven *et al.*, 1960). While the initial presumption and practice was that CPR should be performed on any patient to arrest, it soon became apparent that in patients dying of terminal conditions resuscitation was neither beneficial nor

appropriate (Fritz and Fuld, 2010). Over time different codes were used by healthcare professionals to identify patients who it was deemed would not benefit from CPR. In the UK the DNAR order was developed as an explicit means of identifying patients who should not receive CPR (Fritz and Fuld, 2010).

While DNAR forms were designed to document resuscitation decisions and ensure that patients were not inappropriately resuscitated, research has revealed problems with how these forms are used (Fritz *et al.*, 2013). First, there is concern about the ways that healthcare staff interpret the presence of a DNAR form and research has shown that a DNAR decision can lead to other appropriate treatments being withheld (Fritz *et al.*, 2010). Second, a review of in-hospital CPR in 2012 highlighted that decision-making practice related to resuscitation decisions is variable with the result that patients receive inappropriate attempts at resuscitation because no one has discussed the decision with them in advance (NCEPOD, 2012). Third, there have been growing concerns about the way in which resuscitation decisions are made, often without informing or involving the patient or those close to them (Fritz and Fuld, 2010).

Since 2001 there has been professional guidance published jointly by the BMA, Resuscitation Council (UK) and Royal College of Nursing (previously named the 'joint statement') (Resuscitation Council UK, 2014). DNAR decisions can be made in advance so that if the patient subsequently suffers a cardiac arrest they will not be resuscitated. These decisions have traditionally been made by the medical team on grounds of likely medical futility (Samanta, 2015) and there has been no legal obligation for the doctor to inform the patient or their family that a DNAR had been completed (Fritz and Fuld, 2010).

3.4.2 The Tracey Case

For the sake of clarity, the details of the Tracey case are outlined here (*R (David Tracey) v Cambridge University Hospitals NHS Foundation Trust & Ors [2014]*). The case centred on Mrs Tracey who had been diagnosed with metastatic lung cancer (Fritz *et al.*, 2014). In February 2011 she was admitted to hospital with a fracture of her cervical spine following a road traffic accident. She was cared for in the Intensive Care Unit (ITU) and required ventilation in order to breathe. Despite treatment she was unable to breathe without the ventilator. One of the doctors caring for her signed a DNAR form without

consulting her family. Although the doctor said he had discussed resuscitation with Mrs Tracey, he did not record the discussion in the medical notes. Mrs Tracey subsequently improved and no longer required ventilation. At this time the family discovered the DNAR form and demanded that it be withdrawn which the medical team did. A few months later Mrs Tracey deteriorated. She said she did not want resuscitation, her family agreed and a DNAR form was signed by the medical team. Mrs Tracey died on the 7th of March 2011 (Fritz *et al.*, 2014). The family brought a case against the hospital Trust accusing them of breaching Mrs Tracey's human rights by failing to inform her of the first DNAR.

In 2014 the Court of Appeal ruled that DNAR decisions *do* engage Article 8 of the European Convention on Human Rights (ECHR): 'the right to respect for private and family life' (*R (David Tracey) v Cambridge University Hospitals NHS Foundation Trust & Ors [2014]*). This means that doctors may be considered to have violated a patient's human rights if they sign a DNAR form without consulting the patient who has mental capacity to take part in the decision. The ruling created a new legal precedent, that physicians should discuss resuscitation with patients and/or their relatives before signing DNAR forms (Fritz *et al.*, 2014). Prior to this judgement, though it was considered good practice to include patients and families in this decision, it was not required by law and the decision was up to the medical team.

This case was widely reported in local and national news. Some viewed the judgement as a victory for patient autonomy and reduction in the power of the medical establishment. Some medical professionals feared that doctors would stop making DNAR decisions because of fear of litigation, leading to cases of inappropriate resuscitation (Fritz *et al.*, 2014). Data collection for this research study commenced in June 2014 shortly after the Court of Appeal judgement. I witnessed first-hand some of the effects of this judgement on clinical practice and had the opportunity to speak to healthcare professionals about their views on the case. These findings will be presented in Chapter Seven.

3.4.3 The Winspear Case

The second case involved Carl Winspear, the patient, and his mother Mrs Winspear (*Winspear v City Hospitals Sunderland NHS Foundation Trust [2015] EWHC 3250 (QB)*).

Carl was 28 years old and had cerebral palsy, epilepsy, spinal deformities and associated health problems. He was admitted to hospital on the 2nd of January 2011 with a chest infection and was accompanied by his mother who cared for him. Carl did not have mental capacity to make decisions for his care before or during his admission. Overnight he was reviewed by one of the specialty registrar doctors who signed a DNAR form on Carl's behalf. The doctor's reasons for doing this were based on clinical futility. Given Carl's spinal deformity the doctor felt that resuscitation would not be effective. Though Carl's condition had stabilised, the doctor signed the form to prevent the nurses having to commence a futile procedure (CPR) should Carl suffer an arrest. The doctor wrote in the medical notes that the decision was to be discussed with the family the next day. The following morning the consultant spoke with Mrs Winspear and discussed resuscitation. She strongly disagreed that her son should have a DNAR and felt he should be offered the same care as any other patient. The consultant cancelled the DNAR with the view that it was not in Carl's best interests as it was a barrier to further discussion about his future care planning. Carl's condition deteriorated and with agreement from his mother and discussion with the ITU consultant Carl was transferred to ITU for non-invasive ventilation. Carl died later that evening (*Winspear v City Hospitals Sunderland NHS Foundation Trust [2015] EWHC 3250 (QB)*).

Mrs Winspear contended that signing a DNAR form for Carl, a man who lacked mental capacity, without any consultation with those caring for him or representing his interests led to infringement of his right to respect for private life under Article 8(1) of the ECHR. The judge referred to both the Tracy judgement and the Mental Capacity Act (MCA) in his verdict and maintained that decision-makers should consult relatives and carers of patients who lack mental capacity prior to making a DNAR decision as part of the best interests decision-making process (*Winspear v City Hospitals Sunderland NHS Foundation Trust [2015] EWHC 3250 (QB)*). The judgement was in line with the Tracey verdict and emphasised that clinical futility is not a sufficient reason for not communicating a resuscitation decision. Furthermore, the judge highlighted that 'best interests' is about more than clinical judgement and normally requires consultation with those close to the patient (*Winspear v City Hospitals Sunderland NHS Foundation Trust [2015] EWHC 3250 (QB)*).

The precedents set following the Winspear case and the Tracey case confirm that to make a resuscitation decision healthcare professionals must consider the duty of respect for the private life of the patient. They emphasise the concept of inherent human dignity for patients with and without mental capacity.

3.4.4   Escalation Plans

In light of these cases and in recognition of the problems with DNAR forms, some healthcare organisations have developed new methods of recording patients' wishes about their goals of care should their condition deteriorate while they are in hospital. Examples include the Treatment Escalation Plan (TEP), the Universal Form of Treatment Options (UFTO), and the Emergency Care and Treatment Plan (ECTP) (Obolensky *et al.*, 2010; Fritz and Fuld, 2015; Resuscitation Council (UK), 2016a). In the hospital where data collection took place the TEP form was used on the wards.

Work is now underway to develop a national form, and public consultation on the new national Emergency Care and Treatment Plan (ECTP) began in January 2016 (Resuscitation Council (UK), 2016a). The plan records a personal summary of decisions about the kinds of treatment an individual would or would not want to receive, and about what types of care and treatment would or would not be of potential benefit to them if their health deteriorated and they were unable to make their own decision at the time (Regnard, C., personal communication, February 16, 2016). Following public consultation and interviews to assess the use of the ECTP in different settings, the title was changed from ECTP to ReSPECT (Recommended Summary Plan for Emergency Care and Treatment) (Resuscitation Council (UK), 2016b). It was hoped that the new title would highlight that the form simply suggests recommendations for care and that it provides only a summary of care decisions and does not take away the need for more detailed discussions and plans. The aim of the ReSPECT is to ensure that each individual receives the best treatment for their specific situation in any setting (e.g. their home, nursing home, hospital, hospice, or during an ambulance journey) according to their wishes for care. Evaluation of the plan is underway and it is hoped that the ReSPECT form and supporting materials will be available for use by healthcare professionals from February 2017 (Resuscitation Council (UK), 2016b).

3.5 Decision-Making at End-of-Life

Having discussed the withdrawal of the LCP, the CDP document and new policy and professional guidance for end-of-life care, as well as important new legal precedents relating to resuscitation decisions, I now discuss current healthcare policy and legal guidance on the practice of decision-making in healthcare. Though such guidance is not always specific to end-of-life care, nevertheless, it provides principles for practice which are relevant and applicable to the care of dying patients.

3.5.1 Decision-Making for Patients with Mental Capacity at End-of-Life

In England there is no one legal statute that governs how healthcare decision-making should happen with regard to adults with mental capacity. Instead case law has established a collection of 'common law' principles which govern how adults with capacity can be treated lawfully (Emmett, C. personal communication, February 9, 2016). The GMC has provided professional guidance about how healthcare professionals should behave when making decisions about the investigation and treatment of patients with mental capacity to make a decision. It sets out principles for making good clinical decisions and offers a framework for good practice (GMC, 2008). Furthermore it has expanded on these guidelines to offer specific guidance when providing treatment and care for patients who are reaching the end of their lives (GMC, 2010). The 2008 guidance makes clear that the principles underpinning the recommendations for practice apply to all healthcare decisions, from minor conditions to life-threatening situations and therefore include decisions at end-of-life. In all situations doctors should work in partnership with the patient; this relationship should be built on openness, trust and good communication (GMC, 2008). The 2010 guidance which focuses on end-of-life decisions highlights that the framework for practice at end-of-life is essentially the same as for all other phases of clinical care. Therefore, the principles in the 2008 guidance are also relevant for end-of-life care (GMC, 2010).

The GMC guidance provides four detailed steps outlining the process of decision-making in patients who have mental capacity to make a decision (GMC, 2008; GMC, 2010). First, the doctor and patient should both assess the patient's condition based on past medical history, views, experience and knowledge. Second, the doctor will then draw on specialist medical knowledge, experience and clinical judgement while also considering

the patient's opinions and understanding of their condition to determine which investigations or treatments are most likely to result in the greatest benefit for the patient. The doctor should then explain the options to the patient including the possible side effects, risks and benefits of each option and also the option to have no treatment. The guidance is clear that the doctor can recommend a particular option but must not put pressure on the patient to accept it. Third, the patient should weigh up the different options and decide whether to accept any of the options or to refuse them, and communicate this to the doctor. Fourth, if the patient requests a treatment that the doctor believes would not be of benefit, the doctor should discuss the issues with the patient including reasons for requesting the treatment. The doctor is not obliged to provide a treatment believed not to be of overall benefit to the patient. However, the doctor must explain their reasons and outline other options available including the option to seek a second opinion (GMC, 2010, pp. 7-8).

The principles set out within the GMC guidance emphasise the importance of listening to patients and respecting their personal views, of clearly explaining their diagnosis, prognosis and treatment options, sharing information with patients in order to maximise their ability to make decisions for themselves and respecting patients' decisions (GMC, 2008). The guidance does not advocate one specific model for decision-making but recognises that no single approach will suit every patient or every situation. It advocates flexible decision-making within a doctor-patient partnership that is based on openness, trust and good communication (GMC, 2008).

3.5.2 Decision-Making for Patients who Lack Mental Capacity at End-of-Life

In England and Wales the Mental Capacity Act (MCA) provides a legal framework for decision-making for patients who lack the mental capacity to make a decision (Department of Health, 2005). The GMC's guidance for decision-making at the end-of-life for patients who lack mental capacity is consistent with the MCA (GMC, 2010). The MCA is underpinned by core principles, one of which is known as the 'best interests' principle. It states that: '*an act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests*' (Department for Constitutional Affairs, 2007, p. 66).

The term 'best interests' is not defined in the MCA but the MCA Code of Practice provides guidance about how a decision-maker should work out the bests interests of a person who lacks the mental capacity to make a decision. This guidance consists of a checklist of factors to be considered by decision-makers and it emphasises that decision-makers must take into account all relevant factors related to the decision, not simply those they think are important. This means that healthcare professionals must consider more than the medical or clinical details of the case when making decisions. The following points are recommended as important steps when trying to work out the best interests of a person who lacks capacity to make a particular decision (Department for Constitutional Affairs, 2007):

- The person should be encouraged to be involved in the decision as far as possible.

- Relevant information (things important to the person who lacks capacity) should be identified and taken into account.

- The person's views (including past and present wishes and feelings, their beliefs and values) should be considered and documented.

- Assumptions should not be made about the person on the basis of their age, appearance, condition or behaviour.

- The person should be assessed for whether they might regain capacity in the future and whether the decision could be delayed until then.

- If the decision concerns life-sustaining treatment it must not be motivated by a desire to bring about the person's death and assumptions should not be made about the person's quality of life.

- Where practical and appropriate the decision-maker should consult the views of relevant others (such as those involved in caring for the person, close relatives or friends) for their opinions about the person's best interests.

The code of practice states that when decision-making involves the provision of medical treatment the doctor or member of the healthcare staff responsible for carrying out the particular treatment is the decision-maker. In the event of disagreements over what is

'best' for the patient, the MCA Code of Practice advises the decision-maker to carefully balance the varying concerns and opinions in order to decide between them. However, ultimate responsibility for making a decision lies with the decision-maker. In the case of ongoing disagreement a second opinion, a 'best interests' case conference, or mediation are possible options for resolution. Only if other attempts to resolve the dispute have failed is the court involved (Department for Constitutional Affairs, 2007).

The MCA guidance is underpinned by the important principle of respect for the patient's autonomy. Though the patient is unable to make the decision, the substitute decision-maker is to seek to determine the patient's likely wishes as far as is practically possible and to make a decision on their behalf which respects such wishes and values. The MCA presents this practice as a rational and practical process whereby the decision-maker collects relevant information and then weighs up the pros and cons in order to make a well-reasoned decision. However, some have suggested that reality may be rather more complex (Dunn *et al.*, 2007). While the Code of Practice states that assumptions should not be made about the patient and that the patient's beliefs and values are to be considered, it makes no mention of the decision-makers beliefs and values which may impact on the decision made. Throughout the 'best interests' decision-making process the decision-maker has to weigh up the various opinions and options. However, the Code of Practice offers little guidance about how this ought to occur e.g. how much weight should be given to different opinions. While the MCA provides a clear and helpful set of legal guidance for decision-making, it appears that the 'best interests' decision-making process presents decision-making as a rational, straight-forward and neutral endeavour. Yet, the reality of clinical practice can be rather different as will be described in Chapter Seven.

3.6   Conclusion

In this chapter I highlighted and discussed recent events relevant to decision-making and care at the end-of-life, along with current policy and legislation guiding such practice. Furthermore, I considered some of the principles underpinning current policy. In doing this I sought to place the practice of end-of-life care today within a current context. In the next and final background chapter, I explore the literature findings

related to the practice of decision-making and care at end-of-life in order to gain insight into the varied perspectives of patients, families and healthcare professionals and to understand the challenges involved in providing good care for dying patients and their families.

Chapter 4 End-of-Life Care in Hospital

Having considered the history of end-of-life care in hospitals and recent events impacting on the practice of end-of-life care and current policy, in this chapter I review the relevant literature on end-of-life care in hospital. First, I consider the question 'what is care?' and how this has been discussed in the literature. Second, I explore the literature which describes the perspectives of patients, relatives and staff on end-of-life care in hospital.   Third, I analyse the literature on key aspects which are seen to be central to good care: decision-making and communication. In this chapter I outline the relevant findings in the literature in order to set the scene for the findings of this research study. The literature concerning end-of-life care encompasses many disciplines including medicine, nursing, philosophy and sociology and therefore this literature review is broad and encompassing findings from these different disciplines. In this chapter I outline and critique the relevant literature in order to set the scene for the findings of this research study.

4.1   What is care?

The concept of 'care' has been studied and written about extensively in the literature by authors of varied disciplines and backgrounds. Care has been described in different settings and cultures, the forces shaping care have been considered, the constituent parts of care have been proposed and practical responses to help ensure care is

provided have been set out from many disciplinary perspectives[3]. Care has been categorised into specific concepts which centre on what is considered to be the focus the care. For example, there are now different categories of care such as patient-centred, person-centred, relationship-centred, family-centred and client-centred (Hughes *et al.*, 2008). But what *is* 'care'? And is there a specific thing that 'care' at the end-of-life *is*? In other words, does it have one essential part or an essence? And if so what is it? Knowing this would be extremely useful for examining the presence, absence and quality of end-of-life care.

In the literature and in healthcare policy the word 'essence' has been used in relation to end-of-life care and healthcare in general. For example, in 2003 at a conference at the Royal Society of Medicine Dr Derek Doyle gave the closing speech which was entitled 'The Essence of Palliative Care' (Doyle, 2004). In a publication of the event the essence of palliative care was described with thirteen bullet points rather than one single

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[3] <u>The sociology of medicine and nursing care</u>: for information on the sociology of nursing care in hospital (Menzies Lyth, 1960). For discussion of the components of nursing 'carework' as observed in a hospice (James, 1992). For exploration of care in hospital and the influences shaping moral decisions around care (Chambliss, 1996). Fletcher examines the position of nursing as a caring profession. He examines research from various countries and argues that nursing as practised currently fails to fulfil its caring rhetoric (Fletcher, 1997). For further in-depth sociological discussion of end of life care within American hospitals (Kaufman, 2006). For investigation and critical discussion on the caring role in nursing in the UK (Smith, 2010). <u>Literature on care-giving in practice:</u> Callahan discusses the human need for caring and considers why it is that caring has been 'downgraded' in medicine. He outlines four levels of caring and the importance of both the general and particular when providing care (Callahan, 2001). Improving the quality of healthcare has become the focus of NHS reform in recent years (Department of Health, 2008b). Today however, the importance of care is also championed by the Point of Care Foundation which exists with the aim of 'humanising healthcare' (*The Point of Care Foundation*). Their first report aimed to investigate problems in healthcare and work to improve such care (Goodrich and Cornwell, 2008). In 2009 the Picker Institute Europe published a report investigating the key aspects of patient experience. They advocate assessment of patient experience rather than patient satisfaction for assessing care (Sizmur and Redding, 2009). The appropriate focus of care has been discussed at length with various models of care proposed. For a summary of types of centeredness in healthcare (Hughes *et al.*, 2008). One of the main outcomes of a focus on patient-centred care has been the recognition that patients should be involved in decisions about their healthcare. This has led to the development of shared decision-making (Charles and Gafni, 1997). Opinion pieces continue to be written about the importance of care in healthcare (Benger, 2014). <u>Philosophical, theological and political discussions about care:</u> Much of the philosophical literature on care has come from a background of feminist ethics which has led to the development of a branch of ethics called the ethics of care (Sevenhuijsen, 1998; Lloyd, 2004). For a discussion of how an ethics of care can be applied to healthcare practice today (van Heijst, 2011). For an in-depth discussion on end-of-life care today spanning philosophical, theological, historical, medical and sociological disciplinary boundaries (Bishop, 2011).

aspect[4]. The Department of Health has also published reports on the 'Essence of Care', which set out key benchmarks considered to be fundamental for care (Department of Health, 2010). The most recent version was published in 2010 and sets out twelve fundamental components of high quality care[5] which are designed to enable healthcare professionals to share, compare and drive forward best practice. Therefore, it appears that even in these documents care is not an essence but is made up of certain important elements. The components of care may overlap, change and fluctuate depending on the situation and the people involved. Therefore, while it can be helpful to think about which components may constitute different types of care, such as palliative care, chronic care, acute care, there is not one essence that defines different types of care.

Within philosophy the belief that things have essences is called essentialism. In contrast, the belief that things do not have essences but are instead made up of different component parts is called nominalism. Scadding has argued the case strongly for a nominalist view of illness and disease within medicine (Scadding, 1996). He explains that essentialist ideas about disease are implicit in everyday speech for example, diseases are considered as causes of illness. Yet he argues that this type of speech is misleading because the causes of many diseases remain unknown, causation is often very complex and furthermore the effect i.e. the disease, is not the same as its own cause. Instead nominalist ideas recognise that '*diseases have no existence apart from that of patients with them…………………… the nominalist analysis of the disease concept places the patient firmly in the centre of the picture, and makes the practice of medicine necessarily holistic*' (Scadding, 1996, pp. 594-595). In relation to care the distinction made by philosophy seems important. For if there is no one essence of care, the type of care needed in any situation will be intricately linked to the individual needs of the patient. In their analysis of different types of care centredness in health care Hughes et al. (2008)

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[4] The essence of palliative care: putting the patient first; care, compassion and quality of life; meeting the needs of patients with advanced disease and their carers; the pursuit of the irreducible by the efforts of the unstoppable; making people matter; a model to understand the complex nature of healthcare; relieving total suffering; science, compassion, communication and partnership; supersensitivity; total approach to improving quality of life – particularly in the last phase; receiving commitment – for the patient and family; having the courage to be inspired and act – for the professional; attention to detail.

[5] Essence of Care benchmarks 2010: Bladder, bowel and Continence Care; Care Environment; Communication; Food and Drink; Prevention and Management of Pain; Personal Hygiene; Prevention and Management of Pressure Ulcers; Promoting Health and Well-being; Record Keeping; Respect and Dignity; Safety; Self Care.

consider this issue from practical and philosophical perspectives. They examine types of care centredness in healthcare and describe ten key themes[6] common to all types. Hughes et al. use the analogy from the philosopher Wittgenstein as a means of thinking about the ways in which concepts, like care, are composed of different parts. Wittgenstein gives the example of twisting many fibres to spin a thread: *'The strength of the thread does not reside in the fact that some one fibre runs through its whole length, but in the overlapping of many fibres'* (Wittgenstein, 1978 § 67). Hughes et al. oppose the idea of an 'essence' of care and instead advance the idea that care is a concept constituted by many important component parts. They propose that in different settings of care different components may be more or less required and each is justified according to its use in any given situation (Hughes *et al.*, 2008).

4.1.1 Care as 'doing to' and 'being with'

A further form of thinking about care considers both what staff *do* for patients as well as how they *are* with patients. Wolff has described the important roles of 'doing to' and 'being with' in psychotherapy practice (Wolff, 1971). He suggests that 'doing to' is vitally important in the delivery of competent and responsible healthcare and that it describes the outward behaviour of staff on behalf of their patients. In this way it works to separate the role of the doctor from that of the patient. On the other hand 'being with' describes the doctor's empathy with the patient's experience, their sensitivity to the deeper meanings of a patient's communication and it involves working to see the situation from the patient's perspective. Wolff highlights the vital importance of both of these components and states: *'the 'doing to' function will be properly effective only if it is based on the right kind of 'being with' the patient'* (Wolff, 1971, p. 122). Wolff was a psychiatrist and wrote about this concept of care in relation to psychotherapy practice yet it has also been described by authors from other medical specialties.

From the very start of what is now modern palliative care, Cicely Saunders conceptualised palliative care as including more than just physical care. She called for holistic care which sought to meet the patient's physical needs as well as their

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[6] The ten themes identified by Hughes et al. are as follows: Respect for individuality and values; Meaning; Therapeutic Alliance; Social context and relationships; Inclusive model of health and well-being; Expert lay knowledge; Shared responsibility; Communication; Autonomy; Professional as a person.

psychological, social and spiritual needs. Saunders founded this holistic kind of care on a Christian philosophy of what it means to 'be with' others (Saunders, 2005). She summed up her perspective with the Biblical phrase '*watch with me'*, spoken by Jesus to his disciples in the garden of Gethsemane. Saunders maintains that such an approach demands that work carried out on behalf of the patient should stem from respect for the patient and requires both competent skill and compassion. However, it also involves a willingness to *be* with the patient: '*in watching we should learn not only how to free patients from pain and distress, how to understand them and never let them down, but also how to be silent, how to listen and how to just be there'* (Saunders, 2005, p. 8). However, the importance of such seemingly subjective practices within healthcare may meet with scepticism from healthcare professionals especially on busy medical wards where simply completing physical care for patients is a struggle. The ideas about care expressed by Saunders and Wolff could well be seen as something relevant only for specialties like psychiatry and palliative care where healthcare professionals may have more time to spend with patients. Yet van Heijst opposes this assumption and has developed a philosophy of care for healthcare which she has termed 'Professional Loving Care' (PLC), which seeks to involve both the physical and the metaphysical (van Heijst, 2011).

This approach of van Heijst was formed through analysis of the writings of philosopher Hannah Arendt and the application of an 'ethics of care' perspective. While similar to the principles of palliative care, PLC combines competent and compassionate care for all people, not just those at end-of-life. Van Heijst considers different approaches to healthcare and suggests that modern healthcare focuses on what she terms the 'repertoire of intervention'. She uses the word repertoire to refer to standard practices and routine activity which healthcare professionals are used to carrying out and which patients and society expect (van Heijst, 2011). She describes the 'repertoire of intervention' as the common and predominant mode of perceiving healthcare. From this perspective she proposes that care is viewed as a commodity or product to be passed from one person to another. While recognising the vital importance of healthcare interventions and the role that healthcare professionals have in acting to meet patients' needs, she suggests that this perspective often undervalues the important work of relationships. Furthermore, when care is conceptualised only as an intervention,

healthcare professionals may show little interest when patients cannot be healed and further intervention is futile. In contrast, van Heijst proposes that even in the most desperate of situations when all hope of successful intervention is lost, healthcare professionals can still act in such a way so as to demonstrate the value they see in the patient and their family. She suggests that expressive acts can be used to embody values and it is here that value can be realised and healthcare professionals can transform a situation even when there is no hope for recovery (van Heijst, 2011).

In contrast to the 'repertoire of intervention' van Heijst describes another approach which she terms the 'repertoire of presence'.   From this perspective: '*professionals should carry out their work in such a way that the people in their care experience the professional as "being there for them"*' (van Heijst, 2011, p. 91). A 'repertoire of presence' aims to connect dignity, neediness and relationships. Neediness is recognised and accepted as an inherent part of the human condition and not as something that defies someone's dignity. Patients' needs are met and their dignity respected through caring relationships with healthcare professionals. According to a PLC approach, healthcare professionals need to be able to display and integrate both repertoires in their work with patients, relatives and other healthcare colleagues.

PLC aims to see and respond to the needs of each individual and to ensure that those being cared for feel supported and valued. It also recognises that care is not a unilateral concept but is in many ways reciprocal and acknowledges the worth and value of all people (patients, relatives and healthcare professionals) as unique individuals (van Heijst, 2011). From a PLC perspective relationships are vital for providing and maintaining care. The asymmetry of dependency in the doctor-patient relationship is not denied or ignored but is acknowledged as being of central importance. Patients *are* needy in a way that healthcare professionals are not. Yet despite their differences, doctors and patients are both of equal worth and such asymmetry can be managed through caring relationships, enabling patients to be both dependent on others for care while maintaining their dignity as persons (van Heijst, 2011).

The importance of forming and maintaining relationships when providing care, and the effort that this entails, has also been discussed in the sociological literature and has been described as 'emotional labour'. The term was initially used by sociologist Arlie

Hochschild in the 1980s in her study of flight attendants when she linked concepts of care, feelings and emotions (Smith, 2010). It was later used by nurse sociologists to highlight the emotion work carried out by nurses alongside their physical work (James, 1992; Smith, 2010). The term has since been studied in relation to the work of other healthcare professionals and has been found to affect nursing and medical work (Larson and Yao, 2005; Sorensen and Iedema, 2009; Bailley *et al.*, 2015). The literature highlights the impact of poor relationships and conflict within professional relationships about decision-making at end-of-life as having the potential to cause moral distress (Oberle and Hughes, 2001). How healthcare professionals relate to patients and relatives and so care for them, is necessarily (though often unconsciously) influenced by their values or rationale underpinning care. In the following section I will consider two such rationales which may underpin healthcare practice today.

4.1.2 Rationales underpinning healthcare

Mol (Mol, 2008) has analysed modern healthcare practice for the care of patients with chronic illness (specifically the care of patients with diabetes). Mol outlines two rationales underpinning healthcare today: the logic of choice and the logic of care. She describes these approaches as 'logics'. The term 'logic' is not meant to imply that these rationales are fixed and certain, rather '*it invites the exploration of what is appropriate or logical to do in some site or situation, and what is not. It seeks a local, fragile and yet pertinent coherence. This coherence is not necessarily obvious to the people involved. It need not even be verbally available to them. It may be implicit: embedded in practices, buildings, habits and machines. And yet, if we want to talk about it, we need to translate a logic into language'* (Mol, 2008, pp. 9-10).

In modern healthcare patients are often viewed as customers with the power to choose products (medicines, types of healthcare, devices etc.). Choice is a widely celebrated as a valued ideal, but Mol questions the generalisation of choice as an ideal and suggests that rather than complementing other ideals such as 'good care', more often the two can clash (Mol, 2008). A logic of choice provides patients with many possible products (be it a medicine, device, type of healthcare) which are well defined. The patient has the power to choose (or not) and the transaction (passing of the product from healthcare professional to patient) has a clear start and end point. Yet everything that follows is

viewed as the result of the patient's choice and if things go wrong patients face the consequences and potential guilt and self-reproach (Mol, 2008). In contrast, the logic of care is not based on a transaction but is an ongoing process which may go back and forth as the patient and those caring for them seek to discern how best to meet their changing needs. The logic of care may appear more negative, it faces the reality of the disease that will not go away. But though perfect health is no longer possible it sees no reason to give up (Mol, 2008). From a logic of care perspective the results and outcomes of diseases will always be uncertain, therefore, the art of care is to figure out how various participants (healthcare professionals, the patient, relatives) may act and collaborate to improve or support the patient's condition: '*to act without seeking control. To persist while letting go*' (Mol, 2008, p. 32).

The logic of choice assumes that people are autonomous, independent and equal. In contrast, the logic of care makes no such assumptions and recognises people as being first and foremost inter-related with one another (Mol, 2008). A logic of choice views people as equal, free from hierarchy and with the power to make their own decisions. From a logic of care perspective, people are not equal but come with varying levels of dependency and differing care needs. Good care depends on such specifications and on attentiveness to them (Mol, 2008). Sociologist Arthur Frank, who experienced a heart attack and cancer, highlighted the importance of recognising the differences and particulars between patients:

> '*Most people who deal with ill persons do not want to recognize differences and particularities because sorting them out takes time. Even to learn what the differences are, you have to become involved. Generalities save time. Placing people in categories, the fewer the better, is efficient; each category indicates a common treatment: one size fits all. But…………. Treatment is not care. Treatment gets away with making a compromise between efficiency and care by creating an illusion of involvement………. What makes experience real is particulars. One person's anger or grief may differ so much from another's that calling them by a common name only obscures what is actually going on for each*' (Frank, 1991, pp. 45-46).

This section provides a summary of some of the ways that care has been considered and described in the literature from different disciplinary perspectives. In the remainder of this chapter I will discuss what is known about end-of-life care in hospital, the perspectives of patients, relatives and staff members, and the practice of decision-making and communication at end-of-life.

4.2   End-of-life care in hospital

In England approximately 500,000 people die each year (House of Commons Health Committee, 2015). Between 2008 and 2010, 55% of deaths took place in hospital, 20% in a peoples' homes, 18% in care homes and 5% in hospices (Public Health England, 2014). An analysis of the use of hospital care and social care in the final twelve months of life for over 72,000 deaths in England found that 89.6% of people required some kind of hospital care (79.4% as in-patients) during their last year of life (Georghiou *et al.*, 2012). In a study of Scottish hospitals Clark et al. found that large numbers of hospital in-patients have entered the last year of their life and almost 1 in 10 patients die during their admission (Clark *et al.*, 2014). People aged over seventy five have the highest hospital death rates (National End of Life Care Intelligence Network, 2010) and older people often experience many admissions towards the end-of-life (World Health Organization, 2004). Yet it has also been demonstrated that despite having palliative care needs they have less access to palliative care services than younger patients or patients with cancer (World Health Organization, 2004).

Despite many people saying they would want to die at home, older people have identified barriers to dying at home (Gott *et al.*, 2004). In fact older patients have reported preferences for hospital care because of the reassurance and sense of safety provided by the presence of a medical team (Gott *et al.*, 2004). These findings suggest that hospital wards will continue to be an important setting for end-of-life care in the UK. However, challenges have been reported related to the provision of end-of-life care in hospital. Many hospitals continue to work on a curative model of healthcare which does not prioritise end-of-life care (Bloomer *et al.*, 2011; Bloomer *et al.*, 2013). End-of-life care can be extremely challenging for all healthcare professionals, for example: it can be difficult to know the difference between when a patient is acutely unwell and when they are dying, it can be challenging to achieve consensus about this among healthcare teams and some staff may find themselves continuing curative care when they believe the patient to be dying (Bloomer *et al.*, 2013). Although patients die frequently on acute hospital wards many nurses do not feel comfortable or prepared to provide end-of-life care. The struggle to provide high quality end-of-life care while also managing acute

patients and their every-day workload can lead to task-focused attitudes (Bloomer *et al.*, 2011; Bloomer *et al.*, 2013).

Despite policy advocating the importance of end-of-life care in the UK, there is evidence to suggest that problems and difficulties persist in practice. The quality of care for dying patients has been assessed annually in the National Survey of Bereaved People (VOICES) and has shown that end-of-life care in hospital is rated considerably lower than in other settings such as hospices, care homes or home (Office for National Statistics, 2014; Office for National Statistics, 2015). For example, seven out of ten people (69%) rated hospital care as outstanding, excellent or good which is significantly lower compared with care homes (82%), hospice care (79%) or care at home (79%) (Office for National Statistics, 2015). The questionnaire asks bereaved relatives to assess how often staff in different settings treated the patient with dignity and respect. Staff in hospices were most likely to be rated as always showing dignity and respect to the patient in the last three months of life (87% for hospice doctors and 86% for hospice nurses). This is much higher than staff in other settings, such as care homes and hospitals, where approximately one in four respondents rate that dignity and respect was given most of the time (care homes 26%, hospital doctors 25%, and hospital nurses 27%) (Office for National Statistics, 2015). Interestingly despite only 3% of all respondents stating patients wanted to die in hospital, almost three out of four (74%) respondents felt hospital was the right place for the patient to die (Office for National Statistics, 2015). It is important to consider the limitations of this survey methodology alongside the results. The background notes for the VOICES survey acknowledge that fewer respondents experienced hospice care and therefore the number of hospice-related questions and responses was far lower than for other settings. Questions with fewer responses are therefore less robust, with wider confidence intervals and a reduced likelihood of highlighting significant differences (Office for National Statistics, 2015). Like all surveys, VOICES is subject to selection and response bias. While the results reflect the views of all responders, it can give no information about the experiences of people who were not asked to participate or those who were selected but chose not to respond. In recognition of this potential for response bias, the survey data is weighted to account for the probability of selection and response bias (Office for National Statistics, 2015).

In 2015 the Parliamentary Health Service Ombudsman (PHSO) published an investigation into the complaints it received about end-of-life care (PHSO, 2015). Of the 220 complaints related to end-of-life care investigated by the PHSO between 2011 and 2014, 182 were related to care in hospital settings (House of Commons Health Committee, 2015). Poor communication at end-of-life is a recurring theme in their case work and half of all complaints related to end-of-life feature communication as a key component of the complaint (House of Commons Health Committee, 2015). As described in Chapter Three decision-making at end-of-life has also been an aspect of care to be scrutinised.

In recent years the volume of research into end-of-life care has increased greatly. Within this extensive body of literature the more specific area of end-of-life care within hospitals has been studied and there is now a large and growing body of literature about end-of-life care on acute general hospital wards from the perspectives of patients, their relatives and staff. And it is these perspectives that I will now consider in turn.

4.2.1 The Views of Patients and Relatives about End-of-Life Care in Hospital

Many studies consider the general perspectives of patients and relatives on end-of-life care in hospital. Other research has investigated specific aspects of care in more detail and I will consider the findings on communication and decision-making in greater depth in Sections 4.3 and 4.4.

Robinson et al. (Robinson *et al.*, 2014) and Virdun et al. (Virdun *et al.*, 2015) have both published reviews of research into patient and family experience of end-of-life care in hospital. These are helpful overviews of what is an increasingly vast literature and I summarise their findings here. Four of the studies examined by Virdun et al. had been included in the review by Robinson et al. and it is perhaps unsurprising that the results are similar.

Robinson et al. published an integrative review of thirty two international studies synthesising current evidence about the experience of palliative care in an acute hospital setting (Robinson *et al.*, 2014). They included quantitative, qualitative and mixed methods studies, involving patients with a wide variety of different patient diagnoses and they investigated the perspectives of terminally ill patients and their relatives

(Robinson *et al.*, 2014). The authors identified five recurring themes in the data: symptom control and burden, communication with health professionals, decision-making related to patient care and management, inadequate hospital environment and interpersonal relationships with health professionals (Robinson *et al.*, 2014).

The data suggest that severely ill hospitalised patients have a high burden of symptoms and that the management of such symptoms is often an area of care that patients and families are dissatisfied with (Robinson *et al.*, 2014). Communication was noted as the dominant theme of the review, mentioned in seventeen of the studies, yet it was also an aspect of care viewed to be of a poor standard by patients and families especially when bad news was given. Many families felt that they were not regularly informed about the condition of their loved one and that they had to actively seek out staff to gain information. On the contrary, most patients and families were satisfied that they were involved in decision-making. Factors impacting the ability of families to be involved in decision-making were identified, they included: the provision of information about the patient's condition, care and treatment options, ease or difficulty in obtaining information and quality of explanations. This suggests that the provision of information is an important step before patients and family can know about key decisions and their options for involvement in decision-making.

The hospital environment was viewed by many families as an inappropriate place for dying. The busy hospital wards could cause families to feel ignored and uncared for, a lack of private rooms impacted on their ability to have personal conversations and elements of hospital bureaucracy and organisation (inflexible visiting hours, transfer of patients between wards due to bed-pressures) were seen to contribute to poor care. Finally empathy and kindness of staff was remembered by patients and families while some families felt nurses did not show empathy. A failure by staff to recognise and acknowledge the family's care-giving role could lead to feelings of frustration and helplessness among family members. On the contrary, staff who were approachable, friendly and took the time to check the patient's and family's needs were being met were viewed as providing good care (Robinson *et al.*, 2014).

The systematic review by Virdun et al. looked at eight quantitative research studies to identify the elements of end-of-life care that patients and relatives rank as being the

most important. Virdun et al. identified four domains across patients and families as the most important elements of end-of-life care: effective communication and shared decision-making (SDM), expert care, respectful and compassionate care, and trust and confidence in clinicians (Virdun *et al.*, 2015). The first two domains (effective communication and SDM, and effective care) were mentioned over fifty percent more frequently by all participants than the other domains. This suggest these elements of care were of most importance to patients and families (Virdun *et al.*, 2015). Patients and families noted the importance of the clinicians being knowledgeable about patients' conditions and rated trust and confidence in clinicians as an important component of end-of-life care. Respectful and compassionate care was rated highly by both patients and families and referred to the preservation of the patient's dignity and the compassion and support shown by staff. This was embodied when clinicians appeared to take an interest in family's loved one and staff worked well as a team to care for patients (Virdun *et al.*, 2015).

While these recent reviews have similar findings, it is important to note that their results are consistent with current studies not included in the reviews as well as past research into the experiences of patients and families receiving end-of-life care in hospital. In a study of recently bereaved relatives' responses to questions about hospital care in the last days of life, relatives identified the importance of clear information and communication, involvement in decision-making, acknowledgement of their relationship with the patient, being able to trust healthcare professionals and the importance of rest and privacy (Witkamp *et al.*, 2016). Another study involving ten interviews with bereaved relatives of people who had died within the previous three months on general hospital wards, outlined six recurrent themes which included communication and symptom control (Clark *et al.*, 2015). Donnelly and Battley conducted fifteen interviews with bereaved relatives ten to twenty days after the death of their loved one in hospital. In their study relatives described the importance of regular and straight-forward communication and the distress and panic experienced when such communication was lacking. They also highlighted the attributes of staff and their humanity as being important for good care (Donnelly and Battley, 2010). Caswell et al. conducted an ethnography on hospital wards and highlighted ongoing problems with communication between relatives and healthcare professionals at end-of-life (Caswell *et al.*, 2015).

Kristjanson published findings similar to Virdun et al. over twenty years ago (Kristjanson, 1989; Virdun *et al.*, 2015). Yet while such insights are not new, the ongoing difficulties with communication, SDM and care raise questions about the ability of hospitals to provide curative care alongside high quality end-of-life care and whether individual healthcare professionals, healthcare teams and healthcare organisations are able to ensure that these aspects of care are provided consistently for all patients and their families at end-of-life.

Most of the studies reviewed by Virdun et al. in 2015 used survey methods to gain information about the views of patients and relatives. In an attempt to gain deeper insight into the experience of end of life care, Virdun et al. performed a meta-synthesis of patient and relative narratives reporting on the important elements of end-of-life care in hospital (Virdun *et al.*, 2016). The studies included used one-to-one interviewing, focus groups and surveys with open-ended questions to gain data from patients and relatives. The data highlight similar findings to their previous study. Important aspects of care noted by patients and relatives included themes such as expert care, effective communication, SDM, and respectful and compassionate care. However, the authors noted that compared to previous studies, the data also highlight additional areas of importance such as the need for involvement of family members, the importance of maintaining self-identity for patients and environmental factors which appear to be more important for families than for patients (Virdun *et al.*, 2016).

It is important to highlight some of the limitations inherent within studies investigating patient and family experience of end-of-life care. First, many studies use satisfaction surveys which are highly influenced by individuals' prior expectations. However, such expectations for care or whether they are met, are often not explored (Robinson *et al.*, 2014). Second, when studies use the patient's symptom burden as an indication of their overall experience in hospital it may reflect negatively on their experience. It is known that hospitalised patients often have many symptoms which may be the reason for their admission in the first place. For this reason Robinson et al. suggest investigating the effectiveness of the management of symptoms may be more insightful (Robinson *et al.*, 2014). Third, many studies use patient proxies such as bereaved relatives as a method of learning more about the patient's experience. Research has questioned the validity of using proxies and retrospective collection of data has been shown to vary significantly

over time (McPherson and Addington-Hall, 2003). While there is evidence that proxies can provide reliable data on factors like service provision and observable symptoms, studies show that care must be taken when interpreting their views on more subjective symptoms like pain and anxiety (McPherson and Addington-Hall, 2003). Fourth, for the reviews which synthesise the results of multiple qualitative studies, variable quality of data reporting between studies necessarily influences the quality of the final results and conclusions made. Furthermore, the authors of the original papers select only a selection of quotes to publish and this may introduce a selection bias that must be borne in mind. Fifth, it has been argued that studies taking a prospective approach to investigate patients' opinions at end-of-life may be fundamentally biased as they only represent a certain proportion of the patient population (McPherson and Addington-Hall, 2003). And it is possible that less well patients may be less satisfied with their experience of care on the ward yet are too unwell to take part in research. This is a clear limitation of such studies. However, such a limitation does not lessen the importance of seeking the views of patients, but it must be kept in mind when considering the generalisability of the data. Such limitations must be borne in mind as I continue this overview of the research. However, the congruence of findings between studies published recently and in the past, confers confidence that these findings do represent the perspectives of a wide range of patients and relatives and their experience of end of life on hospital wards.

4.2.2   The Views of Healthcare Professionals about End-of-Life Care in Hospital

The experiences of healthcare professionals providing end-of-life care in a hospital setting highlight interesting findings. Studies have investigated the views of staff about the impact of the acute hospital environment on their ability to provide end-of-life care (Thompson *et al.*, 2006; Sheward *et al.*, 2011; Brereton *et al.*, 2012). The acute hospital ward is considered an inappropriate place for the care of dying patients by some staff members (Sheward *et al.*, 2011). Staff have described the reality of life on a busy hospital ward and the feeling that they are being pulled in many directions. Barriers to good end-of-life care may include: heavy workload, lack of time, availability of private rooms, continuity of care, skill mix and training of staff (Sheward *et al.*, 2011). Difficulties in recognising when a patient is dying and tension between the traditional biomedical goal of curing the patient and the palliative goal of providing comfort care

have been highlighted as a challenge to ensuring good and timely end-of-life care (Thompson *et al.*, 2006; Willard and Luker, 2006; Sheward *et al.*, 2011). It has been suggested that the prioritisation of treatment and routine care on hospital wards today can inadvertently prevent appropriate attention to symptom management and the discussion of patient wishes for care even when a patient is recognised as deteriorating and potentially approaching the end-of-life (Willard and Luker, 2006). While the importance of teamwork and collaborative relationships when caring for dying patients has been described, there is also evidence of professional dissonance and discord when opinions differ about the appropriate goals of care for deteriorating patients (Sheward *et al.*, 2011). Indeed end-of-life issues have been recognised by multi-disciplinary staff members on acute medical wards as the most challenging ethical issues, with the core ethical concern described as the task of balancing the competing moral demands of duty to treat versus the moral imperative to alleviate suffering (McGrath and Henderson, 2008).

In a qualitative study by Thompson et al., ten hospital nurses were interviewed about their experience of providing end-of-life care. The overall theme dominating their responses was the need to create a 'haven for safe passage' for patients as they approached end-of-life (Thompson *et al.*, 2006). The nurses saw themselves as patient advocates, working to ensure that the patient received the care they needed. They described the importance of recognising dying in order to facilitate a change in the direction of care, from curative treatment to palliative care. If such a change in direction was not made appropriate care could be delayed and confusion and inconsistencies in care persisted. The nurses described care at end-of-life as including both physical interventions as well as emotional support to families of dying patients. Such support along with open and honest communication enabled the building of rapport between staff and families. The importance of professional relationships was also highlighted and the nurses suggested that without good rapport with medical staff they were less able to advocate effectively for their patients (Thompson *et al.*, 2006).

The potential limitations of these studies must be borne in mind. They are heterogeneous and vary by sample size, their specific participant groups and data collection methods. One study considered only the perspectives of hospital nurses (all of whom were female) (Thompson *et al.*, 2006) and another the perspectives of

specialist cancer nurses (Willard and Luker, 2006). And while Sheward et al. sought to gain the views of many different healthcare professionals, the response rate for their survey was only 29%, leading to concerns about how well the survey findings truly represent the opinions of healthcare professionals working in that setting (Sheward *et al.*, 2011). The authors also acknowledge that some of the survey questions were potentially ambiguous and included questions about barriers to care but lacked questions about factors which might facilitate good care, thus leading to the potential for negativity in responses (Sheward *et al.*, 2011). Whether surveys or interviews are used, self-reports from staff may not accurately reflect the true opinions or actions of participants. Observation of participant-patient interactions is one way of further investigating participant reports, yet while Thompson et al. conducted participant observation, this focused only on the environment in which they worked and no direct observations were made of nurse-patient interactions (Thompson *et al.*, 2006).

These studies highlight some of the challenges in providing end-of-life care on acute hospital wards. They highlight the potential for conflicting approaches to care especially when there is uncertainty about whether the patient is dying and when different perspectives may be held by members of the same staff team. Studies have also compared the differences in perspectives between patients, relatives and staff and these will be discussed in the next section.

4.2.3   *Comparisons between different perspectives about End-of-Life Care in Hospital*

Patients, relatives and healthcare professionals may experience end-of-life care differently yet few studies have investigated such differences. Two studies examining the concordance of views between bereaved relatives and members of the healthcare team have shown disparities in participants' perceptions (Galanos *et al.*, 2012; Witkamp *et al.*, 2015). Galanos et al. used satisfaction surveys to assess the satisfaction with end of life care of bereaved relatives and healthcare professionals in hospital. While overall satisfaction levels were high, staff satisfaction ratings differed significantly in areas of symptom management, family and patient expectations and spiritual care (Galanos *et al.*, 2012). Witkamp et al. conducted a cross-sectional study of bereaved relatives, doctors and nurses in a large Dutch hospital (Witkamp *et al.*, 2015). Measurements included

concordance on the quality of life in last three days of life, quality of dying, awareness of impending death and communication. Overall concordance was poor in all areas. Relatives gave significantly lower scores for quality of life in the three days before death than staff members. Relatives reported being aware of impending death only 48% of the time, whereas nurses and doctors rated being aware of impending death as 73% and 77% respectively. Doctors more often reported informing relatives about end-of-life than either nurses or relatives (Witkamp *et al.*, 2015).

Both of these studies questioned participants (healthcare professionals and bereaved relatives) a certain time after the death of the patient. While healthcare professionals provided responses within one to two weeks of the patient's death, relatives were not approached until eight to twelve weeks after the patient's death. This may have led to re-call bias in responses, especially from relatives whose views and perspectives might have changed in the intervening time. It is also possible that healthcare professionals involved and spoke to other relatives who were not the relative participating in the study. And neither study can provide data from the non-responders whose views may differ significantly from those of the participants.

Studies comparing the level of agreement between health professionals' and patients' understanding of prognosis and information at end-of-life have revealed considerable discrepancies between the perceptions of patients and health professionals (Fried *et al.*, 2003; Hancock *et al.*, 2007a). For example, in a study by Haidet et al. discussions between physicians and patients did not improve physicians' understanding of patients' preferences for CPR. After discussion with patients, physicians were still incorrect about patients' preferences for CPR 30% of the time (Haidet *et al.*, 1998). Hancock et al. found that where there was disagreement between accounts, most patients underestimated the severity of their disease; while healthcare professionals tended to underestimate patients' need for information and overestimate their understanding of their condition (Hancock *et al.*, 2007b). Authors of such studies suggest that these discrepancies highlight the importance of regular and straight-forward communication between staff and relatives, frequent checking of understanding and greater collaboration between healthcare professionals and relatives as they seek to provide end-of-life care for patients.

In this section I have outlined the literature relating to end-of-life care in acute hospitals from the perspectives of patients, relatives and staff members. Communication and decision-making were highlighted repeatedly as being important parts of such care. Patients and relatives have consistently reported their opinions on the importance of adequate information, clear communication and the opportunity to be involved in decision-making. In contrast, they have reported lower levels of satisfaction with care when these components are lacking. Healthcare professionals' reports often agree with the importance of these components of care and yet they describe challenges in ensuring their provision in acute hospital settings. Furthermore, comparative studies have highlighted divergent reports from relatives and healthcare professionals about the care provided and received. It appears that what is 'clear' to the healthcare professional may not be 'clear' to the relatives and that communication and decision-making require much more than the transfer of information from the healthcare professional. In the following sections I explore specific literature on communication and decision-making in greater depth.

4.3   Communication in End-of-Life Care

In medicine communication was traditionally conceptualised in a mathematical and scientific manner. It involved the transfer of objective information from a transmitter (usually the healthcare professional) to a receiver (patient). Any discrepancy in the understanding of the information as intended by the healthcare professional was seen as due to failings on the part of the patient (Dixon-Woods, 2001; Elwyn *et al.*, 2014). This was the predominant view of language during the twentieth century[7]. Yet many authors from varying backgrounds such as sociology and philosophy have subsequently argued that language is not passive but active. From this perspective language is: '*essentially social and rooted in the struggle and ambiguities of everyday life. Meanings of words are derived not from fixed relationships between abstract signs, but from the accumulated*

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[7] Many of the ideas related to this perspective came from the study of linguistics in the twentieth century, in particular a strand of linguistics known as structuralist. For further information on these ideas and how perspectives changed toward a more social view of language, see: (Kress, 2001)

dynamic social use of particular forms of language in different contexts and for different and sometimes conflicting purposes' (Maybin, 2001, p. 65).

Over the last forty years multiple models of communication within the healthcare consultation have been developed[8]. Within the broader literature of communication in healthcare, is an extensive literature on the specific practice of 'breaking bad news'. Much of this literature has developed from work in oncology and has investigated communication between oncologists and patients with cancer. This literature will be further discussed in the following section.

4.3.1 Breaking Bad News

Bad news has been defined as any information which adversely impacts on the individual's expectations for their future (Kaye, 1996; Ptacek and Eberhardt, 1996; Bousquet *et al.*, 2015). The impact that receiving bad news has on patients, and the impact breaking bad news has on healthcare professionals has been described in the literature (Stewart, 1995; Fallowfield and Jenkins, 2004; Sastre *et al.*, 2011). For cancer patients, poor communication of bad news has been associated with worsened clinical and psychosocial outcomes, inadequate pain control, reduced adherence to treatment, confusion over prognosis, and dissatisfaction at not being involved in decision making (Stewart, 1995; Fallowfield and Jenkins, 2004; Fallowfield, 2009; Haskard-Zolnierek and DiMatteo, 2009; Hanratty *et al.*, 2011). For the clinician, communication difficulties have been found to lead to reduced job satisfaction, higher stress levels, increased errors and complaints (Ramirez *et al.*, 1995; Levinson *et al.*, 1997). Yet evidence suggests that when communication is perceived by patients as good, patient outcomes such as adherence to treatment and quality of life are improved (Ong *et al.*, 1995; Haskard-Zolnierek and DiMatteo, 2009). Therefore, it is important that healthcare professionals are able to communicate bad news well. The practice of breaking bad news in professional contexts, such as medicine, law, and pastoral counselling, has been the topic of considerable research and has been outlined in the literature (Maynard, 1996; Lutfey

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[8] Some communication models focus on tasks, some on processes and outcomes: some models are skills-based, others focus on the relationship between the doctor and patient, or the patient's perspective of illness and some follow a temporal framework. Many models incorporate more than one of these aspects. Silverman suggests that models like these provide the healthcare professional with a framework for communication and can help to identify where problems are occurring within the consultation, and which skills needs to be learned to attain the desired outcome (Silverman, 2014).

and Maynard, 1998; Maynard, 2006). Much of the literature suggests that the delivery of diagnostic news often follows an orderly pattern: introductions, finding out the reason for the consultation, history and examination, diagnosis, treatment recommendation and conclusion of the consultation (Maynard, 2006). Many theoretical frameworks, educational programmes and skills-based teaching have been developed to help improve the communication of bad news by healthcare professionals (Kaye, 1996; Baile *et al.*, 2000; Fallowfield and Jenkins, 2004; Villagran *et al.*, 2010; Silverman, 2014). Maynard has described three strategies for breaking bad news: Forecasting – which involves helping the recipient to anticipate and pre-formulate the bad-news-to-come; Stalling – avoidance or delaying telling the news; and Being Blunt – Dropping the bad news with little forewarning (Maynard, 1996). He proposes forecasting as the optimal method because it helps the recipient to realise the bad news they are being told and understand its likely impact on their life. In contrast, he suggests that narrative evidence shows that stalling or being blunt can lead to recipients felling incapacitated, exacerbate the disruption to their perceived normality and impede realisation (Maynard, 1996).

Many frameworks for breaking bad news propose a step-wise approach to disclosure, such as Kaye's ten-step approach (Kaye, 1996)[9]. Another commonly used framework taught to medical and healthcare students, from which many other protocols have been derived, is called SPIKES (Baile *et al.*, 2000; Villagran *et al.*, 2010). This acronym stands for: Setting up the consultation, assessing the patient's Perception, obtaining the patient's Invitation, giving Knowledge and information to the patient, addressing the patient's Emotions with Empathetic responses, and Strategy and Summary (Baile *et al.*, 2000). Baile et al. describe SPIKES as a six-step protocol which enables clinicians to fulfil the most important objectives when disclosing bad news: gaining information from the patient, transmitting the medical information, providing support and gaining the patient's collaboration in making a plan for the future (Baile *et al.*, 2000).

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[9] Kaye proposes the following ten step approach for breaking bad news: 1. Preparation – find out all the facts before the meeting, 2. Establish what the patient knows, 3. Establish what the patient wants to know, 4. Give a warning sign either verbally or non-verbally, 5. Allow for denial, 6. Explain, 7. Listen to concerns, 8. Encourage ventilation of feelings, 9. Summary and plan, 10. Offer availability (Kaye, 1996; Arber and Gallagher, 2013).

However, frameworks such as SPIKES and Kaye's ten-step approach have been criticised on many grounds. Such popular approaches to communication and breaking bad news training have been critiqued for being scientific, reductionistic and failing to recognise the importance of creativity and individuality in communication practice (Salmon and Young, 2011; Arber and Gallagher, 2013). Many approaches simply focus on the 'telling' of bad news rather than considering the patient's underlying assumptions and emotions (Broom *et al.*, 2014). Villagran et al. argue that SPIKES fails to highlight the importance of critical thinking and recognition of ethical difficulties during the disclosure of bad news (Villagran *et al.*, 2010). Furthermore, they suggest that step-by-step models may diminish the humanness and interactivity of students during consultations and they argue that such models do not help students to learn how to clarify and discuss issues central to breaking bad news such as: patient expectations related to the goals of care, the place of care, involvement of the family etc. (Villagran *et al.*, 2010). It has been suggested that frameworks like SPIKES can lead to the impression that the disclosure of bad news can be completed in one session or one 'moment' between the clinician and the patient, when in reality it is often an ongoing process of discussion between patients, family members and many different healthcare professionals (Bousquet *et al.*, 2015). Therefore, models like SPIKES may fail to prepare students and healthcare professionals to sensitively manage the complex interactions between patients, relatives and clinicians during the disclosure of bad news.

The literature highlights a lack of good evidence for the effect of breaking bad news skills training and that much of the breaking bad news research has focused on the attainment of vital skills by clinicians rather than on the benefit received by the patient (Paul *et al.*, 2009). A systematic review of the evidence base for guidelines on breaking bad news to patients with cancer found that only 55.5% of the 245 relevant publications provided new data and less than 2% were rigorous intervention studies which addressed important psychosocial outcomes for patients (Paul *et al.*, 2009). More recent studies have investigated patient preferences related to the disclosure of bad news (Fujimori and Uchitomi, 2009; Hanratty *et al.*, 2011; Gomes Martins and Palmares Carvalho, 2013). They suggest that key aspects of the disclosure of bad news are important, such as: the setting, the manner of communication (pace and clarity), what and how much information is given and the emotional support provided by the clinician

(Fujimori and Uchitomi, 2009; Hanratty *et al.*, 2011). Furthermore, the patient's cultural background may influence their preferences and must be taken into account by the clinician (Fujimori and Uchitomi, 2009). While many patients may prefer a more empathetic professional approach, some will favour a more distant approach (Gomes Martins and Palmares Carvalho, 2013). These findings highlight the need for clinicians to be aware of and able to tailor information to the needs and preferences of patients. The perspectives of patients approaching the end of their life in hospital related to communication with healthcare professionals will be discussed further in section 4.3.3.

As discussed earlier in this chapter, despite widespread communication skills training for healthcare professionals and students, complaints about communication continue to follow end-of-life care. Furthermore, the concept 'communication' has become so broad in its meaning that almost every aspect of healthcare can be seen to fit into it such that exactly what is meant by this term has become vague and unclear. This has led some authors to call for the concept of communication to be 'disentangled' and for greater consideration of the theory of communication practice (Deveugele, 2015, p. 1288).

4.3.2 Perspectives on Language and Communication

The disciplines of sociology and philosophy have provided insights into the roles and actions of language. A social view of language perceives language as an active concept. It is not simply a passive and neutral tool used by human beings to represent the things they see around them (Wetherell, 2001). Rather it works to create social worlds, minds and relations. This means that while words can and do represent the world, they also work to form the world as they represent it (Wetherell, 2001). It does not mean that the doctor brings the reality of a diagnosis into being by speaking about it. The doctor requires the patient and their physical body in order to make a diagnosis. Yet in a sense, when a doctor and a patient discuss the patient's diagnosis for the first time, what reality is for that patient emerges as they speak together. *'As accounts and discourses become available and widely shared, they become social realities to be reckoned with; they become efficacious in future events. The account enters the discursive economy to be circulated, exchanged, stifled, marginalised or, perhaps, comes to dominate over other possible accounts and is thus marked as the 'definitive truth''* (Wetherell, 2001, p. 16).

Taylor also argues that language does not simply represent things or work to make them explicit, it is also intricately involved in the reality of certain phenomena (Taylor, 1985). He proposes that phenomena such as the feelings we hold about things and the relationships we have with others are in part determined by the way we articulate them (Taylor, 1985, p. 270). As well as formulating and constituting reality, Taylor proposes that language works to make situations public, or to place ideas and information in the '*public space'* (Taylor, 1985, p. 259): *'language serves to place some matter out in the open between interlocutors. One might say that language enables us to put things in public space. That something emerges into what I want to call public space means that it is no longer just a matter for me, or for you, or for both of us severally, but is now something for us, that is for us together'* (Taylor, 1985, p. 259). Taylor maintains that accounts of communication as a transfer of information from one person to another are wrong because they fail to take account of this public space between people (Taylor, 1985). By expressing something out loud to others, we engage others publically in the matter under consideration. This not only allows the matter to be shared, but it can also work to build rapport and shared understanding between people. In this way language enables the formation and maintenance of relationships between staff, patients and relatives, which are an integral part of the ongoing care.

Taylor maintains that language has a further role in expressing peoples' values. Furthermore, he argues that the self is established by moral concerns and that there is an inseparable connection between peoples' sense of good and their sense of self (Smith, 2002, p. 88). If correct, such a theory emphasises the importance of understanding the moral concerns of patients and relatives and the potential relational damage that could be done by ignoring or failing to see them. However, empirical research suggests that moral concerns and ethical issues can and do go unrecognised by staff in hospitals. Chambliss (Chambliss, 1996) conducted an ethnography in various hospital settings in the United States and he proposes that ethical problems arise from the fundamental structure of the hospital. He maintains that routinization works to make the extraordinary ordinary, healthcare professionals assume '*taken for granted*' stances and in this way ethical decisions and values can become invisible (Charmaz, 1997, p. 1484).

The use of language is therefore not a neutral activity and words are, by their very nature, judgemental about the world (Maybin, 2001). The words we use are already

coloured by past uses, where we have heard them used and who we have heard speak them. Bakhtin describes the 'struggle' people go through as they produce meaning from words which already have multiple different connotations and associations:

> *'The word in language is always half someone else's. It becomes one's own only when the speaker populates it with their own intentions, their own accent, when they appropriate the word, adapting it to their own semantic and expressive intention. Prior to this moment of appropriation, the word does not exist in a neutral and impersonal language (it is not, after all, out of a dictionary, that the speaker gets their words!), but rather it exists in other people's mouths, in other people's concrete contexts, serving other people's intentions: it is from there that one must take the word, and make it one's own. There are no 'neutral' words and forms – words and forms that can belong to 'no-one'; language has been completely taken over, shot through with intentions and accents. For any individual consciousness living in it, language is not an abstract system of normative forms but rather a concrete heteroglot conception of the world. All words have the 'taste' of a profession, a genre, a tendency, a party, a particular work, a particular person, a generation, an age group, the day and hour. Each word tastes of the context and contexts in which it has lived its socially charged life; all words and forms are populated by intentions'* (Bakhtin, 1981, pp. 293-4).

Therefore, in these different ways, language can be seen to be active and involve work (Wetherell, 2001). It is not a passive and neutral tool, but is itself active in the formation of reality as it is experienced by participants in a given situation. In his book on end-of-life care in the United States, Gawande, a surgeon, discussed end-of-life care with a palliative care specialist who explained: '*a family meeting [at end-of-life] is a process, and it requires no less skill than performing an operation*' (Gawande, 2014, p. 181). Such a meeting involves the careful choice of words, how they are organised in a given context or in response to a certain query, the building of rapport and relationship, the recognition of one's own values and those of others, careful navigation and negotiation through these values and various possibilities for care, while always keeping in mind that perspectives and opinions may change and alternative plans may need to be made. Writing about language use in palliative medicine, O'Connor et al. maintain that '*great care is needed in choosing words to describe palliative care, since words incarnate the service*' (O'Connor *et al.*, 2010).

4.3.3 Literature exploring End-of-Life Communication in Hospital

In 2007 a systematic review of studies focusing on communication of prognosis and end-of-life issues with adult patients and/or their caregivers in the advanced stages of a

progressive life-limiting illness was carried out (Hancock *et al.*, 2007a; Hancock *et al.*, 2007b; Parker *et al.*, 2007). The authors found that while most health professionals believed patients and caregivers should be told the prognosis, in practice many avoided the discussion or withheld the information (Hancock *et al.*, 2007a). In line with this finding patients reported that prognosis was not discussed unless they directly asked about it, and many felt that information was given only when there was a clinical reason for doing so (Hancock *et al.*, 2007b). One reason proposed for this finding was the anxiety clinicians may have of destroying a patient's hope. Yet the studies suggest it is possible to discuss prognosis without having a negative impact on the patient and that honesty about the clinical situation can be a means of giving hope (Hancock *et al.*, 2007a). In general, patients and caregivers reported a need for more information at all stages on the disease process (Parker *et al.*, 2007). While these studies combine the results of many different studies and thus present the views and experiences of many participants involved in end-of-life care, it is important to keep in mind the potential for publication bias and analysis bias which will necessarily influence with conclusions of the systematic reviews.

In a review of 'information giving' to patients with advanced cancer, almost all patients wished to have information about their condition (Gaston and Mitchell, 2005). Yet some research suggests that a patient's need for information may change as their condition progresses, with a desire for less information while their relatives may want more (Parker *et al.*, 2007). Caswell et al. found that lack of clarity in communication through the use of euphemistic or vague language could lead to unrealistic expectations of relatives (Caswell *et al.*, 2015). Furthermore, the practices and realities of end-of-life care could be foreign to patients and relatives, and relatives sometimes interpreted practices and communication on the ward very differently to staff members. For example, one relative had not realised that she had been granted open visiting because her loved one was dying (Caswell *et al.*, 2015). This helps to explain why it is possible for participants to have different understandings following participation in the same discussion (Haidet *et al.*, 1998; Fried *et al.*, 2003; Hancock *et al.*, 2007b). Caswell et al. highlight the importance of alignment between the relatives' and healthcare professionals' perspectives in order to ensure a correct understanding of the situation (Caswell *et al.*, 2015).

Krawczyk and Gallagher (Krawczyk and Gallagher, 2016) conducted telephone interviews with ninety bereaved family members of patients who had died in hospital four to six months previously and they focused on the last 48 hours of care. They describe their findings with relation to the communication of prognostic uncertainty. Fifty percent of the respondents felt very satisfied with the quality of communication, while 45% wanted more information about what to expect from the dying process. Respondents reported a lack of information about their possible prognosis and the fact that the patient was 'sick enough to die'. Family members described feeling confused about the provision of ongoing acute care. When staff did communicate, respondents complained about the use of euphemisms and the provision of false hope. Because many families had not understood that the patient was 'sick enough to die', some questioned whether wrongdoing had occurred when the patient had died seemingly 'unexpectedly'. Krawczyk and Gallagher identify interesting findings related to the respondents' self-reflexivity around the challenges and benefits of the communication of prognostic uncertainty. Some respondents were aware that they may resist knowing, but surprisingly, these respondents also expressed a retrospective understanding that they would have benefitted from knowing about the prognosis. Respondents who reported that the healthcare professional did communicate about prognostic uncertainty also reported effective communication, information-sharing and greater satisfaction with care. Finally, clear communication was seen to enable the families to spend time with the patient at end-of-life. These findings highlight the importance of healthcare professionals acknowledging uncertainty and clearly and sensitively explaining to patients and relatives when they think the patient is 'sick enough to die' (Krawczyk and Gallagher, 2016). This study used telephone surveys to gain the views of bereaved relatives. The telephone conversations were not digitally recorded and instead the researcher took short notes which were later transcribed. The potential for bias is clear as the notes will focus on topics of more interest to the researcher and may not have accurately represented the full content of conversations.

From the international literature on end-of-life care in hospital it is clear that communication at end-of-life is important to patients and relatives receiving care. Key aspects of communication identified by patients and relatives have included: the use of clear and understandable language, honest communication, staff members who are

available and take time to listen, being kept informed and the manner in which staff explain bad news (Robinson *et al.*, 2014; Virdun *et al.*, 2015). Yet these studies have also highlighted problems with communication leading to dissatisfaction from patients and relatives. In 2008, communication was highlighted as an important aspect of end-of-life care in the UK Government's End of Life Care Strategy and increased training and development was advised for healthcare staff and students alike (Department of Health, 2008a). Yet despite national policy, perceived poor communication at end-of-life has continued to be a frequent cause of complaints within the NHS (PHSO, 2015). Communication was found to be an important component of care in this study and in Chapter Eight, I present an analysis of the data with respect to two important constituents of communication: language and meaning.

4.4   Decision-Making in End-of-Life Care

Traditionally, the approach to decision-making in healthcare has been described as paternalistic[10]: the doctor took the lead role in determining and implementing what he viewed as best management for the patient (Emanuel and Emanuel, 1992; Quill, 1996; Charles *et al.*, 1999). Recently alternative models of decision-making have been proposed such as the informed choice approach[11] and SDM[12]. Other authors have

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[10] A paternalistic approach: suggests that there are objective criteria for discerning the best management plan, which the doctor can determine with minimal if any patient involvement (Emanuel and Emanuel, 1992) While this may be the case in life-threatening emergencies, where the doctor has to act rapidly to preserve the patient's life, such an approach is deemed unacceptable for routine medical practice today. By failing to recognise the importance of the patient's views, this approach disregards the patient's autonomy and their right to be informed about their treatment and care. It also fails to recognise the presence and importance of both the doctor's and patient's values and perspectives on care.

[11] Informed choice approach: positions the doctor as the provider and the patient as the consumer. The doctor is an administrator of technical knowledge and expertise which he provides to the patient, so that the patient may take control of their decision (Emanuel and Emanuel, 1992; Charles and Gafni, 1997) This approach assumes a distinction between facts and values; suggesting that once provided with the 'facts', patients (who are fully aware of their values) can use their values to determine the best course of action for themselves. From this perspective, patients simply lack the requisite knowledge to make the decision (Emanuel and Emanuel, 1992)

[12] Shared Decision-Making (SDM): The assumption underlying SDM is that while the doctor may know more about the options for effective treatment, the patient knows best how changes in her health will impact on her wellbeing (Charles and Gafni, 1997) The SDM model can be thought of as an expert-to-expert approach with each participant bringing important information to bear on the decision. The basic characteristics and criteria of SDM have been outline as follows: first, SDM involves the patient and doctor in the decision-making process

described decision-making as being on a spectrum between doctor-centred and patient-centred approaches or between approaches which are more unilateral or more bilateral[13]. In recent decades SDM has been advocated on both ethical and clinical grounds as a means of ensuring that patients' views are heard and respected (Quill, 1996; Belanger *et al.*, 2010; Muller-Engelmann *et al.*, 2011) and has been promoted as the gold standard in decision-making in healthcare (Salzburg Global Seminar, 2011). Furthermore, empirical research has suggested that SDM may be especially important in the care of patients approaching the end-of-life when there may be multiple and complex decisions, when evidence-based medicine has little to offer and when decision-making is strongly influenced by personal values and preferences (Belanger *et al.*, 2010; Muller-Engelmann *et al.*, 2011). Yet its implementation in clinical practice has been problematic and many barriers to SDM, such as physician related barriers, patient-related barriers and system-related barriers have been identified (Gillick, 2015).

Recent inter-disciplinary and sociological work has also provided helpful perspectives on decision-making. Rapley proposes that much decision-making in healthcare is an ongoing process distributed over time and place. He suggests that recognising the 'distributed' nature of decision-making provides a more realistic approach than other more prescriptive models of decision-making and can work to support 'decision-making-in-action' (Rapley, 2008). While most theoretical approaches to decision-making have viewed it as a circumscribed activity carried out by one patient, Elwyn et al. suggest that in reality it is '*a combination of mental work and embodied actions (or inaction) contingent on engagement with others*' (Elwyn *et al.*, 2014, pp. 158-9). They have developed a conceptual model which they believe underpins key approaches to patient-centred care including SDM. The model, which they have termed 'collaborative deliberation' analyses the process of supporting patients to consider alternative health

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(in practice there may be many more participants, such as family members and other healthcare professionals). Second, both the patient and the doctor must share information with each other, and both must participate in the decision-making process. Third, a treatment decision is made that both the doctor and the patient agree on. Having set out the above criteria, Charles et al. acknowledge that there is no 'single route' to SDM, and that it must be practiced in accord with the patient's preferences for participation (Charles and Gafni, 1997).

[13] Collins et al. *'In a more 'bilateral' approach, decision-making was enacted as an integral part of communication in consultations, negotiated between the practitioner and the patient, and dependent in part on the patient's contributions. In more 'unilateral' approaches, the practitioner more or less autonomously conducted the decision-making process, structuring it somewhat independently of his or her conversation with the patient'.* (Collins *et al.*, 2005, p. 2613)

care options in collaboration with healthcare professionals. The model is composed of five inter-related propositions: (1) constructive interpersonal engagement, (2) recognition of alternative actions, (3) comparative learning, (4) preference construction and elicitation and (5) preference integration. (Elwyn *et al.*, 2014). This model appears to acknowledge and focus on the interaction, discussion and deliberation that is so important in healthcare. In light of these ideas I now present research findings related to the practice of decision-making in end-of-life care.

4.4.1   Patients' Preferences for Involvement in Decision-Making

A systematic review of information giving and decision-making in patients with advanced cancer reported that only around two-thirds of patients wanted an active role in decision-making, though the term 'active' was not defined in the review (Gaston and Mitchell, 2005). Studies showed that as cancer patients became more unwell their desire to be involved tended to decline (Gaston and Mitchell, 2005). However, this review included only English language studies and the authors highlight that their findings may not be generalizable to other cultures. However, similar findings were noted in a systematic mixed studies review of SDM in palliative care (Belanger *et al.*, 2010). Seven of thirty seven studies investigated patient preferences for decision-making and in these studies a passive role was defined as wanting the doctor to make decisions alone or after considering the patient's opinion. SDM was defined as making decisions together with the doctor and an active role was defined as the patient making the final decision alone or after considering the doctor's opinion (Belanger *et al.*, 2010, p. 253). The data show that between 65-87% of the 614 palliative patients questioned had a desire for involvement in decision-making either through SDM or an active role, yet a substantial minority desired a more passive role (Belanger *et al.*, 2010). From these results it seems that a patient's preference for involvement in decision-making may be difficult to predict and may change over time.

4.4.2   Relatives' Preferences for Involvement in Decision-Making

The literature regarding the involvement of relatives or families in decision-making can be thought about in two categories: the involvement of relatives when their loved one

retains mental capacity, and their involvement when their loved one has lost mental capacity to be involved in the decision. In reality, as patients approach end-of-life their capacity may fluctuate before they finally lose capacity, and so this distinction may not be so clear cut. In the literature there is a vast number of research studies relating to 'surrogate' decision-making at end-of-life many of which investigate decision-making in intensive care settings[14]. The term 'surrogate' which suggests that the relatives have sole responsibility of healthcare decisions is not a term used in the UK, where the MCA is in place and the best interest decision-making process is used[15]. The literature has shown difficulties in surrogate decision-making and conflicts between surrogates and physicians (Prochaska and Sulmasy, 2015). It has been argued that Western medicine's focus on the value of autonomy has led to a lack of recognition on the importance of family members in decision-making in end-of-life (Levine, 1999; Winzelberg *et al.*, 2005). This has led many to call for a family-centred approach to end-of-life care which involves SDM (Nelson, 1992; Ho, 2008; Truog *et al.*, 2008). Indeed some research has shown that most surrogates prefer a shared form of decision-making (Prochaska and Sulmasy, 2015).

Excluding situations where patients have lost mental capacity and the family member is considered a surrogate decision-maker, often in intensive care settings, there has been much less research investigating family members' preference for involvement in decision-making when a loved one is dying on general hospital wards (Davison and

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[14] Research investigating surrogate decision-making has tended to centre on end-of-life decision-making in critical care settings, it includes research on the perspectives of surrogate decision-makers: (Heyland *et al.*, 2003); ethical issues in surrogate decision-making: (Berger, 2008; Prochaska and Sulmasy, 2015); surrogacy accuracy: (Meeker and Jezewski, 2005); the toll of surrogate decision-making on surrogates: (Meeker and Jezewski, 2005)

[15] As outlined in Chapter Three, in the UK clinical decision-making is guided by professional recommendations when patients retain capacity, and the MCA when patients have lost capacity. Here, when a patient has lost capacity and choices about healthcare are in question usually their consultant is considered the decision-maker and will involve the family in a best interests decision-making process (unless they have an appointed legal representative for health and welfare). However, in the United States, if patients lack capacity, their relatives are termed 'surrogate' decision-makers and make decisions on their behalf. If no relatives are present, the doctors make what is known in the U.S. as a best interests decision (Meeker and Jezewski, 2005).

Degner, 1998; Belanger *et al.*, 2010). However, one recent study has addressed the experience of relatives of patients dying in hospital on non-intensive care wards in The Netherlands (Witkamp *et al.*, 2016). Four hundred and fifty one recently bereaved relatives (response rate 51%) completed a questionnaire about hospital care in the last days of life and the results underwent qualitative analysis. And while the study cannot provide any data about the views of non-responders who may have held differing perspectives, the results are consistent with previous studies in which relatives expressed the need for comprehensible and timely information about their loved one presented in a sensitive manner. Many relatives reported on their involvement in decision-making both when patients had capacity and when they did not. The relatives who were satisfied with the process described being clearly informed and said they had made decisions together with the doctors (Witkamp *et al.*, 2016). Relatives who stayed on the ward with their loved one felt better informed and involved in decisions than those who were unable to do so. Relatives who did not feel involved in decision-making described feeling neglected and disagreed with decisions or didn't understand the decisions made. Relatives described their need for acknowledgement by healthcare professionals, which meant affirming both the patient and the relatives as people and recognising the role of the relatives in relation to the patient (Witkamp *et al.*, 2016).

Teno et al. conducted six focus groups with forty two bereaved relatives whose loved one had recently died in hospice, hospital, nursing home or at home with nursing care support (Teno *et al.*, 2001). They were asked about their experience of end-of-life care and their opinions about quality end-of-life care. One of the themes identified was that quality care helped the patient to take control over decisions about everyday treatment routines. Family members reported that such control meant that patients and family should be involved in decisions about treatment (like resuscitation) and everyday decisions (such as choosing when to bathe) (Teno *et al.*, 2001). However, while family members wanted to be involved some were critical of staff for implying the responsibility for decision-making rested on family alone rather than being shared with the healthcare team. This could leave them feeling '*abandoned in the decision-making process'* (Teno *et al.*, 2001, p. 743). Many families described a constant, self-imposed burden of advocacy in order to ensure the best care of their loved one. While this study included only a small number of participants whose views may not be representative of

the wide population, they are consistent with the findings of other studies previously discussed. These studies highlight the importance of clear and timely information conveyed in a sensitive manner. This kind of communication is viewed by relatives as central to the decision-making process. Furthermore, these studies suggest that most relatives want to be involved by making decisions together with healthcare professionals.

4.4.3 Difficulties with Decision-Making at End-of-Life

While SDM is regarded as the 'gold-standard' in clinical decision-making, numerous barriers to SDM have been described in the literature (Gillick, 2015). Within a palliative care population barriers may include: unmet needs for information, unrealistic expectations, framing of decisions by clinicians and delaying decisions in order to fit with standard patterns of care provision. All of these have the potential to affect the patient's ability to participate in decision-making and the quality of decisions made (Belanger *et al.*, 2010). For example, if chemotherapy is framed as a positive decision by physicians while palliative care is described as 'doing nothing', it seems that patients will be much less likely to choose palliative care (Koedoot *et al.*, 2003). Furthermore, if a patient is unaware of the severity of their condition and a physician fails to acknowledge the need to make decisions about end-of-life care, decision-making is unlikely to take place. Drought and Koening found that rather than active SDM at end-of-life, families found that end-of-life care 'fell into place' as patients deteriorated and the fact that they were dying could no longer be denied (Drought and Koening, 2002, p. 121).

SDM is based on the ethical principle of respecting the autonomous decisions of patients and is closely related to the concepts of informed consent and informed choice (Agledahl *et al.*, 2011). Yet Agledahl et al. argue that a focus on patient choice fails to grasp the key moral aspects involved in healthcare and is not an accurate representation of the way healthcare takes place in real life. Instead they propose that: '*Clinical practice is better described as a process over time and space in which several participants guide the actions that are taken. Patients are not without influence in this process, since good clinical practice is adjusted to their needs, but opportunities for autonomous choice are, in fact, quite limited*' (Agledahl *et al.*, 2011, p. 213). Agledahl et al. imply that a model of decision-making that focuses on patient choice creates unrealistic and unhelpful

expectations for clinical practice. Furthermore, research involving healthcare professionals who have become unwell and experienced life as a patient, has described real and significant difficulties. Despite their background medical knowledge and experience, the process of decision-making was burdensome for these doctor-patients (Olthius *et al.*, 2014). Olthius et al. argue that: '*good care in everyday practice is a collaborative enterprise in which healthcare professionals and patients continuously cocreate and codirect the course of events that make up the patient's life*' (Olthius *et al.*, 2014, p. 494) and that to make the serious decisions that patients and relatives face at end-of-life requires an understanding of their lived experience (Olthius *et al.*, 2014).

A further critique of SDM and modern healthcare decision-making is the failure to recognise the importance of involving those close to the patient in decision-making about appropriate treatment and goals of care. Lloyd argues that the inter-relatedness of people and importance of their narrative and context has been overlooked by the current societal and political focus on individual rights and autonomy (Lloyd, 2004, p. 247). In their study of the experience of bereaved relatives Witkamp et al. highlight that staff in hospital tend to focus on the individual patient and consider patients to be autonomous, rational and independent in their decision-making (Witkamp *et al.*, 2016). Yet they also propose that at end-of-life patients often think and act in relation to the family and friends around them and suggest that in such situations the idea of individual autonomy may fail to lead to good decision-making. Instead, Witkamp et al. call for healthcare professionals to acknowledge the interdependence of the human condition and to recognise the important role that relatives play in the care of patients at end-of-life. They propose that the concept of relational autonomy is more appropriate at end-of-life, whereby: '*the patient and the relatives are seen as interdependent...... where the involvement of relatives is important in preserving or restoring an overall sense of patients' identity, agency, and selfhood*' (Witkamp *et al.*, 2016, p. 7).

In response to the difficulties of SDM implementation, Gillick proposes a re-engineered form of SDM. Instead of doctors giving information about treatments and patients then being expected to weigh up and to decide which treatments are in accord with their values, Gillick suggests that the focus should be placed on the patient's goals for care. The doctor asks the patient to identify and prioritise the goals of their healthcare and the doctor then translates these value-goals into a treatment plan. Finally, the patient is

able to reject the doctor's plan if they so wish (Gillick, 2015). Such an approach appears to take the focus away from 'choice' and re-focus the discussion on the patient's 'care'.

A further and potentially unrecognised problem may be caused by the reluctance of relatives to express their views. In an interview study with fifteen relatives whose loved ones had suffered a severe stroke in the preceding two to six months, relatives were asked about their experiences of involvement in the decision-making process (de Boer *et al.*, 2015). Data revealed that relatives found making decisions under time pressure extremely challenging and were reluctant to express their opinions about withdrawing treatment even when they believed this was in line with the patient's wishes (de Boer *et al.*, 2015).

Different strategies to facilitate patient involvement in SDM have been described and assessed[16] however, most have not been rigorously tested (Gaston and Mitchell, 2005). Studies attempting to assess the impact of information disclosure and encouragement to participate in decision-making on patient outcomes such as anxiety, depression, patient satisfaction and life expectancy have reported mixed results. The impact of encouraging participation in decision-making remains unclear (Belanger *et al.*, 2010).

While the desire to respect a patient's autonomy has been a key impetus in decision-making research, the findings of the studies mentioned here suggest that decision-making at end-of-life requires a different approach. These studies have highlighted that rather than being a once-off choice made by an autonomous individual, as patients approach the end-of-life decision-making is distributed over time and between many different key people (including the patient, those close to the patient and healthcare professionals). What is needed is a more relational and distributed process of decision-making which nonetheless keeps the patient and their wishes and feelings at centre stage.

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[16] Interventions to improve information giving have included audio or videotaping the consultation and giving a copy to the patient at the end; providing a summary letter of the discussion; and patient information leaflets (Gaston and Mitchell, 2005). Strategies to encourage participation in decision making have also been developed, such as the question prompt sheet, which the patient uses to consider the questions they want to ask before entering the consultation (Clayton et al., 2003).

4.5   Conclusion

In this chapter I have discussed the literature concerning end-of-life care in hospitals. It has highlighted that care is a complex concept constituted by multiple and potentially varying component parts. Within studies investigating the perspectives of patients, relatives and staff, recurrent themes include information needs, communication and decision-making. In Chapter Two I traced the history of end-of-life care in the UK and the rise of palliative care and the prioritisation of end-of-life care in government policy. Yet as discussed in Chapter Three, concerns remain about the provision of end-of-life care in hospital. End-of-life care in the UK has recently undergone external scrutiny following the review of the LCP and the court cases concerning resuscitation decisions at end-of-life. For these reasons new end-of-life care policy has been introduced. The result of these influences on care remains unexamined and there is a need to investigate end-of-life care as it happens in practice. This thesis aims to provide a fresh examination of end-of-life care on hospital wards in light of such changes. By conducting prospective observational and interview research on acute hospital wards from the perspectives of patients approaching the end-of-life, relatives and staff, I seek to address this research need. In the next chapter I outline the way in which this research study was conducted.

Chapter 5   Methodology and Methods

In this chapter I outline the theoretical perspective underpinning this research study. The assumptions inherent to this perspective and the implications of this approach for the collection of data and analysis will be explained. The quality and value of this kind of qualitative research work will be discussed. An explanation of the way the study was conducted on the wards will be given and the research setting will be described in detail in order to provide a clear context for the research work. Finally the methods employed in data analysis will be explained.

5.1   Theoretical approach

This section outlines the ontological and epistemological assumptions which form the basis for the theoretical approach taken in this research project. My ontological approach is based on subtle realism and my epistemological stance is that of social constructionism. Three further perspectives which are central to the approach taken in this project are: symbolic interactionism, ethnography and grounded theory. Each of these perspectives will be described in turn, with an explanation of their influence on the research methodology.

5.1.1   Subtle Realism

Conducting research is not a passive or neutral endeavour (Rock, 2001). Everyone, whether conscious of it or not, holds assumptions and perspectives about life and knowledge which influence the way they act and respond to the world around them. In the same way, different approaches to conducting research assume different beliefs about the nature of knowledge, what it is and how it can be acquired and about the nature of reality including how one can study the world. Hammersley writes about the philosophical underpinnings of ethnographic research and contrasts the doctrine of realism with that of constructivism (Hammersley, 2002). Realism is the belief in an objective reality which can be discovered through precise and objective methods. Naturalist ethnography, commonly associated with anthropological research, is underpinned by the idea that by observing people in their 'natural' setting it is possible

to provide new knowledge and truth about them (Skeggs, 2001). Traditional enlightenment ideas maintained a realist approach and proposed that for true knowledge to be discovered methods must involve logically deduced hypotheses, systematic methods and replicable experiments (Charmaz, 2006). The assumptions underlying this positivist approach implies that it is possible for a researcher to be unbiased and neutral in their research work (Charmaz, 2006). Hammersley (2002) describes the constructivist approach as being in opposition to realism. Constructivism is the idea that people create knowledge through their interpretations of the world around them rather than discovering true and objective knowledge. In this way, they construct their own 'social worlds' which are seen as subjective and incommensurable (Hammersley, 2002, p. 67). Hammersley critiques this kind of constructivism as being on par with relativism, the belief that there is no absolute or objective reality, which is in conflict with realism. Hammersley critiques both stances. First, he argues that traditional realism is too simplistic in outlook by suggesting the impossible: that one can abandon all bias and underlying presumptions and thereby discover true reality (Hammersley, 2002). Second, he maintains that fundamental constructivism is just as problematic. For if what each researcher creates is simply one version of the world, true only for themselves from their particular cultural perspective, then it is likely to have little value for others (Hammersley, 2002, p. 71). Instead Hammersley suggests that relativistic constructivism and traditional realism are not the only two positions available and instead outlines a 'middle way' which he calls subtle realism (Mays, 2000; Hammersley, 2002, p. 73).

Subtle realism is characterised by the following criteria: first, knowledge should be considered as beliefs with which we are reasonably confident rather than absolutely certain. Second, there are real phenomena, which researchers may study, which are independent of any claims researchers may make about the phenomena. Any claim may represent these phenomena more or less accurately. Third, social research seeks to represent reality not to reproduce it. This acknowledges that the researcher is not neutral and always brings their own perspective to the research work (Hammersley, 2002, pp. 73-74). An additional view is that being a realist is not incompatible with being a constructionist: "*One can believe that concepts are constructed rather than discovered yet maintain that they correspond to something in the real world*" (Andrews,

2012, p. 2). Schwandt describes ordinary constructionism as believing that the mind is active rather than passive in knowing. For example, the mind does not simply receive knowledge like an imprint of what it perceives, but rather uses the impressions it receives to form concepts and frameworks to make sense of experience (Schwandt, 2003). He maintains that social constructionism is a matter of epistemology rather than ontology and that it neither affirms or denies the nature of reality (Schwandt, 2003).

Throughout this research project I have chosen to adopt the ontological perspective of subtle realism which is compatible with the epistemological stance of social constructionism. I will now outline my approach to data collection and analysis by describing three perspectives which are central to this research project: symbolic interactionism, ethnography, and grounded theory.

5.1.2 Symbolic Interactionism

Symbolic interactionism (SI) was the name given to a certain type of sociological perspective and methodology that developed in the University of Chicago in the 1920s and 1930s (Rock, 2001). George Herbert Mead, a philosopher at the University of Chicago is thought of as the originator of this approach however, it was advanced and defined by one of his students, Herbert Blumer (Charon, 1995; Cuff *et al.*, 2006). Blumer defined SI in the following way: "*the symbolic interactionist approach rests upon the premise that human action takes place always in a situation that confronts the actor and that the actor acts on the basis of defining this situation that confronts him*" (Rock, 2001, p. 27).

According to Blumer (Blumer, 1969), SI rests on three premises. First, people act according to the meanings that things have for them. The meanings that people make and understand from their interactions with the world are of central importance in terms of determining their subsequent action and interaction. The second premise is about the source of meaning and where it arises. For the symbolic interactionist, meaning originates in the process of interaction between people (Travers, 2001). Blumer contrasts this position with two other traditional perspectives of his day, those of realism and social psychology. The realist believes that meaning originates directly from the object and is intrinsic to it. Therefore the object must simply be observed for the meaning to be understood. From the social psychologist's perspective, meaning

arises from a combination of psychological elements (such as sensations, feelings, ideas, memories, and motives) that the person brings to the object. Blumer contrasts both of these approaches with that of SI, explaining that meaning arises in the process of interaction between people. SI views meaning as social products: "*as creations that are formed in and through the defining activities of people as they interact*" (Blumer, 1969, p. 5). The third premise is about the manner in which people use meaning. Blumer argues that it is a mistake to suggest that people simply apply pre-established meanings to things. Rather he maintains that people use meaning through a process of interpretation. First, in response to a situation a person determines which things have meaning. In this way the person is interacting with himself through an internalised social process. Second, the person then manages meaning by checking, selecting, and changing it depending on the situation and his desired course of action (Blumer, 1969). Charon describes this process as follows: "*we all define that world we act in; part of that definition is our own; our action involves conscious choices. We direct ourselves according to choices we make, we assess our actions and those of others, and we redirect ourselves*" (Charon, 1995, p. 24). SI views social interaction as of vital importance because it is through the process of social interaction that human conduct and behaviour is formed. These premises have important implications for research methodology in social science which will be discussed later in this section.

SI is underpinned by both empiricism and idealism. Empiricism is the view that all knowledge is derived from experience of the world. Mead was critical of those who tried to understand and explain the social world from a purely scientific perspective. He maintained that people do not respond to the world according to how it has been categorised by science but according to how they perceive it to be (Cuff *et al.*, 2006). On the contrary, idealism is the perspective that reality is mentally constructed and it exists only as much as people think it exists (Filmer *et al.*, 2004). Influenced by idealist views in the work of Kant (1724-1804), social science developed an interpretive approach to studying the social world (Filmer *et al.*, 2004). From an idealist perspective, people do not simply react to the world as it 'really is' but rather they respond to their consciousness of the world which is interpretive and experiential (Rock, 2001). While Blumer agreed with an idealist approach, he suggested that people are mistaken if they believe that reality can *only* exist in terms of ideas or conceptions independent of the

empirical world. He argued that this kind of fundamental idealist position makes empirical science impossible. Furthermore, he argued against it because of the fact that the empirical world '*can "talk back" to our pictures of it or assertions about it*' (Blumer, 1969, p. 22). Therefore SI is balanced by ideas from both idealism and empiricism (Rock, 2001).

If taken seriously the premises underpinning SI have important implications for research methodology. In the 1920s and 1930s in the United States, a positivist paradigm was dominant and the trend in social science was to examine the social world using standardised scientific procedures and methods (Blumer, 1969; Travers, 2001). It was believed that close adherence to strict research protocols would ensure valid results (Blumer, 1969; Travers, 2001). However, a symbolic interactionist approach opposes this perspective and instead calls for the direct examination of the social world through first-hand observation of daily life often using methods such as participant observation and ethnography (Travers, 2001; Filmer *et al.*, 2004). At that time this kind of direct observation was viewed as 'soft' science or journalism (Blumer, 1969; Travers, 2001). But Blumer argued that in order to study the social life one must conduct direct examination of real-life human interaction: the researcher must place himself or herself in the position of those under study in order to see from their perspective and the researcher must observe long enough to identify the main problems within the setting (Blumer, 1969). A further common view at the time was that by proper use of scientific methods the researcher could remain neutral and have little or no direct impact on the results (Blumer, 1969). In contrast, a symbolic interactionist approach acknowledges the unavoidable impact of the researcher on the research. All researchers cannot help but use their beliefs and pre-set ideas to create an intelligible construct of the phenomenon under study (Blumer, 1969; Rock, 2001). Therefore, researchers must guard against their own pre-established ideas and deliberately test their own developing ideas and theories. In line with the symbolic interactionist approach discussed here, I conducted my research using ethnographic methods and a constructivist grounded theory approach to data collection and analysis which will be explained in the following two sections.

5.1.3 Ethnography

Ethnography is a method originally used in anthropology in the nineteenth century, when ethnography referred to a descriptive account of a foreign culture (Hammersley and Atkinson, 2007). From the 1920s onward, sociologists began to develop this method as a means of studying the social life (Brewer, 2000). Ethnography involves observing participants in their 'natural' setting rather than in a controlled and predetermined environment. The researcher observes daily life 'in the field' often for a prolonged period of time. Data are collected by observing daily practice and by asking participants questions in formal and informal interviews. In this way, close-up study of social phenomena becomes possible (Charmaz, 2006). Because ethnography is used to provide in-depth information about phenomena, ethnographic research tends to focus on a particular setting and only a small number of participants. During analysis the researcher seeks to provide an in-depth interpretation of the data, focusing on the meaning, function and outcomes of observed behaviour (Brewer, 2000; Hammersley and Atkinson, 2007). Thus ethnography aims to provide a '*disciplined unravelling of the breadth and complexity of relations*' (Rock, 2001, p. 31). Ethnography has been used previously to study medical and healthcare settings (Lawton, 2000; Bloor, 2001; Zaman, 2008) and to study end of life care on hospital wards (Mills, 1994; Seymour, 2001; van der Geest and Finkler, 2004). During my study I observed daily medical practice on two acute medical wards. This included observing doctors' ward rounds, nurses' medication rounds, multi-disciplinary team meetings, hand-over meetings, and routine practice in and out of hours on the wards. I sought to explore the complexities of social interaction during end-of-life care on hospital wards and to examine the underlying beliefs, values and attitudes of patients, their relatives and the staff members caring for them. Ethnography provided an in-depth method of exploring these issues, which meant that I could observe end-of-life care in practice, rather than simply relying on retrospective interview data. The analysis of such data does not follow a pre-set structure but instead develops iteratively. However, this does not prevent a disciplined and rigorous approach. I chose to adopt a constructivist grounded theory approach to analysis, which seeks to allow the data to speak for itself and to ground theory in the data, rather than imposing pre-defined ideas or theories onto the data (Charmaz, 2006). This approach to analysis will be described in the next section.

5.1.4 Constructivist Grounded Theory

Grounded Theory was developed by Barney G. Glaser and Anslem Strauss in the 1960s (Glaser and Strauss, 1967). They sought to outline clear strategies for collecting and analysing qualitative data that would assist researchers in conducting competent field work and in developing theory rather than simply descriptive accounts of the data (Charmaz and Mitchell, 2001). Glaser and Strauss brought together distinct approaches. Glaser had a more positivist approach, emphasising the importance of rigorous methods, while Strauss came from a pragmatist perspective influenced by symbolic interactionism and experience in traditional field research (Charmaz and Mitchell, 2001). For Glaser and Strauss, Grounded Theory consisted of the following key components:

- Simultaneous data collection and analysis
- Developing analytic codes from the data rather than applying pre-determined hypotheses to the data
- Making comparisons of the codes and themes developed from the data at all stages of analysis
- Writing memos to expand on the codes and categories and the relationships between them as well as to identify gaps or inconsistencies
- Purposeful sampling aimed at furthering theory construction rather than statistical representation
- Conducting the literature review after analysis so as to avoid forcing the data into preconceived categories (Glaser and Strauss, 1967; Charmaz, 2006).

Since the publication of 'The Discovery of Grounded Theory', the methods proposed have been influenced by various schools of thought. Glaser and Strauss have taken grounded theory in different directions and there are now many different approaches to conducting this method (Charmaz, 2006). Charmaz and Mitchell have developed and described an approach to grounded theory based on symbolic interactionism and social constructionism (Charmaz and Mitchell, 2001): "*A constructivist approach to grounded theory complements the symbolic interactionist perspective because both emphasize studying how action and meaning are constructed*" (Charmaz and Mitchell, 2001, p. 160). This approach steers away from some of the positivist assumptions of the original grounded theory. Whereas Glaser and Strauss describe the researcher as a detached

observer who is discovering theory from the data, Charmaz argues that the researcher is part of the world under study and the data collected. Rather than discovering theories, Charmaz describes constructing theories through interaction with the research setting, participants and methods, in order to provide an interpretation of the studied world (Charmaz, 2006). Rather than viewing grounded theory as methodological rules to follow, Charmaz presents her approach as 'a set of principles and practices' (Charmaz, 2006, p. 9). And she highlights the many ways that grounded theory as a method of analysis can complement ethnographic research methods (Charmaz and Mitchell, 2001). Throughout this research study I have chosen to use Charmaz's constructivist grounded theory approach which fits with my chosen epistemological perspective and also provides a pragmatic approach with which to conduct this study. For example, in their original conception of Grounded Theory, Glaser and Strauss advised waiting until analysis was well underway to conduct a literature review. Their concern was that preconceived ideas may influence data collection and analysis, leading to 'forcing' of the data into predetermined categories (Glaser and Strauss, 1967). However, before starting this study I had already been working as a palliative medicine registrar for two years and had worked with patients in hospital for many years before that. I had clinical experience and my own ideas about the key issues and problems involved in this area of study. Furthermore, in order to apply for funding and for the required permissions to conduct this study I first had to outline why such a study was important, relevant, and worthy of support. I could not have done this without initially studying the relevant literature with which to strengthen my case. Rather than seeking to set myself apart from the research setting and subjects, I aimed, as far as possible, to acknowledge my impact on the data and to be explicit about my underlying assumptions. This requires a reflexive attitude. In practice this meant constantly looking for and questioning my own assumptions and being open to the comments and challenges of my supervisory team as I conducted the study.

5.2   The Quality and Value of Qualitative Research Methods

Because of my background, my knowledge and experience of research prior to this project had been dominated by quantitative research methods. Therefore, I was familiar

with terms such as 'reliability', 'validity', and 'generalisability' as they relate to quantitative methods but remained uncertain of how one can assess the quality of qualitative research. It is clear that these terms developed from the scientific tradition and a positivistic paradigm (Lewis and Ritchie, 2003; Seale, 2004) and there has been much debate about whether qualitative research should or can be assessed using the same criteria as quantitative work (Mays, 2000; Lewis and Ritchie, 2003; Seale, 2004). While it is now generally agreed in medical research that qualitative work is important, as yet there are no agreed criteria or ground rules for identifying when qualitative findings can be generalised and how rigour can be ensured (Lewis and Ritchie, 2003). Some qualitative researchers have attempted to develop terms more suitable for qualitative research such as 'credibility', 'plausibility'(Glaser and Strauss, 1967) and 'transferability' (Lincoln and Guba, 1985). Others have developed checklists and strategies in order to demonstrate the thoroughness of qualitative research methods (Mays, 1995). However, Barbour has cautioned against the 'one size fits all approach' to qualitative research (Barbour, 2001). Murphy et al. support Hammersley's proposition that all research should be judged on two criteria: validity and relevance (Hammersley, 1990; Murphy *et al.*, 1998). He defined validity as "*truth: interpreted as the extent to which an account accurately represents the social phenomena to which it refers*" (Hammersley, 1990, p. 57). While he maintained that it was impossible to know something beyond all doubt, he argued that nevertheless, research can and should be examined for the likelihood of possible error (Murphy *et al.*, 1998). Murphy et al. suggest a range of methods for improving the validity and limiting the likelihood of error in qualitative research. In this research study I have sought to incorporate many of their suggestions. For example, when analysing the data I have submitted the data to my supervisory team and anonymised sections of data to a separate qualitative research methods study group at the University enabling further analysis and discussion. In this way my ideas were critiqued and I was forced to provide clear evidence to underpin my conclusions. A clear exposition of both the data collection method and process of data analysis are essential to demonstrate how conclusions have been reached and the likelihood of their accuracy. Attention to negative cases, seeking to respond fairly to all participants under study and ongoing reflexivity also help to ensure validity (Murphy *et al.*, 1998). These are all approaches I have sought to incorporate into this research. The relevance of research findings relates to the extent to which they can be generalised to

other populations, settings and contexts (Murphy *et al.*, 1998). The generalisability of qualitative research remains a contentious issue, however, Murphy et al. have proposed that it should be for the reader to determine whether the research is generalizable or not (Murphy *et al.*, 1998). According to this view, the researcher is responsible for providing adequate detail such that the reader can make their own informed judgement (Murphy *et al.*, 1998). Popay et al. suggest that one of the key aims of qualitative research is to '*illuminate the subjective meanings, actions and context of those being researched*' (Popay *et al.*, 1998, p. 345). Therefore, claims to generalization in qualitative research refer not to probabilistic generalisations to a population, but to a more logical generalisation (Popay *et al.*, 1998; Crossley, 2007). This logical generalisation is based on a deep understanding of phenomena and the context in which they occur in order to determine their relevance to other settings (Crossley, 2007). In this study I do not claim that my conclusions are generalizable to other acute hospital wards in a statistical sense. However, it has been my aim to provide a sufficient description of the research process so that a reader familiar with a hospital ward setting may recognise my conclusions as credible and will have enough information to judge whether such findings are useful in other settings. Having described the theoretical approach and methodology taken in this research study, I now explain how the project was conducted.

5.3   Description of the Research Study

This research study used ethnographic methods of participant observation and individual in-depth interviews to investigate the perspectives of patients, relatives and staff to end-of-life care. The study received research ethics approval from the Newcastle & North Tyneside 1 committee (Reference 14/NE/0104). Data collection took place over a twelve month period (from June 2014 to May 2015). Clinical practice on two wards (wards A and B) was observed. I initially spent three months on ward A, before moving to ward B for three months. I then returned to ward A for two months, before completing a final two month period of observation on ward B (Figure 3). The time between observation periods was used to continue transcription of interviews, initial coding and analysis of the data. In total, 280 hours of observation was conducted on the wards (161 hours on ward A, 119 hours on ward B). These observations occurred over

98 field note days. Observation included clinical practice on all days of the week, in and out of hours. In this way I sought to gain as much relevant, in-depth and varied data as possible. I also conducted thirty-six individual interviews with patients, relatives and staff members on wards A and B: nine with patients, eleven with relatives, and sixteen with staff members (Figure 4). In this thesis, for simplicity I use the term 'relatives' to refer to family members, close friends and those important to the patient in question.

Figure 3: Time Spent on the Wards

| June | Sept | Oct | Dec | Jan | March | Apr | May |
| 2014 | 2014 | 2014 | 2014 | 2015 | 2015 | 2014 | 2015 |
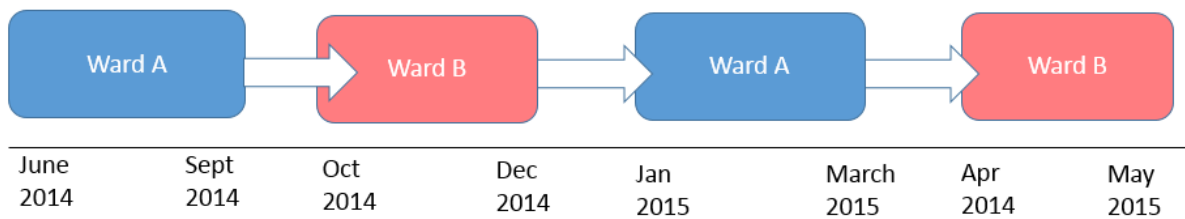
Figure 4: Numbers and Roles of Participants Interviewed

Interview Participants	Numbers of Participant Interviews
PATIENTS Ward A Ward B **Sub-total**	 6 3 **9**
RELATIVES Ward A Ward B **Sub-total**	 7 4 **11**
STAFF MEMBERS <u>Ward A</u> Healthcare assistant Nurses Physiotherapist Junior doctors	 1 3 1 2

Consultants	3
<u>Ward B</u>	
Healthcare assistant	1
Nurses	2
Physiotherapist	0
Junior doctor	1
Consultants	2
Sub-total	**16**
Total Number of Interviews	**36**

In order to place the research study in context, I will now provide a detailed description of the research setting.

5.4   Research Setting

This study took place at a hospital in England. The hospital had a 24 hour A&E department, over twenty in-patient wards, as well as maternity services, diagnostic facilities and out-patient clinics. This setting was chosen for pragmatic and organisational reasons: the hospital was local to me and I had contacts with senior medical staff members there. My contacts on the ward meant that accessing senior staff members to discuss the study was straightforward, and from the start, all of them were supportive of the project. The research was conducted on two wards: an acute respiratory unit (ward A) and an acute care of the elderly ward (ward B). Data collection took place over a twelve month period from June 2014 to May 2015.

5.4.1   Ward A

There were thirty in-patient beds in total on the ward (including bays and side rooms). The ward was an L-shape with individual patient rooms on one corridor and four patient bays on the other. In between these two corridors was a central desk called the nursing station at the right hand side where the ward clerks sat and where the ward telephones were located. Each patient bay had six patient beds. Opposite the bays were patient showers and toilets. Next to the fourth bay was a large day room with comfy chairs and

dining tables and chairs. The ward also had a small doctors' office where two doctors could sit and a kitchen.

When I started data collection in June 2014 there were approximately 22 nursing staff members (this included qualified staff and health care assistants) employed on the ward, working to provide 24 hour nursing care, seven days a week. Allied healthcare professionals working on the ward included physiotherapists and physiotherapy assistants, occupational therapists, social workers, speech and language therapists, pharmacists and pharmacy assistants. Other specialist teams, such as the specialist palliative care team, visited the ward when requested. There were three consultants for the ward and two more were recruited by the beginning of my second period of observation in early 2015. There were four junior doctors (Foundation Year 1, Foundation Year 2, and Core Medical Trainee or General Practice Specialty Trainee and one specialty registrar) on the ward.

The ward manager estimated the average length of patient stay at around 10 days. Although ward A was described as a respiratory ward, the ward accepted adult patients with both acute general and respiratory conditions. Staff were experienced in managing patients with acute respiratory problems such as exacerbations of chronic obstructive pulmonary disease, asthma, pneumonia and lung cancer. One therapy given on the ward was Non-Invasive Ventilation (NIV). This involved the application of a tight-fitting mask over a patient's nose and mouth (some masks covered the whole face) in order to supply high pressure ventilation to support the patient's breathing. At times patients would remain 'on NIV' for much of the day and/or night, with only short breaks, because they were unable to breathe without it. Usually as patients recovered from an acute illness their NIV would be gradually weaned until they no longer required it. The physiotherapists organised and managed NIV therapy under the direction of the ward consultants. Patients on NIV required frequent blood tests to monitor the levels of oxygen and carbon dioxide in their blood. This test (termed arterial blood gas, ABG) involved a blood sample from an artery and was most commonly taken from a patient's radial artery at the wrist.

Each morning there were hand-over meetings on the ward when one set of staff would handover patient details to the staff covering the next nursing shift. The first handover

of the day took place in the ward manager's office at 7.30am and was attended by one of the night nurses, who would give the handover, and all of the day nurses (trained nurses and healthcare assistants). Another handover took place at 9am, which was given by one of the senior ward nurses and attended by the junior doctors and allied healthcare professionals. Consultants and specialty registrars did not attend these handovers. When I first started my observation this meeting was held in the centre of the ward at the nursing station. However, over the course of the year the venue changed, first into the ward manager's office, and then into the day room. The handover was followed by the doctors' ward rounds. There were further nursing handovers throughout the day as nurses started and finished their various shifts.

5.4.2 Ward B

There were thirty-one in-patient beds on ward B (including bays and side rooms). The structure of ward B was similar to ward A: it was an L-shape with side rooms down one corridor, patient bays down the other and a nursing station in the middle. It also had a day room (which functioned as a dining room at meals times and was the venue for the weekly MDT meetings), a small quiet room (where doctors could speak to family, and staff ate their lunch), a kitchen, and a large office for all ward staff.

When I commenced observation on ward B there were approximately 22 nursing staff members (this included qualified staff and health care assistants) employed on the ward working to provide 24 hour nursing care seven days a week. Allied healthcare professionals working on the ward included physiotherapists and physiotherapy assistants, occupational therapists, social workers, speech and language therapists, pharmacists and pharmacy assistants, nutrition assistants and a specialist nurse for complex patient discharges. Other specialist teams such as the specialist palliative care team and the mental health team visited the ward when requested. There were three consultants for the ward (one full-time and two part-time) and there were three junior doctors (Foundation Year 1 and Foundation Year 2 and one specialty registrar).

The ward manager estimated that patient stay ranged from one week to a few months. Patients who came to ward B were typically over 65 years of age and had multiple co-morbidities. Many patients had some degree of cognitive impairment, often due to an acute delirium, long-standing dementia, or both. Common reasons for admission

included falls, increased confusion, and infections. Patients varied in their functional abilities but generally had higher levels of dependency than those on ward A. For example, patients on ward B required more assistance with activities of daily living (washing, dressing, walking, going to the toilet) than those on ward A. There were frequently patients who were acutely confused and would wander on the ward, as well as those who were verbally and physically abusive to staff members. Many patients needed increased care provision on discharge and planning this could be complex and time consuming to organise and coordinate.

There were regular handover meetings on ward B. The first was a nursing handover from the night shift to the day shift, and there were nursing handovers at various times in the day as nurses started and finished their shifts. At 9am there was a handover for the junior doctors and allied health professionals and one of the senior nurses would run through relevant details for each patient on the ward. This meeting was attended by junior doctors, medical students, physiotherapists, the social worker, the speech and language therapist and the specialist discharge nurse. Consultants did not regularly attend this meeting. When I first started my observation, this meeting was held at the nursing station in the middle of the ward. By the second period of observation, the meeting had been moved to the multidisciplinary team office at the end of the ward.

The patients on the ward were divided into two teams. One team was covered by the full-time consultant and the other by the two part-time consultants. Each consultant was allocated one or two junior doctors to cover their patients. Each team met once a week for the multi-disciplinary team (MDT) meeting. This meeting lasted an hour and was a chance for medical, nursing and allied healthcare professionals to meet and plan for the care and discharge of their patients. Having provided a detailed description of the research setting, I will now outline how the research was conducted on the two wards.

5.5   Gaining access

In preparing to observe participants in their natural setting, Zaman outlines two things that the researcher must do: gain access to the setting and take on a role within that setting (Zaman, 2008). Here I will address the former and in the section titled 'observation' I will address the latter. Zaman highlights potential difficulties previously

described in the literature for a researcher seeking to access healthcare settings: physician resistance due to dislike of regulation and fear of criticism, and the bureaucracy of healthcare organisations which can make access difficult (Zaman, 2008). Hammersley and Atkinson describe gaining access as a practical matter but also as an ongoing process which requires the use of intra- and inter-personal skills and strategies in order to navigate potential obstacles (Hammersley and Atkinson, 2007). In preparation for data collection, I made formal contact with the ward staff in January 2014 and first emailed all of the consultants on wards A and B. I then met individually with all but one of the consultants to explain the research. The consultants provided the names and contact details of the senior nurses on the wards, whom I emailed and met with individually. All of the senior staff members were positive about the research and gave permission for the project to go ahead on wards A and B.

Following approval by the NHS Research Ethics Committee (Reference 14/NE/0104) and from the Research and Development department at the NHS Trust, I contacted the senior medical and nursing staff on wards A and B to inform them of these permissions and arrange to meet the wider staff team. Correspondence with senior ward staff prior to commencing data collection was entirely positive and encouraging. During my observation on the wards I found the same attitude amongst ward staff as I had from the senior staff. They were interested to hear about the research, and happy for me to observe their practice. However, though gaining access was relatively straightforward, I found the description given by Hammersley and Atkinson of gaining access as a process to be correct (Hammersley and Atkinson, 2007). While the 'gatekeepers' of the ward (consultants and senior nurses) gave permission, I felt it was important to work continually to build rapport and respect with each staff member in order to ensure ongoing permission for observation.

I had never worked as a doctor in this hospital, however, the staff asked me about my background and knew that I was a palliative medicine registrar. I wondered if my status as a doctor, rather than simply a researcher, caused them to see me as an 'insider' (Brewer, 2000). I initially felt very out of place as a researcher, but I found that the staff members quickly began to treat me as one of the team. Though some acknowledged that it was a bit 'weird' to have me observe them initially, none of them objected and some told me that they were always happy for me to observe and I need not ask their

permission. I was made welcome in all aspects of ward life, both formal and informal, and was even invited to nights out with the staff team. Brewer describes the importance of maintaining the balance between the dual roles of 'insider' and 'outsider' when working as an ethnographer in order to avoid either 'going native' or appearing cold and aloof (Brewer, 2000, p. 60). While it was nice to feel so welcomed, I remained aware that I was not a 'regular' member of the team. This was sometimes an uncomfortable position especially when work as a researcher felt lonely and I missed the companionship of a clinical team. However, it made me conscious of the need to reflect on my impact on the environment around me and how I ought to behave as a researcher. I hoped that if staff viewed me as part of the team they would conduct their work in their usual manner, almost forgetting that I was observing them. And I think this was often the case, as on many occasions I observed staff members making comments about the patients, their own practice, and general ward life, which were neither politically correct nor polite and that I would not have expected them to say in front of a researcher.

Gaining permission to conduct research with deteriorating and dying patients involved careful thought and negotiation. Research in end-of-life care has been discussed in the literature with concerns raised about the risk of overburdening patients and their family members at a very vulnerable time (Agarwal, 2003; Casarett, 2005; Duke and Bennett, 2010; Blair, 2012). However, it has also been argued that to exclude the views of dying patients and their relatives stops important views from being heard (Henry. B. and Scales, 2012). Furthermore, in a critical interpretive synthesis of the literature Gysels et al. found that the majority of patients were willing to take part in research. In fact some found the process empowering and described it as therapeutic and something that gave them comfort (Gysels *et al.*, 2012). They conclude that the concern that all patients at end-of-life are too vulnerable to participate in research is unjustified and paternalistic. Instead, they call for carefully planned research conducted with due care and attention to the needs of this specific group of participants (Gysels *et al.*, 2012).

The NHS research ethics committee and the research and development department at the Trust, granted me permission to conduct the research study as planned in the study protocol and in line with foreseen events. However, in spite of thorough planning there will always be unforeseen events with which the researcher will have to grapple during

time in 'the field'. Seymour et al. outline some of the many unexpected ethical dilemmas that researchers may face while conducting research in palliative care (Seymour *et al.*, 2005b). For example, ethnography and participant observation present the researcher with particular ethical difficulties such as: defining the boundaries of data collection, managing different roles, knowing their varying responsibilities while in 'the field' (Seymour *et al.*, 2005b). A researcher's underlying theoretical assumptions will naturally influence what they perceive to be an ethical issue and therefore ethical issues in qualitative research are closely tied to methodology (Seymour *et al.*, 2005b). Seymour et al. encourage all researchers to develop an ethical mind-set and to reflect on the ethical challenges faced throughout the research process (Seymour *et al.*, 2005b). In the next section, I will outline how I conducted this research project and sought to apply an ethical mind-set in response to unanticipated challenges.

5.6   Observation

In his typology of roles in sociological field observations Gold defines the different roles researchers may adopt when conducting observational research (Gold, 1958). These include: complete observer, complete participant, participant as observer and observer as participant (Gold, 1958). Walsh suggests that in reality most researchers conducting overt ethnography adopt a position between the latter two roles (Walsh, 2004), as was the case with this research project. I described my role as that of a non-participant observer. This meant that I clearly identified myself as a researcher with the role of observing clinical practice of all participants on the ward. I did not have a clinical role or clinical responsibilities on the ward. However, I found that observing practice often required a certain level of involvement on my part with general ward activities. For example, when attending ward rounds if the doctors clearly needed help carrying medical notes or required someone to fetch a cup of water for a patient, I was often the person to help. If a patient or relative wanted a cup of tea, I would offer to make it. I hoped that by being willing to participate in these ways, staff would appreciate my presence, or at least not resent it (even if they consented to my observation) and that it would facilitate further observation work on the ward.

I sought to differentiate myself from the clinical team. This was important as I wore smart clothes similar to those of the junior doctors, rather than a uniform worn by the

other healthcare staff. It was apparent that on first meeting, some staff, patients and relatives mistook me for one of the medical team. Goffman describes the importance of the way in which people present themselves to others and attempt to control the impression others receive (Goffman, 1959). He describes each individual as putting on a performance and a 'front', that is, the ways they regularly express themselves and define the situation to those around them (Goffman, 1959). The social actor must give a confident performance in order to be perceived as a 'proper' researcher by the audience (De Laine, 2000). I felt this acutely as I began observation work on the wards: a familiar setting but an unfamiliar role. I was aware of the need to explain my role and research to many people in a confident and self-assured manner in order to build rapport and gain their confidence and respect. De Laine describe this 'impression management' as a necessary part of all successful fieldwork (De Laine, 2000). I sought to be conscious of this 'front' in both the way I looked and in the way I spoke and behaved. In order to make my identity clearer I wore a professional ID badge which stated my name and my role as a researcher in bold print. While I always wore a hospital ID badge this hung around my neck and was difficult for patients to see. I hoped my researcher ID badge would make me easier to identify. Though I was not part of the clinical team and had no clinical role on the ward, I still participated in the events taking place. For example, when observing on a ward round I participated as one of the team members in simple tasks like helping to draw curtains around a patient's bed, carrying a set of notes when the doctors had their hands full, or getting a patient a cup of tea. By participating in these ways, I intended to be perceived as friendly, helpful and approachable in order to put participants at ease and encourage participation in the research.

My purpose in observing on the ward was to generate data by participating in daily life of the ward. This involved watching, listening and talking to participants in order to understand the setting and activities taking place from their perspective (Brewer, 2000). Brewer describes two key purposes in participant observation: first, to understand the situation and setting from the perspective of those being studied. Second, to illuminate taken-for-granted and common sense understandings of the world under study (Brewer, 2000). This kind of method views the researcher not as a collector of data but as a generator of data. It reinforces the view of Burgess that '*the main instrument of data collection is the researcher*' (Burgess, 1982, p. 45). However, Brewer also highlights

some of the limits of participant observation. The researcher cannot be in all places at once and has only limited time to observe. Therefore, what is recorded by the researcher about their observations is necessarily limited. It is also a personal and selective account of what has been observed, influenced by non-random assumptions and beliefs of the researcher (Brewer, 2000). Brewer suggests that participant observation can be at risk of focusing on the unusual, extreme, or exceptional events observed. For these reasons Brewer advises the importance of reflexivity when analysing the data and suggests that participant observation should be used in conjunction with other methods such as interviewing (Brewer, 2000). I sought to respond to this advice, as will be further outlined in sections on analysis and interviews.

During my initial time on the wards, I sought to observe as much of ward life as possible to learn about the daily ward routine and practices. I attended regular ward handover meetings which occurred throughout the day, starting first thing in the morning and finishing with the handover to the night team. I observed nurses on their medication rounds in the mornings and I shadowed healthcare assistants as they worked their way around the ward documenting patient observations and weights. I also regularly attended consultant and junior doctor ward rounds which usually occurred in the mornings. On ward B, I attended the weekly multidisciplinary (MDT) meetings (ward A did not have a weekly MDT meeting). In this way, I learned about the regular pattern of ward life. My regular observation work on the wards also allowed me to get to know staff members. I found that these relationships did not end when the particular period of observation finished and months later ward staff would still say hello if we met in the hospital corridor and stop to ask me how my research was going. Furthermore, when I returned to both wards for a second time, though the junior medical staff had changed, the nurses and consultants remained and remembered me and welcomed me back. These amicable relationships with staff members made my observation work enjoyable and much more straightforward than it might have been. I found returning to wards A and B easier because staff already knew me and their friendly response to my return seemed to give me credibility with new nurses and junior medical staff who had started during my time away. However, while it was nice to be welcomed back, feeling 'comfortable' with the ward staff members at times made it difficult to maintain my perspective as a researcher. As I chatted with and observed ward staff members, my

background as a doctor was sometimes difficult to suppress. At times I found myself longing to 'help out' and feel useful, especially when there were staff shortages and staff on the ward were so busy. I regularly had to reflect on my behaviour and consider what kind of impression I was giving. The research supervisory team also helped to keep me accountable and discussed my experiences of observation work on the wards at regular supervision meetings.

My initial observation work was broad in scope, and I aimed to observe many different aspects of healthcare practice on the ward and not simply the care of deteriorating and dying patients. But after my first few weeks on wards A and B, my subsequent observations became more specific as I sought to focus on end-of-life care on the wards. From the beginning, staff knew that I was interested in learning about the care of patients who were deteriorating and thought to be approaching the end of their life. At the start of each observation I spoke with the junior doctors or nurses, asking them about their patients. I then sought to spend time with the staff members who were caring for unstable and/or dying patients. The morning handover at 9am provided an excellent opportunity to learn about new patients and the ongoing clinical course of patients who I had already met. For the junior doctors, the afternoons were generally thought of as a time to 'get jobs done' and to speak to families and I often accompanied doctors when they spoke to relatives. While I was specifically interested in the care of patients who were deteriorating and or dying, I chose to attend entire ward rounds rather than simply step in when the consultant was reviewing the patient I was interested in. While this was time consuming and often meant that I observed many patients with chronic stable conditions, it provided further opportunity to observe staff members at work, to see how they made decisions and to observe their interactions with each other, patients and relatives. I also found that apparently 'stable' patients frequently became 'unstable'. Thus I observed how staff members categorised or labelled patient's conditions and the impact this had on their care. If there were patients I was interested in I asked staff members about them and sought to spend time on the wards when staff members would be interacting with them. For example, I would arrange to be on the ward when a consultant was speaking to a specific family.

5.7   Consent for general ward observation

5.7.1   Staff Consent for General Ward Observation

Given the large numbers of staff, patients and relatives regularly moving on and off the hospital wards, my supervisory team and I deemed that to gain written consent from all possible participants would be impractical, burdensome and unnecessary given the low risk to participants. It would require considerable time to obtain consent from participants who may have very minimal, if any, further involvement in the study. For this reason, as an alternative to written consent an opt-out form of consent, which was approved by the research ethics committee, was used for the general ward observation. Every effort was made to inform healthcare staff about the research and the observation study. With permission from senior staff I attended staff meetings on wards A and B, such as staff handovers and multidisciplinary team meetings in order to introduce myself to as many ward staff as possible. I met all of the junior doctors on the ward and gave them an information sheet (See Appendix F). I made a conscious effort to introduce myself to medical, nursing, secretarial, and allied healthcare staff on the ward and to explain the research project. This often involved quick conversations at the nursing station or before and after the MDT handover meeting. I had to be pro-active in introducing myself and efficient in describing the purpose of the study so as to make them aware of it without taking up too much of their time. I knew that it would be more difficult to meet with all of the nursing staff members (because of their varied shift patterns), so with permission from the ward managers on both wards, I sent emails to all nursing staff members (ward sisters, staff nurses, and healthcare assistants) at the start of the observation period, explaining my research project with an attached copy of the staff information sheet. I pinned a copy of the research information sheet on the notice boards in both ward offices where doctors and other staff members worked and I emailed copies of the information sheet to any other individual staff members if requested. No staff members opted out of general ward observation during the twelve months of data collection.

5.7.2   Patients and Relatives Consent for General Ward Observation

In order to inform patients and relatives about the general observation study I made and displayed a poster on wards A and B (See Appendix B). The poster explained that

research was taking place on the ward, provided my contact details should they wish further information and displayed a photograph of me so that I could be identified and recognised. I had hoped that all patients on the wards would receive a one-page information sheet about the research study. At the start of the first data collection period I prepared several information sheets for staff members to hand out to patients (See Appendix C). My original plan had been to ask staff members to hand out information sheets so as not to put pressure on patients to participate. However, in practice I encountered many difficulties with this approach. First, many patients were unable to read the information sheet because of acute ill health, reduced cognition and visual impairment. Second, I found that the ward staff were extremely busy and already had extensive paperwork of their own to complete. At the start of my observation I asked the nurses and ward clerks to hand out information sheets to patients and provided them with numerous copies, but I repeatedly found that the sheets were not given out. As I was unable to be on the ward 24 hours a day, I had no way of knowing who had received one and who hadn't. In the end I took a pragmatic approach. When patients or their visitors asked me about who I was or about the research project, I handed out information sheets and took the time to provide verbal information about the project to whoever asked.

I sought to make it clear (in written and verbal information) that all participants (patients, relatives, or staff members) could withdraw their consent at any time even after giving verbal or written consent. Prior to observing any specific ward activity e.g. ward rounds, I sought permission from staff members involved in the activity, such as the consultant and his team. I also asked staff members to seek permission from individual patients and relatives involved in the activity. If staff members, patients or relatives refused consent, I stopped my observation of the activity and did not record any data about the specific activity or individuals involved. Consent for the general ward observation phase was verbal and was assumed unless I was informed that consent had been refused. I sought to take all possible steps prior to any observation to ensure that potential participants were aware of my presence and purpose and were happy for me to observe their activity on the ward. There were only a few occasions when patients requested not to be observed, such as when the staff member I was observing was going to provide them with personal care. I did not encounter any

objections from relatives about the general ward observation. Throughout my time on the ward, during observation and individual interviews, I watched closely for any signs of distress, fatigue or unwillingness from participants and withdrew if I felt that any of their verbal or non-verbal communication suggested a reluctance to participate.

5.7.3 Involvement of Patients Lacking Mental Capacity

Prior to commencing data collection on the wards I gave much thought to the involvement of patients with reduced mental capacity and this was discussed with the research supervision team. Patients approaching end-of-life may have physical conditions which impair their mental capacity such as dementia or a brain tumour. Many may have impaired capacity due to regular analgesic and sedative medication required to control symptoms. As patient physical condition deteriorates prior to death it is likely that consciousness will reduce and mental capacity will be lost. We all agreed that in order to improve care for patients at the end of their lives it was vital that the research include these very patients, their relatives and the staff caring for them. The MCA 2005 sets out the law in relation to the care of people who lack mental capacity. In chapter eleven of the MCA 2005 Code of Practice (Department for Constitutional Affairs, 2007) clear guidance is given for research involving patients who have lost their mental capacity and this guidance was followed during the course of this research. It was important for me to observe the management of these patients and to assess any difficulties in practice. To exclude this group of patients from the research would reduce the potential benefit to the care of patients approaching end-of-life in the future. In all cases I sought to gain the views of relatives about the patient and where possible the views of the patient themselves.

5.8 Interviews

There are many different types of interview but Brewer captures the essential feature of all interviews as '*a verbal stimulus used to elicit a verbal response*' (Brewer, 2000, p. 63). Hammersley and Atkinson (2007) characterise interviews as either 'solicited' or 'unsolicited'. Unsolicited accounts refer to the verbal accounts about daily life and work that participants may give to each other while the researcher is observing. Participants may also provide such an account to the researcher spontaneously and unexpectedly. This was often the case on the ward, for example staff members were sometimes keen to

explain their practice to me or occasionally they wanted to inform me about aspects of the ward they felt needed improvement such as increased training in end-of-life care. These kinds of accounts were a useful source of information about the setting and of the perspectives of the participants (Hammersley and Atkinson, 2007). During this research study I conducted informal and formal interviews. Informal interviews were conversations that I had with participants on the ward which were not recorded and often took place spontaneously or in response to a questions I asked about what I was observing. In order to record informal interviews I took short notes during interviews and immediately afterwards I would write a detailed description of the discussion. Formal interviews were those that I undertook with participants in a quiet room on the ward. They required written consent and were digitally recorded. During formal interviews I used a topic guide to guide the questioning process. However, as much as possible I aimed to ask open questions and allow the participants to share their experiences of end-of-life care. My time observing on the wards prior to conducting formal interviews was useful, in that it allowed me to build rapport with participants prior to interviews. I hoped that this helped participants to feel at ease and encouraged honest accounts. However, I remained aware that being neutral is an impossible interview stance (Rapley, 2003) and that the context of the interview, my presence, manner, behaviour and questions all shaped the data produced during each interview. I aimed to follow the advice of Hammersley and Atkinson: '*All accounts must be interpreted in terms of the context in which they were produced. The aim is not to gather 'pure' data that are free from potential bias. There is no such thing. Rather, the goal must be to discover the best manner of interpreting whatever data we have, and to collect further data that enable us to develop and check our inferences*' (Hammersley and Atkinson, 2007, p. 102).

5.8.1 Sampling & Recruitment

Recruitment of participants (patients, relatives and staff members) for interview was conducted with the aim, as far as possible, of reflecting the diversity of views and opinions present on the wards (Barbour, 2001). As I interviewed participants and gained new data I formed ideas about the data. After reflecting on the initial data I would plan how to investigate these ideas further and consider which participants would provide the most information. I aimed to compare participant's accounts in order

to identify similarities, contradictions and variant ideas. This type of sampling is often referred to as 'purposive' or 'theoretical' (Mays, 1995). As data collection continued, new ideas and areas of interest emerged and I would then alter my sampling strategy accordingly. In this way sampling was not pre-planned but inductive. All participants were chosen after considering the data collected so far, aiming to target those who had experience of end-of-life care and with the purpose of answering questions or expanding on areas of interest (Hammersley and Atkinson, 2007). For example, I had planned to interview doctors and nurses on the wards, but during observation work on ward A I realised that the physiotherapists were often involved in end-of-life care when patients deteriorated while on NIV. Thus I purposely sought to interview one of the physiotherapists in order to gain a new perspective on end-of-life care on the ward. During the course of data collection I was also aware of the need to be pragmatic in my recruitment. For example, though I might identify a member of staff whom I wished to interview, sometimes it happened that the day I came in to ask them to participate, I found that they were on annual leave for two weeks and then working night shifts. However, as many staff members were involved in caring for deteriorating and dying patients this never posed too much of a problem. When interviewing staff members who had been involved in caring for deteriorating or dying patients, I aimed to interview them after the patient had died or been discharged so as not to influence the patient's management. I purposely interviewed staff members of different professions, working at both junior and senior levels, in order to identify varied perspectives.

When recruiting patients for formal interviews, I also had to be pragmatic as I was aware that many deteriorating patients were not well enough to be interviewed. By observing staff hand-over meetings I heard of patients who staff members thought were likely to deteriorate further but had not yet had discussions about their condition and were potentially unaware of their poor prognosis. During formal interviews I wanted to ask patients and relatives questions related to end-of-life decision making, yet I was acutely aware of the possibility of upsetting them and therefore sought to be sensitive during recruitment and interviews. For this reason I tended to ask open questions about their care and their understanding of their condition. I was also aware that some patients may be keen to take part because of loneliness or boredom, rather than their interest in the research topic (Seymour *et al.*, 2005b). Right at the start of my data

collection period a patient, after reading the general information sheet for patients, offered to be interviewed without me even asking her. She was a lady with many chronic conditions who had been admitted acutely unwell but had responded to treatment and was no longer actively deteriorating. However, I agreed to interview her because I felt it would provide a baseline level of ideas about a patient's experience of care on the ward.

I discovered that relatives were most likely to agree to an interview if I approached them at what I have termed 'the right time'. I defined this as when the patient was unwell and the relatives knew that the patient was sick enough to die, but they were not imminently dying. At this 'right time', relatives had the insight and awareness of the situation to discuss issues related to end-of-life care, but they did not feel the need to spend all of their time at the bedside of the patient. When recruiting patients and relatives, I sought the advice and permission of staff members. On some occasions, staff members suggested relatives who they felt might be willing to talk to me and provide relevant information.

Hammersley and Atkinson describe this as the need to negotiate with gatekeepers in order to access research participants and they explain that in this way the gatekeepers determine who will be interviewed (Hammersley and Atkinson, 2007). In this study it is true that staff members, in their role as gatekeepers, influenced and determined to a large degree which patients and relatives were interviewed. This was necessarily the case, as I relied on staff members for information about the patients and relatives and I required their permission to approach a patient or relative. However, on the wards I spoke to many staff members about their patients and thus my recruitment was not determined by the opinions of one or two powerful gatekeepers, but a diverse and varied staff team. Furthermore, I found that I was rarely advised against approaching patients. If I was, it was because the staff member felt they were too unwell to participate in a formal interview. On the rare occasion that this happened, I tended to ask many staff members for their opinion of the patient's condition and I always found agreement. In fact, usually I found that staff were very encouraging of my research work and sometimes suggested patients for interview who, after meeting, I deemed too unwell to participate. Therefore, I think that this method of recruitment though

potentially limiting, worked well in the ward setting on wards A and B for this group of participants.

5.8.2   Consent for interviews

All participants were required to provide written consent prior to participation in a formal, digitally recorded interview. Only patients who were deemed to have full mental capacity by the staff team were invited to participate in individual interviews. Within research studies it is normal to allow 24 hours after giving information about a study before seeking written consent to participate. This is to allow time for participants to consider the implications of their participation and to reduce any sense of imminent coercion. However, in this study a rigid "cooling off" period of 24 hours or more was not imposed. From the beginning, it was recognised that patients may be keen to participate but were very likely to have unstable physical conditions with variable symptoms. Patients approaching end-of-life have the potential to deteriorate over a relatively short period of time and may feel a sense of urgency to participate in an interview.   For this reason, after giving potential participants information about the individual interviews, if they were keen to take part in an interview, I negotiated a "cooling off" period with them. Often patients were keen to conduct the interview the same day, usually a few hours later, but sometimes they requested to participate there and then. This approach was not designed to coerce or undermine participants' freedom and autonomy in making a decision, but rather aimed to promote these values by allowing for individual preference. Relatives were also considered as a group in need of individual consideration in terms of "cooling off" time. When approaching staff member participants for interviews, I had planned to impose a "cooling off" period of 24 hours or more, as I felt that staff members would not need to request an urgent or same-day interview and so should be offered the standard "cooling off" period. However, on a few occasions staff members were keen to participate but were unable to take part on subsequent days (due to shift patterns, annual leave etc). In each of these cases, the staff members had known me for several months during my observation on the wards and knew about the research and purpose of the interviews before I asked them to participate in an interview. Therefore, for these exceptional cases, and with the permission of their ward manager, I agreed to interview certain staff members after a period of a few hours. All participants were informed that their participation or refusal

to participate in the research would have no influence on their medical care, the care of their loved one, or their work, considering patients, relatives and staff members respectively.

5.8.3   Patient interviews

All inpatients over the age of 18, considered by the clinical team to be suitable for the study were eligible to participate in an individual interview. Only patients with mental capacity were invited to participate. In total, nine formal individual interviews were conducted with patients, six on ward A and three on ward B. No informal individual interviews were held with patients. I found that many patients on ward B had degrees of cognitive impairment and therefore there were fewer patients on ward B who were able to consent to take part in an interview. It is for this reason that the majority of patient data comes from ward A. Prior to each interview, all participants provided written consent. All interviews were digitally recorded and transcribed verbatim. When considering which patients to interview, I asked the clinical team to identify patients on the ward who were thought to be deteriorating. However, if I identified a patient who I thought might be approaching end-of-life but had not been identified to me by the clinical team, I approached the clinical team and asked permission to speak to the patient about an interview. I would also ask if there was any reason that the patient should not be included and about the patient's mental capacity prior to approaching the patient. By using this method of recruitment only patients who the team felt were 'appropriate' for the research were recruited as discussed above. At the same time, I was able to use my experience as a palliative medicine registrar to recruit patients I thought may be approaching end-of-life. If the clinical team advised against speaking to a patient or interviewing them, I would not approach the patient. By seeking to interview a patient who had not previously been highlighted to me by the clinical team, it is possible that I may have altered the management of that patient. For example, it may have highlighted the patient's deterioration and caused the staff members to consider the need for end-of-life care more quickly than they might have otherwise. However, in reality all of the patients that I interviewed were those recognised by staff members to be deteriorating or with the potential to deteriorate. Therefore, I felt that my requests to interview patients were unlikely to have a significant influence on their management. Sometimes I was asked questions about why I felt a patient was

appropriate for the study. In this situation, I sought to give honest answers based on my observations on the ward.

5.8.4   Interviews with relatives

All relatives (aged over 18 and who had mental capacity to consent) of patients on the ward were eligible to participate in an individual interview. There were often situations when the patient did not have mental capacity to participate, but their family members did and were keen to do so. In total, eleven interviews with relatives were conducted. The interviews were mostly conducted one-to-one with individual participants, however I did conduct interviews with two relatives together if that was their preference. For example I conducted one interview with two sisters, both daughters of a patient. Prior to each interview all participants provided written consent. All formal interviews were digitally recorded and transcribed verbatim.

I encountered a few situations when relatives said they did not feel up to participating in a formal recorded interview, but were happy to talk to me there and then. On one occasion a relative agreed to give an interview the next day and then proceeded to speak to me for several minutes. The next day she said she no longer felt up to being interviewed as her mother had deteriorated further, but continued to speak to me at length in her mother's side room. Sometimes these conversations were fairly brief, but on two occasions, relatives spoke to me at length such that I considered the accounts as interviews even though they were not recorded. I took short notes during the conversations and I wrote-up detailed accounts of the conversations immediately after they took place. These situations mostly arose when patients were very unwell and seemed close to death. I think the relatives involved were keen to participate but didn't want to leave the room of their loved one to give a formal interview. I had not anticipated this type of situation before starting the data collection and consequently the interview consent forms all stated that interviews would be recorded. Therefore, on occasions such as this I repeatedly checked that family members were happy to speak to me and I confirmed this again during the conversation. Often they spoke for much longer than I expected. In these situations, though not formally written down, I gained consent verbally on many occasions during the conversation and afterwards.

5.8.5 Staff interviews

All clinical staff members on wards A and B including: doctors of all grades, nurses of all grades, healthcare assistants, occupational therapists, physiotherapists, social workers, were eligible to participate in an individual interview. If a member of staff had been involved with the care of a dying patient and I was keen to interview them, I approached them directly to inform them about an individual interview and ask if they would consider taking part. If they said they were interested in taking part I provided verbal and written information about the interview. In total, sixteen interviews were conducted with staff members: five with medical consultants, three with junior doctors, five with nurses, two with healthcare assistants, and one with a physiotherapist. Prior to each interview all participants provided written consent. All interviews were digitally recorded and transcribed verbatim. I transcribed all interviews personally which allowed initial analysis to begin during the transcription process, as I listened, re-listened and typed the data.

5.9 Data Analysis

5.9.1 Coding

Throughout the analysis of the data I sought to use constant comparison methods which were first advocated by Glaser and Strauss (Glaser and Strauss, 1967). In practice this means making comparisons within the data at each stage of the analysis so that each new section of coded data is compared with previous codes (Payne, 2007). I compared coded statements and incidents in my first interviews and field notes. Later on, I was able to compare earlier data with accounts collected later on in the process. In making these comparisons I aimed to establish analytic distinctions in the data (Charmaz, 2006) and develop a way of explaining the data rather than simply describing it (Payne, 2007). I collected data and analysed it simultaneously. In practice this meant that as I started collecting data, in the form of field note observations and interviews, I sought to familiarise myself with them through transcription, reading and re-reading of the data. As I collected data I made a note of recurrent themes, ideas, apparent problems or difficulties mentioned by participants. After periods of data collection on the wards, I

spent time analysing the initial field note and interview data in more detail by performing line-by-line coding. This involved reading the data closely and assigning a 'code' to each line or short section of data. These codes provided a way of labelling what was going on in the data, of examining the perspectives and actions of the research participants and of seeing and understanding different processes occurring in the data. Charmaz explains that this kind of initial coding allows the researcher to familiarise themselves with the data, search for analytic ideas which can be pursued in subsequent data, while all the time aiming to remain open to different possible theoretical directions (Charmaz 2006). After my first period of data collection on ward A, I spent time analysing the field note and interview data collected thus far. I coded the data line-by-line, choosing to see everything as of potential importance (Figure 5). In this way I developed a broad and extensive list of codes about the data (169 in total). I then grouped similar or relating codes under broader titles which left me with twelve key codes. After the first observation periods on wards A and B (from June 2014 – December 2014), I used line-by-line (or small section-by-small section) coding to analyse all of the field note and initial interview data.

Figure 5: Example of line-by-line coding of individual interview

During the second period of observation on ward A and then on ward B, I sought to keep in mind my initial codes and compare them with the new data I was gathering. When data collection was complete I returned to my initial data and once again performed line-by-line and section-by-section coding in order to re-code the data in its entirety. This may sound unnecessary but it allowed me to re-consider the data with the perspectives that I had gained over the course of the data collection period. Re-coding of

the data enabled me to assess all of my data using the codes and ideas I had gained throughout the year. I also found that returning to the data after subsequent observations and interviews led to new ideas, comparisons, and insights.

Following the re-coding of field note data, I performed incident-to-incident coding on the data. This meant that I compared events of a similar nature. For example, as I was particularly interested in end-of-life care on the ward, I carefully read through the data and selected all sections that related to patients who were deteriorating or dying. I grouped the data for each individual patient in order to build up an account of each patient's experience on the ward, gained through my observations. On large sheets of flip chart paper I documented the data pertaining to each patient, in order to produce a very visible account (Figure 6). These accounts demonstrated the timing of their clinical course (how quickly they deteriorated, received treatment etc.), and the observed impressions of participants in relation to the patient and their care. Documenting these accounts in such a visible way helped to familiarise me with each case and enabled me to see comparisons and contrasts between cases. Having found incident-to-incident coding helpful I used this technique for other ideas of interest, such as data relating to resuscitation, Do Not Attempt Resuscitation (DNAR) forms and Treatment Escalation Plans (TEPs).

Figure 6: Example of individual patient accounts
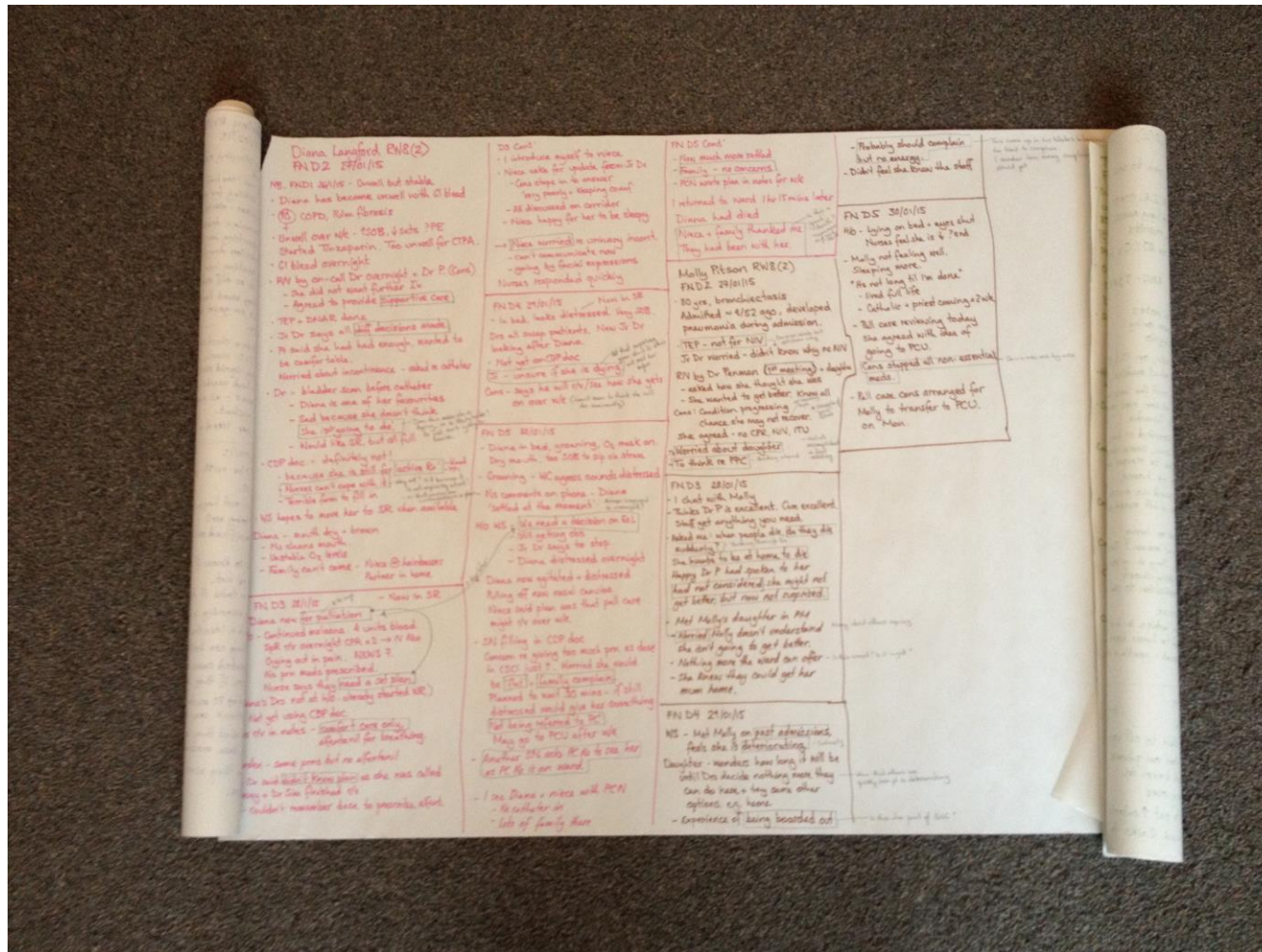
Charmaz describes the use of 'in-vivo' codes (Charmaz, 2006). These are terms which participants may use to describe phenomena. These codes are often widely used terms which condense meaning and which participants use assuming a shared understanding of the term (Charmaz 2006). I found such codes throughout my data, for example terms related to types of care: 'palliative care', 'comfort care', 'supportive care'. I compared these terms as they were used by participants to describe patient care and found that while the terms appeared to suggest a shared and common meaning, often a participant's understanding of what that specific care entailed varied.

Following the initial coding described so far I began to see that certain codes were more significant than others. The significance of codes sometimes became apparent because of their frequency in the data, but codes also gained significance as they provided links with other codes or sections of data. I was then able to apply these focused codes to the data in order to explain larger sections of the data (Charmaz, 2006). This focused coding led to the development of three key themes, which I have called Care, Decision-Making, and Language and Meaning. These three themes provided a way of understanding the data and they form the basis for my results chapters.

5.9.2   Memos

Throughout the process of data analysis, I sought to write analytic memos about any recurrent themes, interesting ideas and comparisons and contradictions that I saw in the data. I shared these with the research team, which led to further discussion, questions, and new lines of inquiry. I discussed sections of anonymised data with the research supervisory team, as well as with a separate qualitative research methods study group at the University. The process of presenting my data to others was important for highlighting my unconscious assumptions about the data and forced me to provide clear explanations for my conclusions.

5.10 Conclusion

This chapter has provided an explanation of the theory which underpins the research methods, a detailed description of the setting, the recruitment and sampling strategy

and an account of the way the study was conducted on the wards. The next three chapters will describe the key findings of this study under the following themes: Care, Decision-Making and Language and Meaning.

Chapter 6   Care at the End-of-Life

In Chapter Four I outlined perspectives on the concept of care from different disciplinary backgrounds. In this chapter I interrogate the data to gain a greater understanding of what good end-of-life care means on acute hospital wards within an NHS hospital in England. I explore the perspectives of patients thought to be approaching end-of-life, their relatives and the staff caring for them in order learn about their experiences and uncover their views and values related to care at the end-of-life. I highlight current challenges to providing good end-of-life care and consider how these may be better understood to ensure optimal care. All participant data quoted in this thesis have been anonymised and the names of patients, relatives and staff members are pseudonyms.

6.1   Perspectives on End-of-Life Care

There are two important issues to consider before presenting the data. First, it is known that the way that people die may vary considerably between patients. Some patients may deteriorate and die suddenly, some may take longer to die than predicted by healthcare professionals and others may fluctuate for indefinite periods of time before dying. Therefore, it can be extremely difficult if not impossible to be certain about which patients are approaching the end of their life. Furthermore, because of the potential for uncertainty, the care needs of deteriorating patients receiving general acute care may overlap with those in need of end-of-life care. Though I sought to explore end-of-life care on hospital wards in this study I came to recognise that there is significant overlap between general acute care and end-of-life care. Because of this much of what is described in the following three chapters may also be relevant and applicable to both general acute hospital care and end-of-life care. Second, in the following data chapters I present the perspectives of patients, relatives and staff as well as my own perspectives on the practice I observed. Though generally positive, participants sometimes described experiences which were extreme examples of both good and poor care. These examples can highlight difficulties in practice and be helpful to learn from, but they need to be

taken in context with the rest of the data. I have tried to maintain a reflexive stance with regard to the data in order to present a balanced view of care on the wards, which takes into consideration extreme examples as well as the more mundane and every-day experiences.

6.2   Patients' Perspectives on Care

Patients provided varied perspectives on their experiences of care on the wards, mentioning and highlighting different aspects of such care. Many commented on the busyness of the staff and issues with short-staffing, but the data suggest that patients didn't blame the staff for this:

> *I: And how have you found the care since coming onto this ward from HDU?*
>
> *RD: Oh they're lovely, you know? No complaints at all. Except that they come and say, there's your nebuliser, and then it's still there two hours later, you know? Or they hang the thing up on the drip and antibiotics into us and they tie you to the bed. And I say, I need to go to the toilet. Cannot get anybody, cannot catch anybody, you know [RD laughs]. But, you know, they've got too much on their minds…………………*
>
> *I: Right, so maybe a few more staff needed or?*
>
> *RD: Well the way the governments cutting the staff, they're not even going to, they'll probably have to cut more off here. You know it's horrendous!*
>
> Interview with Robert Davies, patient on ward A, 02/02/15 p2

Though Robert described waiting two hours to have his nebuliser removed and being attached to a drip and unable to go to the toilet, he did not complain about the staff but instead focused on wider issues. A patient on ward B expressed similar comments about delays in care:

> *"Yeah, sometimes you have to wait a little bit. I haven't but one of the other ladies that needed help, and one time she had to wait about half an hour for to go to the toilet. But, of course they're so busy".*
>
> Interview with Jennifer Toomey, a patient on ward B, 27/11/14 p2-3

Patients didn't appear to like to complain and when they did make negative comments about the care received, they prefaced them with phrases about how busy the staff were or the problem with government cuts.

Maureen Brown, a patient on ward A described a mixed experience of care which included delays in the provision of care because of what seemed to her to be too few staff. Yet she also felt that the attitudes and personal experience of staff members could make a difference to how they provided care. Maureen required diuretics to reduce swelling in her lower limbs and was connected to an IV drip which frequently beeped:

> *"And the noise and, I feel like saying, I think all of these nurses should be sat for ten minutes with one of those on, so they experience it, it would make the diff- and you know, then giving them an injection to make them go to the toilet, and say "yeah, I'll get you a bed pan in ten minutes". You know? Some personal experience, that's important, some personal experience of the situation to the nurses, would perhaps give them an insight of what its like…"*

> Interview with Maureen Brown, patient on ward A, 17/07/14 p13

I observed that the wards were sometimes short staffed and this meant that at times patients did have to wait longer to receive the care they needed.

While this section focuses on the perspectives of patients, here I outline some of my observations of care and some of the perspectives of staff in order to place the care of patients into context. On ward A there was a chart on the corridor wall documenting the numbers of staff expected for the morning, evening and night shifts, alongside the actual numbers of staff present that day. It was not uncommon for the numbers to be down by one or two fewer staff than recommended for a given shift. On ward B, the numbers of staff were written up on the big white board opposite the nursing station. Staffing levels were an issue that staff members on both wards spoke to me about both informally in discussions on the wards and formally during individual interviews:

> *Pam [senior staff nurse] explained that the ward had been extremely short-staffed and that some staff had left. I asked why and she told me that one staff nurse had left because she felt the ward was an unsafe place for patients with so few staff. Pam said the staff nurse was worried that with such poor staffing something bad would eventually happen and she didn't want to be a part of it…………. Pam told me that another staff nurse had left for similar reasons. Then she explained that one nurse was off sick and one was on compassionate leave. Pam said that they had recruited some new staff but they were not yet 'up to speed' and took a lot of time. She told me that there were frequently only 'two and two' [two staff nurses and two HCAs] on for the ward of thirty one patients. I looked at the board and saw that this was the case for that afternoon. Pam said that it just wasn't safe with such a small number of nurses. She explained how many patients they had who were at high risk of falling and said that if you only had two staff nurses you couldn't be everywhere at once.*

She went on to say that in one week the staff had recorded incident reports for twenty patient falls on the ward.

Field Notes Ward B, 22/04/15 p2

When the nurses were short-staffed on both wards I observed that they informed the Matron and appropriate senior management staff. And when they felt staffing was unsafe they completed incident reports to document their concerns. Pam's response to these situations highlighted her frustration. Her account also described her ongoing actions to care for patients by following appropriate procedures for documenting her concerns and through her continued work on the ward.

Two of the staff nurses on ward A described the staffing situation to me and I observed their difficulties as they sought to care for confused patients:

> *Penny [staff nurse] said the staffing situation was terrible. She explained that the two staff nurses on the early shift finished at 3.30pm and then she would be the only qualified nurse on for the whole ward. She said there would only be two HCAs. She had been on the phone to another ward who were supposed to lend her one of their qualified nurses in exchange for an HCA, but she said she couldn't spare an HCA as she had two patients who needed 1-to-1 nursing. Another staff nurse, Viv arrived and listened to Penny. Viv said that she didn't mind short staffing as long as she didn't have confused patients. But with confused patients she said she was always worrying they might fall. She said that you couldn't take your eyes off them…………………*

> *I stood at the nursing station and observed that the two confused patients, George and Mable, required a lot of assistance. Frequently when all of the nurses were busy the HCA had to leave George in order to go and help Mable. Then George would start to wander and Mable would try to get up. The HCA was running continually between the two.*

> *Field Notes Ward A, 29/06/14 p3 & 6*

In general the staff members I spoke to felt that problems of poor care were due to short-staffing and could be resolved when they had appropriate levels of staff. And I observed that the wards were not always short-staffed. There were days on both wards when staffing levels were as they should be and staff seemed to feel much more able to ensure the provision of timely care:

> *Amy [staff nurse] told me that the ward only had twenty one patients and that they were very well staffed that morning. They had three qualified nurses and three HCAs and the matron had just phoned to say they were getting another HCA. She told me how organised the ward was and that yesterday they had managed to get all of the patients washed by 11am.*

Field Notes Ward B, 25/05/15 p1

However, despite frequent instances of staff shortages, patient experience surveys conducted regularly on ward A by the patient experience team and shared with ward staff, had revealed a high level of satisfaction with care. On two occasions one of the senior nurses showed me the ward's results. The first time 71% of patients said they would highly recommend ward A to friends and family. On the second occasion twenty two patients had been asked and 100% had said that they would recommend the ward to a friend or family member. However, there was also one occasion on ward B when the results were not so good:

> *Dr Auburn [junior doctor] asked if I had seen the patient and family feedback for the ward? I said I hadn't and she said 'it isn't good'. She got the report up on the computer and let me read the comments. Some of them were very critical about the nursing and medical staff. A lot of the complaints related to lack of communication as well as personal care.*

Field Notes Ward B, 22/05/15 p2

I asked what was being done in response to the comments. Dr Auburn told me that the consultants had seen the feedback and were thinking about what action to take. In order to address the communication issues, she thought they might introduce a booking system like they have on some wards so that relatives can book appointments to speak to the doctor. Though this observation describes an account of poor care, it highlighted important issues. First, the account suggest that care was not viewed as simply the prerogative of nurses. Rather, the doctors *and* nurses were shown to be accountable. Second, by informing staff of patient and relative experiences this feedback provided an opportunity for senior staff to demonstrate care by actively planning strategies for how care could be improved.

Keeping the problems with short-staffing and examples of poor care in mind, it is also important to note that in general the patients I interviewed on both wards were positive about their experiences of care:

> *"They're [the nurses] caring, they look out for you. Everything you want, they put it there for you".*

Interview with Arnold Hamilton, patient on ward B, 28/11/14 p2

Arnold suggested that the nurses didn't simply meet his needs, they cared for him by watching out for him. Other patients gave similar responses:

I: What's been your experience of the care that you've received on this ward?

JT: Very good.

I: Okay. And in what ways has it been good?

JT: Well, I've seen so many doctors, helping to find out what's wrong with me. The nurses have been always pleasant, and I'm quite happy with what happened.

Interview with Jennifer Toomey, a patient on ward B, 27/11/14 p1

For Jennifer, care included the medical investigations arranged by staff to help to diagnose her condition. But care also included how staff members interacted with her and whether or not they were pleasant. Hannah Snow a patient on ward A, suggested that care was about the competency with which staff carried out their tasks, their manner and the way they acted to respect a patient's modesty and dignity:

"I've always had this thing about hospitals, and I've got a thing about needles. God, I've had more needles this week than…..but it's, it isn't bothering me really, em now. Like the doctors put me so much at ease, you know? When they did this, whatever they do, drains or something, it was just amazing, I never felt a thing, they were wonderful. I couldn't fault them on any score at all. And the doctors sort of never embarrass you in any way, you know? They're really, really good".

Interview with Hannah Snow, patient on ward A, 24/03/15 p1

Yet care was viewed not simply as what staff might do to patients or for patients but how they *were* with them and how they took time to interact with them. Brian Cook a patient on ward A described how the staff responded when he felt very down because of his health problems and symptoms:

"And….. I know that as long as I make them aware of how I feel….. They don't, they don't mollycoddle, they don't fuss me. But they keep a little, we'll have a chat and……. They don't make light of the situation, but they try…. and ease my thoughts if you understand what I mean? They reassure me that I've got…. somebody there that's on my side".

Interview with Brian Cook, patient on ward A, 01/07/14 p17

Care seemed to engender a feeling in patients that the staff member was there for them, they had the patient's interest at heart and would look out for them. Maureen Brown expressed a similar sentiment:

> *I: And from your point of view, what would you say are the really important aspects of the care that you want to receive here in hospital? What's most important for you?*
>
> *MB: Em…… could I say…. care but not smothering. Does that make sense? Because em, I don't need someone, I'll change my own clothes today, but I sometimes don't need, you know…….. em someone to come to the toilet with me, all I need is… my oxygen bottle put on…..*
>
> Interview with Maureen Brown, patient on ward A, 17/07/14 p8

Maureen explained her desire to be given the freedom to do what she could do for herself while also receiving the support she needed.

During his interview, Brian Cook compared the care on ward A with another ward in a different hospital.

> *BC: Its eh……. totally different scenario to here, whereas here………Anna [staff nurse]… knocks at the door and says is it okay and everything, but at the other hospital, there's a knock on the door, I've got your tablets and that, they wouldn't bother, it's just like there you go. Eh… they just don't tend to listen to the patient so much at all……………………It, it, it is like an auto-pilot, from when you come in at 8 o'clock in the morning til the end of the shift. They say, we'll do this, that's the beds, let's do the beds, they've been washed, tea break. Go through it again. Whereas here… I've seen staff go without tea breaks to make sure a patient's had a wash properly …Been cared for….they'll go the extra three miles to make sure somebody is comfortable……………*
>
> *I: And why do you think that is so important, that difference?*
>
> *BC: It meets, well for me personally….. I'm not just another person sat in a bed. I, I'm me, I'm Brian Cook, and I…. feel individual things. And I feel…. I'm not just a number, I'm not just a thing that's occupying a bed, I am a person …That's not very well…. And I need looking after. And it makes the world of a difference when you feel, you're not just another, another body lying there. Another, well the way I look at it, you're not just another piece of meat…. That's come in and just trolleyed in and out.*
>
> Interview with Brian Cook, patient on ward A, 01/07/14 p19-20

Brian was critical of staff who appeared to work rather mechanically to get jobs done without any sense of a human connection with the patients. For Brian, good care meant that staff related to him as a fellow human being. He recognised himself as dependent and in need yet this did not take away from his equal worth and dignity.

Some of the patients also commented on the importance of the staff teamwork in order to provide good care:

"Well the care I've received is very good, very good indeed. Like I say, even the girls [nurses], all of them, sometimes they're very tired. You know they've always got something nice to say to you. And they are as gentle as they can be, especially when they're shoving stuff in and out all the time. But eh, it is, it's very good………………………………

It seems as though the girls on this ward, I don't know how busy they are, so I can't really say, this is just my observation that they've got it down to a fine art, who's doing what, where, and after each other, and they've got an order. And I think that helps [I: okay, okay. So they seem to work well and have a way of doing things?]. They do, they all seem to work well. And you don't hear any of that, you don't say "oh she's not done this", like I have done in hospitals before".

Interview with Sue Webster, patient on ward A, 28/08/14 p1

Care was not just a matter between patients and staff, but a matter of teamwork and care between staff members. This comment was particularly interesting in light of the staff shortages I had observed. A well-functioning team appeared to be extremely important to ensure that good care was experienced by patients. Care was a community activity and responsibility that involved everyone on the ward:

BC: it really is a team attitude. They really are a full team here. From my point of view… I see it working from the outside and I can see them working together….. and…. You see when someone's [staff member] having a bad day and….. they're unsettled in themselves… and you see the other members of the team going, 'come on love, you do that and then I'll take over this'. It makes a difference. Not just to that person doing that without, but to the patients, cos you know, that person cares about that person and if they care about them, they care about everybody else as well. Which is true.

I: So they care about each other and the patients.

BC: Yeah. It's great! And the, all the consultants care about the staff on the ward ….. the staff care about each other…. And everybody cares about the patients.

Interview with Brian Cook, patient on ward A, 01/07/14 p22

Analysis of the data suggests that patients were generally positive about their care and did not complain. Patients recognised that staff were often busy and could be short-staffed and that their care could be affected as a result. However, few patients criticised staff and instead some blamed external factors and were quick to excuse delays in care on the seemingly unavoidable busyness of staff. Of course, this does not mean that

patients were completely happy with their care and it is possible that some were reluctant to complain. The issue of why participants do or don't complain will be further discussed in the next section. However, from the data discussed in this section and from a patient's perspective, good care includes attending to the patient's physical, psychological and social needs in a competent, empathetic and kind manner. This kind of care engendered the feeling in patients that the staff members were there for them. Patients described the importance of a team approach in the provision of care and care was needed between staff members as well as between staff and patients.

6.3   Relatives' Perspectives on Care

When speaking about the care of their loved one, many relatives also acknowledged the busyness of staff on the wards and difficulties with short-staffing. Just like the accounts from patients, some relatives also appeared reluctant to criticise staff and often blamed external factors on what they might deem poor care.

Naomi Peters a relative whose father was dying on ward A, recognised the potential for her father's needs to go unnoticed or be delayed due to short-staffing. She ensured that she (or a member of her family) was always present to provide care for her father:

> *Naomi explained that she chose to stay with him [her father], but not because she didn't trust the nurses. But she knew how busy they were and that there weren't enough nurses, and she didn't want him to be alone and waiting for something. She told me that she had heard patients calling out for nurses overnight, and they had had to wait. But she said she blamed this on the government rather than the nurses.*

Field Notes Ward A, 17/02/15 p2

Though Naomi denied a lack of trust in the nurses, she certainly did not feel confident that her father's needs would be attended to appropriately. She blamed this not on the nurses' competency or care but on their busyness, which she attributed to government cuts. Therefore, she acted to ensure that her own father's needs were attended to.

Moira Porter a relative on ward B whose mother died on the ward, acknowledged poor communication with staff members during her mother's admission, but was anxious to express that her comments were not to be understood as criticism. This perhaps

suggests that relatives may be wary of complaining or find it difficult to complain about care, as discussed further below:

> *Moira described being interrupted when talking to staff members on the ward, so that when her mum was first admitted she never felt she knew what was happening with her mum. Now that her mum was more unwell she saw the doctors frequently. Otherwise, she said that the care was excellent and she was keen to emphasise that she was not being critical.*

Field Notes Ward B, 11/12/14 p2

It appeared that the busyness of staff was perceived as an understandable reason for suboptimal care, though it was often not expressed so explicitly. From this perspective, the staff were busy and it was not their fault. They were simply doing the best they could under the circumstances. This perspective seemed to come from low expectations about the kind of care that could or should be expected from staff on the wards.

I found that a recurrent narrative running through the data was the lack of complaint or criticism from patients and relatives. Both groups described situations of good and poor care, but when care was lacking they were often reluctant to complain or criticise staff. Accounts suggested that patients and relatives perceived that the NHS was stretched and the staff members were simply doing their best under the circumstances. However, comments from one relative also highlighted the potential for fear of reprisal to have an impact on patient complaints. Naomi Peters described her father's reaction when the family had wanted to make a complaint about the care he had received on another ward:

> *Naomi also told me how her Dad would tell the family not to make a fuss or complain. When I asked why she thought this was, she said he was afraid. He had said to them that he was the one who had to stay on the ward after they left, and he was worried their complaints would affect his care.*

Informal Interview with Naomi Peters, relative on ward A, 18/02/15 p2

The phenomenon of 'under-complaining' or being reluctant to complain has been previously discussed in the literature and is well recognised as a difficulty in gauging

healthcare quality[17]. It has also been suggested that for this reason, it is more reliable to ask patients and relatives about their experience of care (asking them to give factual responses about what did or did not happen during their time on the ward) rather than asking questions about their satisfaction (which expects them to provide subjective responses on a ratings scale) which has been shown to be unreliable (Sizmur and Redding, 2009).

Not all relatives were reluctant to give negative feedback on their experiences of care. Bill Walker's mother Mary, was seriously unwell on ward A and went on to die on the ward. In an interview he expressed his concerns about the care on the ward. He recalled a situation when Mary's bandages were left soaking wet and bloodstained for hours without being changed:

> *BW:It's the care and the general-, and it's the, it's just, Fiona, you ask them [the nurses] to do something and it's never done straight away. And its, you're made to feel as if you're being a nuisance. And to me, it's basic stuff that at home you would, you know, you wouldn't think twice about doing. And, I know that there's obviously staff shortages, all the cut backs, it's not the staff's fault all the time, em.*

Interview with Bill and Norma Walker, relatives on ward A, 24/07/14 p5

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[17] The 'under-complaining' phenomenon or reluctance or refusal to complain has been previously identified in the literature. Attree (Attree, 1999) interviewed patients from an acute medical ward and some of their relatives. She found that critical responses about their experiences of care were less frequent and less specific than the positive responses. Furthermore, though patients sometimes described experiences which healthcare professionals would probably have described as 'not good' care, not one of the patients had complained even informally about their experience of care. Attree outlines the broader literature on this phenomena and demonstrates that patients often do not complain even when they have the grounds to do so. She suggests the following possible explanations for this behaviour: the passive nature of the sick role, a culture which simply accepts healthcare without question, and fear of impact on ongoing care all of which can lead to a culture which discourages complaints about healthcare (Attree, 1999). Quoting Lamont (Lamont, 1994), Attree highlights that many patients often preface any negative comments with phrases about the lack of time and work pressure on healthcare staff. Bismark et al. (Bismark *et al.*, 2006) conducted research to estimate the proportion and characteristics of patients injured by medical care in New Zealand public hospitals who complained to the independent health ombudsman. They found that for adverse events only 0.4% resulted in complains and for serious and preventable adverse events 4% resulted in complaints. However, the 'under-complaining' phenomenon was not found to be distributed evenly over the patient population and elderly patients and those who lived in the most deprived areas were least likely to complain. The authors argue that the low propensity to complain among these patients highlights worrying disparities about the access to and use of patient complaint procedures (Bismark *et al.*, 2006). The UK Organisation *Healthwatch*, describes itself as the 'the consumer champion for health and social care'. It has a webpage devoted to the issue of under-complaining by British citizens. Their report called 'suffering in silence' found that patients often find complaints procedures confusing and lack the confidence that their complaint will lead to beneficial change (Healthwatch, 2015).

Bill recognised the impact of staff shortages but felt that this was not the only problem. He perceived the actions of some staff members as indications of begrudging attitudes leading to slow, unwilling behaviour in spite of what he felt was obvious patient need. Bill did not feel that his expectations were unreasonable or that he was asking for anything exceptional. He expected his mother's 'basic' needs for care to be met. On this occasion he felt that basic care was lacking, yet he also felt that the staff were unapologetic for the lack of care, which caused him to feel like a 'nuisance'.

Bill described a further situation relating to his mother's care. He explained that his mother had only been tolerating sips of fluid. On this occasion, she had had an NIV mask strapped tightly to her face and IV drips in both arms which meant that she had limited movement of her arms:

> *"There was one day, there was a packet of sandwiches on the table and they weren't even opened. They weren't even opened. And I says to the nurse, I says "she'll not eat them, she's just having drinks". She [the staff member] just opened them up, cut them in four "there you are Mary" and left her. She's sitting with her arms up like that [holds arms out in front of him], with all the stuff in and the mask on......I mean"*

> Interview with Bill and Norma Walker, relatives on ward A, 24/07/14 p6

This staff member, though seemingly unaware of the impact of her action, provided 'care' in such an insensitive and unperceptive manner that it was not care at all. From this account it is impossible to determine the reason for her actions. Perhaps she was simply uncaring, though she did respond to Bill's statement. Perhaps she was so busy and distracted that she failed to recognise that Mary wouldn't be able to eat the sandwich. Or maybe she assumed that because the family were present they would assist Mary yet such an assumption was not verbalised. From Bill's perspective the nurse failed to recognise Mary's needs and neglected to provide the care that Mary needed.

However, I found that relatives on the same ward sometimes praised the selfless attitude and caring manner of staff. Though Naomi Peters voiced concern about the potential for poor care, nevertheless she praised the actions of the ward staff in caring for her father and other patients too:

> *Naomi said that the nurses were lovely to them [the family] and to her Dad, and very caring. I asked what she meant by caring. She explained that the nurses didn't screw*

up their faces when she asked them for something and they were never sharp. She described watching the nurses as they cared for another elderly patient with dementia. Naomi said that the lady had persistently asked to go to the toilet even when she had just been, she would forget and ask again. However, the nurses never got impatient and always took time with her and joked and laughed with her.

Informal Interview with Naomi Peters, relative on Ward A, 18/02/15 p2-3

From Naomi's perspective the nurses' patience and willingness to help the patients despite repeated requests and potentially frustrating situations was a demonstration of their care. Her experience contrasts with Bill's experience on the same ward.

Alongside concerns about poor care many relatives commented on very positive experiences of care that they and their loved ones had received on the ward. Mary Murphy was a relative on ward B, whose husband had come in extremely unwell and was receiving end-of-life care:

Mary said that the care had been very good and she had no complaints. When I asked her what made the care good, she told me that it was the kindness of the staff. She said that they spoke to her kindly, and also spoke to Kenneth and called him by his name. She said that they were gentle with him and took time to care for him. Then she told me about one of the nurses this morning who had come in while she was there. The nurse had noticed that Kenneth's mouth was dry and immediately went to get sponges to sponge around his mouth and lips.

Field Notes Ward B, 20/04/15 p2

For Mary good care included the manner of the staff members, in particular, behaving in a kind and personable way as well as being perceptive and responsive in seeking to meet her husband's physical needs.

On another occasion, I spoke with the wife and daughter of Paul Hart, a patient on ward B. Paul had a chronic neurological condition and had been steadily deteriorating but was now thought to be dying. I asked them about their experience on the ward:

Paul's wife said that she gave the ward staff ten out of ten, and that they had been brilliant. She commented that they had cared for him so well, and treated him like a real person, rather than just another old man. Paul's daughter said she couldn't think of anything that could have been done better, apart from offering open visiting a bit earlier. She said she couldn't get over how clean they kept him, commenting that he always looked so clean and smelled so fresh.

Field Notes Ward B, 07/05/15 p3

Marjorie, a relative on ward B, whose mother Anna was receiving end-of-life care on the ward, told me how lonely her mother often felt because they had few relatives or friends nearby who could come in and visit. Marjorie described the importance of a human connection between staff and patients:

> *Marjorie spoke about the nutritionists on the ward and said that she felt that because they didn't have a medical or nursing job to do, somehow they could be more human with the patients. I asked her more about this and whether she thought it was possible for doctors and nurses to retain that human connection when they were so busy. She thought this was possible, but only for the good ones, who had the right manner.*

Informal interview with Marjorie Pringle, relative on ward B, 10/10/14 p2

Marjorie highlighted the importance of a 'human connection' between patients and staff. I found that a 'human connection' (understanding of the other's perspectives and needs) was also important during interactions between relatives and staff. Liz White's father had been deteriorating and had been thought to be dying on ward A. In an interview she told me that she had made a complaint to one of the senior staff nurses about her father's care. The family found that the bandages on his legs were often left soaking wet without being re-dressed and they became concerned about the cleanliness of her father's room when they found urine on the floor:

> *"And so the senior staff nurse was very concerned and em, said 'they aren't our standards', em she was gonna look into it, she'd get back to me that afternoon, never did. I think she spoke to me about a week later. So...em......I mean the thing is, it got done, but you know, if you say you're going to get back to somebody then get back to them. I mean I work in a job. And if you say you're going to get back to somebody, you get back to them. I think she was a bit frightened, not that I was nasty with her, I just said, in fact I just sat down and cried. I just said 'the nursing care is fantastic, the doctors are great, but look this, this and this shouldn't happen, shouldn't happen to anybody's Dad and it's not going to happen to my Dad.' And she [the staff nurse] gave me a hug and said I'll get back to you and then never did. You know, so, some little things"*

Interview with Liz White, relative on ward A, 25/08/14 p3

Liz did complain about her father's care, and received an immediate response. But the fact that the nurse didn't keep her promise to get back to Liz about the matter was also perceived as a lack of common courtesy and care.

I observed that relationships were the medium through which physical care was provided, but the companionship and friendship provided within such relationships were also an important component of care itself. Marjorie Pringle recognised that good care could be facilitated by the structure and organisation of the ward:

> *Marjorie said that when her mum first came to the ward they had one nurse for the first three days, but then she went off for three days and they had to start again with someone new. Whereas the nutritionists seemed to work five days a week and her mum felt as though she had really got to know them.*

> Informal Interview with Marjorie Pringle, relative on ward B, 10/10/14 p1-2

For Marjorie good care was facilitated by continuity of staff members and by the relationships established with staff members. Yet Marjorie herself identified the lack of continuity of the nutritionist who worked only five days per week. Clearly no staff member can provide continuous care for the whole duration of a patient's admission. This account highlighted the importance of consistent communication between staff members when handing over the care of a patient. It also demonstrated the importance of staff being able to quickly and effectively establish rapport with patients and their families who may also be on the ward for only a short time.

These contrasting experiences suggest that both good care and poor care are possible on the same busy hospital ward and that though care can be influenced by the surrounding environment and staffing levels, these are not the only important factors in ensuring good care. As highlighted from data earlier in this chapter, the health and functioning of the staff team[18], the attitude of individual staff members[19], the ability of the staff team to recognise and provide for subjective and objective care needs[20] were all important aspects of care. In the next section, I consider relatives' perspectives on a particular aspect of care – assistance with eating and drinking – and consider how roles and relationships influence care provision.

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[18] See Section 6.2 p112-113 quotes from Sue Webster and Brian Cook.

[19] See Section 6.3 p116-118 Bill Walker's quotes and Naomi Peter's account.

[20] See Section 6.3 p119 Marjorie Pringle's account.

6.3.1 Caring Roles

While staff had clear roles in the provision of care for patients on the wards, I observed that relationships between patients and relatives could also be important for the provision of care. Some relatives provided assistance for their loved ones while they were on the ward. This could take different forms, for example: asking questions on behalf of their loved one, bringing in their favourite food, or assisting by feeding them. Some relatives voiced opinions about the role they played on behalf of their loved one:

> *"One of the comments that my sister made when I was telling her that I was coming to talk to you today, she said 'well God help anybody that doesn't have somebody, a family behind them'. You know? Who's going to ask the questions for them? And, you know push people [staff] for different things?"*

> Interview with Liz White, relative on ward A, 25/08/14 p1

Liz explicitly highlighted the advocacy work that she and her family took part in on the ward on behalf of her father who was very unwell. Other relatives, while acknowledging the potential for unmet care needs of patients in need of prolonged assistance with eating, appeared more accepting or understanding of the situation as simply being the way things were:

> *Moira Porter explained that she had noticed that her mum was not eating………………… So Moira had started coming in every meal time to feed her mum. She said she was aware that the nurses could not provide a one-to-one nursing service, and said that that was just reality.*

> Field Notes Ward B, 10/12/14 p2

Florence Howarth was an elderly patient with dementia on ward B, who had been admitted with severe pneumonia and was initially thought to be dying. She had recovered following treatment with antibiotics yet Florence had been refusing to eat at meal times and was losing weight. Both her daughter (Sarah Mackinnon) and niece (Sue Black) were retired and asked the ward manager if they could come in at meal times to feed the patient. Permission was granted and from then on they took it in turns to come in to assist with feeding at meal times:

> *Sarah: "Yes well, what we realised was that possibly they [the nurses] wouldn't have the time. I mean with the best will in the world, when you've got six beds per bay, and several bays, you can't expect the nursing staff to be constantly coaxing them to eat. And because we are both retired, we can offer our services, and Sue suggested that*

when we realised that she [Florence] actually, you know, wasn't really eating. And it just seemed to be the obvious thing to do was to say, well do you mind us coming in and bringing food in to try and coax her? And they were fine about it".

Interview with Sarah Mackinnon & Sue Black, relatives on ward B, 25/11/14 p2-3

Sarah and Sue became aware of Florence's need for assistance with feeding and realised that without this they knew she would continue to lose weight and likely deteriorate. Though feeding would normally be part of the nurses' role, they recognised that due to her need for prolonged assistance, the nurses were unable to provide the care she needed to ensure adequate nutrition. Rather than being critical, they were understanding of the nurses' situation and pragmatic about their own involvement. I observed that the voluntary involvement of relatives was often allowed and appreciated by staff members. However, it appeared that when families were unable to visit regularly the potential for unmet needs could be a real concern. This issue highlighted possible cultural variation in expectations around care. Marjorie Pringle was the only relative living near the hospital where her mother was dying. She worked during the day and was unable to visit regularly to assist with feeding at mealtimes:

Marjorie had been told that her mum had hardly eaten at all in the last few days, and she wondered if that was just because there was no one to sit and take the time to feed her. She said that it took about half an hour to feed someone, and the staff on the ward just didn't have that time, and that there were just not enough of them. She wondered aloud whether patients who had more family nearby, who came in to visit all the time would get fed more. But she said that it was not always convenient for family to come in at meal times. And she again wondered aloud whether families should have to do that?

Informal Interview with Marjorie Pringle, relative on ward B, 10/10/14 p1

I observed the care of Marjorie and Anna over several days and found that though Anna was often asleep, on many occasions she did drink whole cups of water or juice, or eat pots of yogurt if they were offered to her by Marjorie when she was visiting. This situation highlighted an important issue on the ward: the potential for inequality of care for patients without family or friends, or those who could visit frequently. It seemed that there was a real possibility that these patients would go without the care they needed because they did not have anyone to advocate for them and provide the care lacking on the ward. The term 'disadvantaged dying' was first used by Seymour et al. to highlight the disadvantages in care experienced by older people in the UK and seems

applicable to this issue (Seymour *et al.*, 2005c). While care from extended family is expected in hospitals in many countries around the world, it is not and never has been part of the provision of necessary care for patients in NHS hospitals. During my observation on the wards relatives were not told that they may need to provide assistance if their relative had particular care needs. Instead it seemed from the data that they made their own observations and provided care where they felt it was lacking.

Relatives voiced concerns about their loved ones but on occasion fellow patients also made similar comments. Maureen Brown a patient on ward A, highlighted the plight of patients who were too unwell to communicate their needs:

> *MB: You know I can communicate. Some of these others [patients] can't………………*
>
> *……………But the elderly lady opposite me, Enid…….. she wasn't eating. And I said, she's not, three days, to the, the girl next to me, 'she hasn't eaten for three days'. Yes they put her dinner down, but she needed someone to assist her…………………*
>
> *and suddenly though….since we encouraged her to eat… she's picking up… And, yes, that's what she needed. When we said, "she needs somebody to feed her" she started getting fed, and now she's feeding herself! And I know the nurses do try their best. But, I mean, little things……….*
>
> *But, they would put her dinner down, and then walk away. And you think, aw-ay!........*
>
> *And then, ah yes, and then eventually….. eventually em, someone would realise, and come and perhaps say "do you want your soup?" And I think, well no cause its freezing cold!*
>
> Interview with Maureen Brown, patient on ward A, 10/07/14 p6-13

Maureen highlighted the unmet care need of a fellow patient who needed greater assistance with eating and drinking. In the interview Maureen went on to suggest that this problem stemmed from short-staffing and what the ward needed was more HCAs who could spend time meeting the 'basic' needs of patients, such as help with washing, toileting, eating and drinking.

While patients and relatives voiced concern about unmet care needs, on two occasions I observed medical staff concerned about the possibility of unmet patient need. Dr Coral, a junior doctor on ward B told me about one of her patients Caroline Brenner, who was an 85 year old patient with advanced Parkinson's disease and dementia.

Dr Coral told me she had reviewed her yesterday, and while she was supposed to be getting fed, she wasn't convinced the nurses were giving her much as she didn't have any drinks or food on her table. Dr Coral had tried feeding her some yogurt. She thought that because of her dementia she didn't understand how to eat and sometimes would grit her teeth against the spoon. But Dr Coral said when you took the spoon away she would open her mouth for more as if she was hungry.

Field Notes Ward B, 16/04/15 p1

Dr Coral questioned the absence of food and drink in Caroline's room, but also acknowledged the difficulties involved in trying to feed her because of her dementia. The following day, Dr Pink a consultant on ward B, reviewed Caroline. I noticed there was still not a tray for mouth care or any drinks or food on her table.

Outside Caroline's room Dr Pink questioned aloud how much the nurses were going in to see her and try to feed her.

Field Notes Ward B, 17/04/15 p1

Caroline Brenner had family but they had not been in to visit for several days. I wondered if they had been present, whether she would have received more regular mouth care, sips or mouthfuls of food. Dr Pink advised giving Caroline sub-cutaneous fluids and changing her medication so that it was given through a skin patch.

It appeared that in these cases, unless patients had relatives who were willing and able to assist with their care, on occasion (as outlined in the above examples) those who needed prolonged assistance with eating and drinking might not receive the necessary care. In these instances families often did step in and offer to provide assistance if and when they were able to. But for relatives unable to provide such regular assistance the fear that their loved one was receiving substandard care was distressing. The data highlight the potential for inequality of care for patients without friends or family members and questions about the roles of relatives. But it also highlights the need for solutions where this problem is identified.

The data analysis shows that relatives and patients identified similar components as being important for their care. Good care included provision for physical and metaphysical needs and the objective and subjective needs of patients. Such care is complex and requires careful consideration for each patient. It also requires a well-functioning team with a clear understanding of their goals and purpose with regard to

patient care. Care is not simply the remit of nurses but involves the whole healthcare team and relatives. Finally, where there are difficulties and challenges in the provision of care - as described above with patients who need assistance with feeding - the importance of clarifying roles and the need to think more broadly about possible new solutions for care are also part of good care provision at end-of-life on hospital wards.

6.4   Staff Perspectives on Care

I spoke to many different staff members about their experience of providing end-of-life care and their opinions about what constituted good and poor care. In an interview with Kathy one of the HCAs on ward B, I asked what care and compassion meant to her:

> *"It's just being nice. Just taking your time. Just going at whatever speed, or however they need you to be. Somebody might not want much help, but need it. So then you've got to find your way of giving it without them feeling as if you're, you know. And just being how, whatever way suits them".*

Interview with Kathy, HCA on ward B, 22/05/15 p3

Kathy's repetition of the word 'just' seemed to minimise the importance, sensitivity and skill required to provide care and compassion[21]. It may also be an implicit reference to or indication of the lack of priority or precedence given to caring roles within society today[22]. Kathy described how important she felt it was to give patients choice and a sense of control over their care by asking about their preferences. She recognised that there were HCAs who didn't act in this way. I asked her why she thought they didn't take time with patients:

> *I: Okay. And why do you think they do that?*

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[21] Heaven et al. examined the practice feeding assistance on hospital wards and found that it was conceptualised by staff as being mundane, routine and common sense. Yet in practice they observed that such work required tacit knowledge and skill (Heaven *et al.*, 2013).

[22] Much has been written in the feminist ethics and ethics of care literature about the failure of society to recognise the importance of care. This has been attributed to the supremacy given to principles like autonomy and independence by modern society which some suggest has led to the principle of care being devalued (Tronto, 1993; Lloyd, 2004; van Heijst, 2011).

K: Because it's quick. It's quicker just to do things isn't it? And the same job's done. At the end of the day you've got somebody clean and washed and sitting in their chair.

I: So what makes you want to take the time over it?

K: Oh I couldn't not! I think I would feel guilty. I would feel I hadn't done a very good job. I would want, if it was my relative. I would want somebody to take care of them, not just look after them. There's a difference between looking after somebody and taking care of them. I would want somebody, if they needed it, to be taken care of.

Interview with Kathy, HCA on ward B, 22/05/15 p5-6

For Kathy there was a clear difference between meeting a patient's needs (for assistance with washing and dressing) and taking *care* of them. To care for someone involved recognising their needs and preferences and seeking to honour them. It was about putting the patient's needs and preferences before her own desire to get jobs done quickly.

Dr Red consultant on ward A, also described the importance of listening to patients when I asked what care and compassion meant to his daily practice:

"It's just, I guess it's your manner with the patient. The way you talk to patients, involving them in their care, em…….trying to be pretty clear from an early stage what they do and don't want, what they do and don't expect or understand. And then, adjusting things and correcting things, or you know, accordingly. It's just treating people like human beings, isn't it?"

Interview with Dr Red, consultant on ward A, 04/03/15 p7

Like Kathy, Dr Red used the word 'just' to describe his practice of care. This could imply a lack of the value and importance of such care work. Yet in an individual interview he also described the importance of this kind of relational care[23]. The quote here seems to suggest that he believed that his ideas about care were obvious. And indeed many other staff members did describe 'good' care in the same way, as did the patients and relatives: it was about good medical care, but care was also about treating the patient like a human being, providing care at their pace and taking time to listen to their wishes and concerns. Yet staff members also described the difficulties they faced in trying to provide such care:

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[23] See Section 6.4 p130-131 Dr Red quote.

"You know it's just, and quite often the little things that you do for the patients, they really remember those, little things, you know. Like that extra thing, one of the healthcare assistants has done or the shower that they've had that they've been waiting for, for two days, and it took 'til the third day before they could actually get in the shower, and…..you know? Putting some rollers in somebody's hair or, just all those little things just make a big difference. But we just, I don't know, can't seem to get them done very often".

Interview with Susan, Senior staff nurse on ward A, 20/08/14 p6-7

Susan recognised the importance of so-called 'little things'[24], the personal aspects of care which made a big difference to patients but also her struggle to ensure they were provided. Some staff blamed the difficulty in providing such personal care on a lack of time and a lack of staff:

"I think it [end-of-life care] could be better. And I've always said it could be better. And it's basically because of the staffing levels. Poor staffing levels, you can't give the care to patients that you would like. I would love to be able to sit with patients in their end of life, and in their last hours and be able to sit with them and comfort them. Sit with their family and have a cup of tea with them. You know, have a good chat with them. And it isn't possible. It just, with all the will in the world, it is not possible for you to do that. So I find that side of things hard. I would like to spend more time with families and patients, and not be just rushing in to make sure that they're not in pain, rushing in to make sure that their pain relief has worked, rushing in to make sure that their driver's working. Or get to be able to sit with them and do their hair, and make sure that they're comfortable, and. But it's just not possible".

Interview with Nicola, staff nurse on ward A, 26/03/15 p1

For Nicola, when the ward was short-staffed spending time to ensure that the personal and individual aspects of care were met appeared to be impossible. Though she recognised the importance of such needs, in these situations, her priority was on ensuring the patient's most urgent physical needs were met.

Dr Lavender, a junior doctor on ward A described her understanding of care as being broader than simply medical treatment:

"I think care is quite a difficult one, cos when like you think about the word care I think it depends on which part of care. Because then there's obviously the medical care. But I think the reality is when patients think about the word care, they're not

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[24] Such 'little things' or 'gestures of care' have been described in the literature, and their importance emphasised (Smith, 2010). Smith questions why such important components of care are labelled as 'little', and suggests the answer lies in the stereotyping of care as women's work, such that its importance remains unacknowledged and undervalued in increasingly high-tech healthcare environments.

really talking about the Midazolam you're giving them and things. You know, they're talking about the fact that you made them a cup of tea and stuff. And that's what's actually, and it's quite sad that, because you're so busy, it's not actually what you can do, it would be nice. It's nice, I think that does happen on this ward quite well. The nursing staff are all quite good at looking after, it's nice when you see the relatives who have been there like all night, and that, and they have got like the sandwiches and things that have been in the fridge. You know, the tea people are giving them cups of tea, not just like offering the patients a cup of tea. I think that's more the care that patients maybe want at that point".

Interview with Dr Lavender, junior doctor on ward A, 02/03/15 p7

While Dr Lavender admitted that while this kind of personal care was 'nice' it was not her primary focus, though she acknowledged the importance of such care for patients and relatives at end-of-life. She described the need for teamwork with other staff members (primarily the nurses) in order to provide such care.

On one occasion I observed two staff members talking about the importance of care beyond the medical treatments they were used to providing. Dr Pearl, a junior doctor, asked Dan one of the physiotherapists if he would see one of the patients who was feeling low:

Dan agreed to go and see him and said he would give him one of his motivational pep talks. I asked about this and whether they actually did any sort of counselling as part of their therapy. He said no, but that it was what most of them [patients] really needed most of the time. He said they didn't do anything like counselling that was evidence-based. Dr Pearl said that it was time, and that was what a lot of patients needed, someone with time to listen. She said she always felt guilty that she didn't spend enough time with patients. Dan agreed and explained it was like he asked the patient how they were but even while he asked he was backing away.

Field Notes Ward A, 19/08/14 p3-4

These two staff members emphasised the importance of non-medical care, though they also felt that busyness hindered their ability to provide this kind of care. Yet as Dr Lavender described earlier, I observed that such non-medical care (like getting a patient a cup of tea, or spending some time talking and listening to patients) could be facilitated when staff members worked as a team to support each other in providing care.

During interviews with staff I asked them about how they understood the word 'care' and what it meant during their daily work on the wards. However, from my observations this was not a regular topic of conversation between staff members. And

while staff might comment if they believed a patient had received poor care or disagreed with the care given[25], I did not observe any staff talking regularly together about what it meant to provide good care. Instead, it appeared to be assumed or taken for granted that staff members knew and agreed on what 'good care' was. I wondered if such care could be further encouraged and facilitated by regular discussion between staff members about what good care actually involved and how staff could work together to provide it. For I observed that even with limitations in time and staffing levels some staff found strategies to ensure good care was provided. Lisa, one of the staff nurses on ward B described her approach to caring for dying patients on a busy ward:

> *"So I do quite often, and we often work in pairs with a healthcare and stuff so, we'll do the job together but then I'll kind of say, right, and delegate other tasks to them so I can then spend more time with the family and the patient cos it is the last things you're doing for them, and also when the family are there, they need to know that that support and things is there, and that you can build up a bit of rapport with them, so they can sort of come and speak to you even if they think it's a silly question. Like, there's not any silly questions, so you want to build, be able to build up a rapport. So you do feel like you're getting torn in a million directions, but I do probably focus more on them, cos I think it's the final sort of things that you're doing, so it's really important that it's done"………………………………*

> *I think I always want to go in and get them….they are like the first priority for going in and getting like washed and dressed, cause you think the family are going to be coming in so you don't want to disturb the family as soon as they arrive. So you want them to kinda look presentable and comfortable when the family arrive. And then it would be kinda a case of doing certain things for other patients and then it's just like popping back and just even sticking your head in the door just to check that the family is okay, are they okay?*

> Interview with Lisa, Staff Nurse on Ward B, 21/11/14 p5

By working as a team, delegating tasks and being organised about how she cared for all of her patients, Lisa tried to ensure good end-of-life care even when she had multiple tasks to do. Interestingly when one of the junior doctors heard I was going to interview Lisa, he spontaneously told me how good she was at end-of-life care, which on reflection is perhaps another indication that such good care is possible on busy wards. Later on in the interview I asked Lisa what made her prioritise end-of-life care:

> *"It's hard but I find it rewarding. The patients when you do get that five minutes to sit down, you kind of remember that they've been in the war, and a lot of them are*

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[25] See Chapter Eight, Section 8.4 p177-8, quotes from staff nurses Anne and Pam.

kind of the reason that we're here, like. A lot of these patients like fought for our country……………… Whereas actually when you sit down and realise that a lot of these guys were like, sort of eighteen, nineteen, and they've been through all that, you kind of realise that it's a little thing that I can do for them, for what they kind of did…for us"

Interview with Lisa, Staff Nurse on Ward B, 21/11/14 p11-12

Lisa saw her patients as fellow human beings and though she had no direct familial relationship to them she felt there was a reciprocal nature and inter-dependence in the relationships between patients and staff and as a fellow member of society.

Dr Purple described similar values underpinning his approach to patient care:

"I think what's really important is that we remember that we're dealing with other human beings, really…………………And there's also a hierarchy within the hospital and I think that can sometimes sort of de-humanise the patients really. I know the system exists there for a reason, it's to do with safety and maintaining the system that can look after people as well as possible, but I think the bottom line is your interaction with the patients should always be, you know, a conversation between two people. And as much as possible, a sort of, I know it's difficult, but an equal sort of relationship really. It has to be a human interaction, and I think that's where compassion comes in. It's to do with trying to recognise you've got another human being in front of you, another person who's got as much value as anybody else, and to, I think just to try and, I think what's really important particularly in end of life care, is to know what that person wants really, isn't it? It's knowing what they're wanting, what their hopes are. Where they want to be".

Interview with Dr Purple, consultant on ward A, 03/03/15 p7

For Dr Purple to 'care well' meant to value the patient as a fellow human being of inherent worth, and he highlighted the importance of this value when working in an impersonal and hierarchical system within the hospital.

Dr Red a consultant on ward A, felt keen to remain involved with care when patients were dying and described a relational aspect of care:

"Because, once that's happening [patient is dying], for that patient and the family that is one of the most important things that's gonna happen to them, often. Sounds a bit stupid doesn't it? And so if things aren't right, that's a terrible, you've done them a terrible disservice. So, I think I'm almost involved more………………………

Obviously there're patients coming up from ECU that you've never met before and don't know, and that's happening. But I think because you quite often have that relationship with them already, then actually you are seeing through that relationship as best you can".

Dr Red described the importance of care for patients and relatives at the end-of-life, but his perspectives on the importance of end-of-life care are split by the rather unexpected comment, 'sounds a bit stupid'. Is it stupid because he considers it to be obvious, or perhaps because this human-side of care is not something that is discussed regularly in medical discourse on the wards and so it feels uncomfortable? He recognises that end-of-life care is not simply about physical and measurable clinical need but about other human factors. But there is a sense that to acknowledge this might be seen as ridiculous. Yet Dr Red cared for many dying patients on the ward, some of whom had chronic respiratory conditions whom he had come to know well over many years. And he felt that these relationships became increasingly important as he cared for patients when they were approaching the end-of-life.

In this chapter I have considered care at the end-of-life from the perspective of patients, relatives and staff. When combined, these perspectives can be used to build up an impression of the important constituent parts of end-of-life care as experienced by patients, relatives and staff on hospital wards. The care described is holistic in nature and takes into account physical, psychological, social and spiritual care[26]. Of course, the idea of holistic care or person-centred care in end of life care in not new. But the data also highlights some of the challenges to providing such care on busy, acute hospital wards. These challenges included busyness, staffing levels, determining when a patient was dying and balancing priorities when caring for acutely unwell patients and patients who were receiving end-of-life care side by side. While many patients and relatives reported generally positive accounts of care, I found that when given the opportunity to discuss their experiences in greater depth, examples of both excellent and poor care were described. This highlights the importance of not simply asking patients and relatives if they are satisfied with care but giving them the opportunity to share their experiences. Poor care was often attributed to short-staffing which clearly has an

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[26] Though participants in this study did not specifically mention 'spiritual needs', the needs they did describe such as the need to be treated like a person, with respect, and to be listened to, are encompassed by definitions of spiritual care. In a publication on the Spiritual and Religious Care Capabilities and Competencies for Healthcare Chaplains, spiritual care is defined as follows: '*Spiritual care can be provided by all healthcare staff, by carers, families and other patients. When a person is treated with respect, when they are listened to in a meaningful way, when they are seen and treated as a whole person within the context of their life, values and beliefs, then they are receiving spiritual care*' p3. See: (NHS Education for Scotland, 2008)

influence on care. Yet what was also apparent was the teamwork and strategy used by staff to ensure good end-of-life care even in the midst of busy hospital wards.

6.5   Conclusion

In this chapter I have discussed the concept of care at end-of-life from the perspectives of patients, relatives and staff members, along with my own perspectives on my observations. Analysis of the data highlighted challenges in providing end of life care in the acute ward setting. However, though staff members were often busy and short-staffed, I observed that teamwork and support in prioritising patient care could help to ensure good care at the end-of-life. Furthermore, the attitude of staff members appeared to be key in determining their manner and how the care they provided was received by patients and relatives.

In this chapter I have shown that care is a complex and multifaceted concept. It is about meeting patients' needs, including objective and subjective aspects of physical, psychological, emotional, spiritual and social needs. While each aspect can be seen to be an important part of care, none of them provides the basis of care in all situations. Instead, the analysis of the data is in line with the idea that care is constituted by many component parts which may vary in their importance and prominence in any given care situation. This is important because it highlights the need for staff to think carefully about the care needs of patients in every situation, as they cannot be assumed to be the same as those with similar conditions. There is not one essence of care which if provided will ensure excellent care, rather good care requires a careful and thoughtful approach to the felt needs of patients and relatives. The data also point to the varied levels at which care operates. It is required between individuals (patients and staff) working on the wards, but it also operates at a ward team level in the way that teams respond to complaints of poor care, and at an organisational level when decisions are made about the distribution of resources (the provision of staff). These conclusions will be further discussed in Chapter Nine and Ten. Having discussed the concept of care in general, in the next chapter I focus on a key aspect of care at the end-of-life: the practice of making decisions.

Chapter 7 Making Decisions at the End of Life

In Chapter Six I explored the concept of care at the end-of-life from the perspectives of patients, relatives and staff. As highlighted in Chapter Four, involvement in decision-making and communication have been shown to be important aspects of end-of-life care for patients and relatives. These components of care are clearly related, for example, it is impossible for patients to make informed decisions about their healthcare without the communication of relevant information from healthcare professionals. Therefore, analysis of decision-making practice will necessarily involve discussion about communication. However, not all communication involves decision-making and communication is simply one (albeit an important) part of decision-making. Therefore the two can also be considered separately. In this chapter I consider the practice of decision-making and how interactions occur between participants when decisions are made. I then consider the practice of communication in more depth in Chapter Eight. As previously discussed in Chapter Three and Four there are varying perspectives on decision-making, what it consists of and how it ought to be carried out. Decision-making can be viewed in a very legalistic manner as in the MCA where some might view it as a list of actions to be carried out in order to make a best interest decision. In contrast, decision-making may also be viewed as a process of good communication and deliberation between patient, healthcare professional and others. In this chapter I consider participant perspectives on how decisions are made on hospital wards when patients are approaching the end-of-life. I describe the particular challenges encountered by staff when making decisions about resuscitation. The aim of this chapter is to understand what it means to 'care well' when making decisions at the end-of-life and how difficulties related to decision-making may be overcome.

7.1 Patients' Perspectives on Decision-Making at End-of-Life

As I interviewed and spoke informally with patients on the wards I found that, in line with the current literature, many patients expressed how important it was to them to be involved in their care, especially when changes were being made:

> *I: So what aspects of your care really, would you say are really important to you?*
>
> *BC: Involvement… with.. the consultant, who is Dr Purple at the moment. Being made aware all the time of… any changes to me treatment. I really do need to know if they're thinking about changing the medication…. Or…. If they're thinking about something, I, I need to know in advance. So I find it, it's very important to me, that I am kept… well within…. the loop. Which I, I always do with Dr Purple, he's eh….. understanding of my needs, shall we say. Yeah, eh….. But they always have a……good sit down and a chat when he comes in and see me, on his ward round. I never feel pressured to say, oh well bla bla bla, and get it over with, cos they just take as long as I need to.*
>
> Interview with Brian Cook, patient on ward A, 01/07/14 p4

Dr Purple took time to speak with Brian and listen to his thoughts. In response, Brian described feeling as though Dr Purple truly understood his needs.

Maureen Brown a patient on ward A also described how important it was for her to be involved in decisions about her medication. In the following account she described her desire to be involved for a specific reason – she was the expert on her insulin regime:

> *"It's taken me a week to convince them [staff] that one, I know my insulins…. because one doctor prescribed ten units more than I really should have had, and I had two nights running hypos, because, and I kept saying "it's too much". And, you know, you don't have insulin for years without knowing your own body. So now, most of the sisters just say "how much are you taking?" And I tell them, which is brilliant. I know.. obviously, Enid [a patient in her bay] across from me couldn't do that, you know. And one has to be aware that there are patients who are incapable. But I think…. I think when I first came in, the nurses just tret me, "oh yeah there's another one" sort of, you know".*
>
> Interview with Maureen Brown, patient on ward A, 17/07/14 p1

Maureen's situation demonstrates that information is not simply provided by healthcare professionals. Patients may also have important information to explain to them[27].

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[27] The idea of patients being experts about their conditions was highlighted by the Chief Medical Officer for England in 2001 and has been used widely since then (Department of Health, 2001).

Maureen wanted staff to listen and get to know her so that she could be involved her in her care as much as she was able rather than staff simply making assumptions about her ability. I found that this was important for decisions about medication as the above two examples show but also for decision-making regarding every day care on the ward:

> *"Like yesterday was a bad day, and she [staff member] came in and she went "I'm going to change your sheets now". And I thought, no you'll not change my sheets now. But she's been in today and said "do you feel like having your sheets changed today?" I said "oh yes, I'll have them changed today". So they do listen".*
>
> Interview with Sue Webster, patient on ward A, 28/08/14 p3

Sue described wanting to be informed about what was happening and given the opportunity to express her preference and opinion. As Sue expressed above, it was important to her that they asked and listened.

Patients described varying experiences when asked about being informed about their condition and whether they were involved in decision-making. None of the patients in this study described not wanting information or feeling burdened by information. However the literature has highlighted that patients may desire less information as their condition deteriorates (Parker *et al.*, 2007). In general patients were positive about their experiences and few were critical about these aspects of care. As described in Chapter Six, this may result from a reluctance to complain or perhaps generally low expectations about what they can expect from healthcare professionals' communication and decision-making:

> *I: And in terms, when you have to make a decision about things, maybe treatment, or investigations, do you, are you involved in the decisions?*
>
> *JT: Oh, I always, I was told eh uh huh, when they said, eh, when Dr Blue came a couple of days ago he wanted to see what I thought about having a scan. He says, well if you don't want it, that's entirely up to you. So I mean I was given a choice.*
>
> *I: And did he give you information about why you might want to have the scan or not.*
>
> *JT: Yeah, he wants to see why the oxygen keeps going down…………… They said this one can spot any blood in the lungs, in the chest, rather, you know, so.*
>
> Interview with Jennifer Toomey, patient on ward B, 27/11/14 p2

This account gives little detail about the discussion between Jennifer and Dr Blue and it could be interpreted as a fairly minimal and quick explanation of the situation with little

guidance for Jennifer as she made the decision. It does not sound like a description of SDM as outlined in the literature. It appears that Jennifer interprets 'involvement' in decision-making as being 'told' and given a 'choice'. Yet this also sounds like a fairly straight-forward and routine decision which doesn't offer many varying options or require in-depth deliberation. So, this could be considered an appropriate level of information and involvement. Either way, Jennifer appeared positive about her involvement in decision-making; she had been given information she felt able to understand and then given a choice. This was also the case for Rosemary Floss, a patient on ward A:

> *I: And have you been involved in the decisions about your care, or?*
>
> *RF: Oh yeah. It's my decision.*
>
> *I: What sorts of decision have you been involved in?*
>
> *RF: Well, I said I would try the care. And one of them is stopping at home and going out a couple of days a week to a day centre, just to get us out and about again. Which I think will be alright……………………..*
>
> *I: And have you had any decisions to make in hospital about the treatments they're going to use, like antibiotics, or scans?*
>
> *RF: Well, while I've been in, I had a CT scan about four weeks ago, with Dr Red. And eh, I had this nodule on me lung. And, I mean we spoke about it before, a few month back when they found it. And I said, well what'll the options and that be with it if it grows, you know? He says, well, to have anything, we can't do a biopsy. He said to do a biopsy is going to be very, sort of, a bit dangerous, because of where it is and all that, I don't know what's up there, different things. He says, he could send us up to see someone at Mount Pleasant hospital. And he says, 'but I think he would be of the same decision'. So, I says, well to be honest with you, I don't want anymore. You know, if that's it, don't bother doing anything………………You see they can't do anything. But, and then, this week they're on about, it's nothing that'll be done about it, but it is well more or less cancer. I asked them, and they said…..I would be looked after. And then they says palliative care.*

> Interview with Rosemary Floss, patient on Ward A, 29/01/15 p3-4

Rosemary described a few of the decisions she had been involved in. She gave the impression of having a choice and some control about whether to accept or reject the care. She was not agreeing to it without reservation but was willing to see how it went. Equally she wanted to know her options for investigation and potential treatment of her lung nodule. And though she agreed with Dr Red not to have a biopsy, her decision

appeared to be based both on his recommendation and her own preference. While patients varied in how explicitly they described their roles in decision-making, it appeared that what they valued was the opportunity to share their views and feel listened to by staff. This involved hearing about their clinical situation and the recommendations of the doctors and deliberating between available options with healthcare professionals in order to come to a decision. What seemed to be most important for patients was the process of discussion and dialogue between the patient and healthcare professional. The final decision was simply the result of the more important process of shared interaction and understanding. And while much of the SDM research has concerned patients with chronic conditions who are relatively well with limited and often mutually exclusive choices (Elwyn *et al.*, 2014), end-of-life care poses different challenges which I will now discuss.

Though patients might wish to be involved in decisions I observed that there were occasions when patients felt limited in their ability to be involved:

> *I: And in terms of the decision-making around your care, have you felt that you've been involved in making decisions in terms of your treatment or?*
>
> *SW: Yes and no. Em, I feel involved, but I haven't had any input. But that's not because I couldn't have, or I should've had, that's because I was spaced out. See they were like giving us as much information, like em, when he [Dr Indigo] was in yesterday morning, and he was saying….in fact he says em, we did say that the chemo might not work. I was trying to jog me brain before he said anything, but I did remember, cos I said yes I did know. He says, well unfortunately things are looking worse. And so then he went off on a tangent, he wanted to base how I felt about it and how em……..and then I asked how long he would think. Cos originally without any treatment at all, I was given six months. But obviously I've lost, already lost two months. And if the chemo didn't do absolutely anything at all, so that's only going to leave us four [I: okay, what did he say?]. More or less. So, well he couldn't say anything else, but he had to get his point over. Or else it would have just been a point about a waste of the time he was coming to see us, you know? So they are very good.*
>
> *I: And then in terms of decisions about what you want to do now and in terms of where you want to be?*
>
> *SW: Yes, discussed that as well. Em, he says: "what do you want to do?" I says "well". He says: "no, what do you want to do about your care?" He says: "because I'd like to keep you in here for a little while longer". I presume that's to get us a little bit stronger. But I'd like to go home for a little while. To sort out, eh…..when it happens, what me son's got to do.*
>
> Interview with Sue Webster, patient on ward A, 28/08/14 p4

Sue said she felt involved but said she hadn't had any input. Exactly what she meant by this is not clear. Perhaps this was because she felt 'spaced-out' and wasn't able to contribute to the decision-making or offer her opinions in the way she might have normally. This highlights a challenge with decision-making at end-of-life, when patients' thinking may be impaired by medications, metabolic disturbances, infections and difficult symptoms such as pain, nausea and fatigue, yet they retain the ability and desire to be involved to a varying degree in the decision-making process. Knowing how much information and involvement is enough without being too much is extremely difficult. According to Sue, she felt that Dr Indigo was there to break bad news about her prognosis. Sue wanted information and he provided it clearly and honestly and it appears that she felt that Dr Indigo did a good job.

I observed that the decision-making capacity of patients approaching the end of their life on the wards often fluctuated and it could be the case that some days a patient was more or less able to be involved in decisions about their care than on other days. Therefore a patient's level of understanding was not always obvious. Other factors also impacted on a patient's ability to be involved. I found that for different reasons (including speech or hearing difficulties) patients varied in their ability to communicate and the speed at which they could do so. I made the following notes after a ward round with Dr Pink, consultant on ward B:

> *I noticed that Dr Pink took time to explain things slowly and clearly, bending down and speaking right next to the ear of a very deaf man so that he could hear. Dr Pink took time to listen to the patients and didn't seem in a rush when she was with them.*

> Field Notes Ward B, 17/04/15 p2

Dr Pink had several patients to see but appeared to take as much time as each patient needed to discuss information and decisions about their care. However her approach was not as quick as some of the other consultants. In contrast I observed that sometimes patients were not asked about their opinions by other doctors at all. Dr Amber, a consultant on ward A, and Dr Saffron, one of the junior doctors, were discussing a patient called Mary Walker. She was deteriorating and Dr Saffron asked about which treatments were appropriate in the event of further deterioration:

> *I asked Dr Amber and Dr Saffron if the patient had been asked what she wanted to do. Dr Amber said no. And then he said that they were not very good at doing that.*

He commented that this was Mary's first admission and so they were trying very hard to treat her.

Field Notes Ward A, 18/07/14 p2

I observed that Mary's mental capacity fluctuated and it was not always possible to hold a conversation with her. However there were days when her condition improved and she could express preferences about her care when asked by healthcare professionals. Dr Amber acknowledged the fact that they had not involved Mary by asking about her preferences. His comment about this being Mary's first admission could imply that 'trying hard to treat her' was the right thing to do because she had not previously been unwell and therefore they need not ask her. During her admission I observed conversations between Dr Amber and Mary's family members and it is also possible that Dr Amber felt that their involvement in decision-making was more appropriate than asking Mary and was sufficient to make decisions about Mary's care.

Yet even with more able patients I observed that the quantity of information given and time taken for discussion and decision-making varied considerably. On my first day of observation on ward A I observed Dr Indigo, a consultant, as he conducted his ward round. I made the following notes after he reviewed a patient called Enid Black and made a decision about resuscitation:

> *Enid had had a stroke in the past and needed full nursing care. She had been admitted with a chest infection and Dr Indigo told her she was improving on IV antibiotics. With the curtains drawn around her bed he asked her how much she could do for herself and she said not much. Dr Indigo bent over and said they would try and get her home later that week. Then he talked about continuing antibiotics but there being the possibility of her getting unwell again. He said if that happened and her heart stopped he didn't think resuscitation would work and therefore they would just focus on keeping her comfortable. She nodded but seemed a little unsure of what he said. He said okay, and told Dr Plum [junior doctor] that Enid would need a DNAR form. As we left the bedside I looked back and Enid was frowning and looked anxious.*

Field Notes Ward A, 23/06/14 p2-3

Dr Indigo gave Enid some information about her condition but from her expression it seemed quite possible that she had not understood it. He presented his opinion and she responded by nodding. There are perhaps two ways of regarding this interaction. First, Dr Indigo may have felt that given the limited time for his ward round this kind of information and decision-making was good enough. However it is interesting to

compare this example of his decision-making with that experienced by Sue Webster[28]. Sue seemed to be much more informed and involved than Enid. Second, Dr Indigo may have felt that the question of whether or not to resuscitate Enid was so clinically straight forward that it needed little discussion or the opportunity for Enid to deliberate. However if Enid did have decision-making capacity, she should have been more informed and involved. And if she lacked capacity the best interests process should have been clearer.

On a ward round with Dr White, a consultant on ward B, I observed as she and two junior doctors made decisions about a patient's treatment:

> *Adrian Moore was an 82 year old man who had been admitted with a severe urinary tract infection and acute kidney failure. Dr White told him that he was much better than he had been on admission and that his blood tests had improved. After speaking to Adrian, Dr White stood with Dr Crimson and Dr Mauve [junior doctors] talking about his medications and treatment plan. Adrian looked frail but watched the doctors and seemed interested in what they were saying. None of them explained their discussions but just said he was doing much better.*

Field Notes Ward B 17/11/14 p1

The doctors were making clinical decisions about this patient's treatment but they didn't inform or involve him in the decisions. One interpretation might be that the doctors felt that Adrian lacked the mental capacity to understand so did not involve him in decision-making as they would have a patient with capacity, instead planning to speak with his family later. During an individual interview Dr White spoke about the importance of speaking with families when patients lacked mental capacity[29]. Another interpretation might be that they felt that these were minor and routine decisions and didn't want to burden him unnecessarily. Or perhaps they were aware of the time pressure and provided what they felt was appropriate information within the time available. Either way their actions do not seem to be in accord with the GMC guidance which makes clear that their recommendations for practice apply to all healthcare decisions, from minor conditions to life-threatening situations; and that in all situations doctors must work in partnership with the patient (GMC, 2008). However at end-of-life, patients may have

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[28] See Section 7.1 p137, quote from Sue Webster.

[29] See Section 7.3 p150, quote from Dr White.

little energy for discussion and as highlighted previously their ability and desire for information and involvement may fluctuate. Therefore it is important for doctors to be committed to decision-making which will not unduly burden and tire patients yet also seeks their involvement as far as possible and aims to keep central the patient's wishes. In Chapter Nine I will propose that the rationale underpinning practice is an important consideration for healthcare professionals in decision-making practice.

On one occasion when the capacity of the patient was difficult to determine, Dr Sienna, a junior doctor, highlighted the importance of trying to speak with the patient and their family. Charles Knight was a patient with lung cancer and I observed as Dr Sienna reviewed him on a ward round:

> *Dr Sienna asked if she could ask Charles some questions. He said no. Dr Sienna started to ask him something and Charles said angrily 'I told you no'. Dr Sienna explained she needed to find out a bit more about him. For a few questions she seemed to distract him, and he told her where he had lived before he came into hospital. Then he said 'that's enough! Ta rah, no more'. He wouldn't say anything else. Dr Sienna asked if she could come back later and Charles said not to bother.*

> *Outside his room, Dr Sienna explained to Dr Saffron [junior doctor] that she had met this patient a few months ago and he was very different now to how he had been then. She said it was impossible to assess whether he had mental capacity or not. She wondered whether he might have brain metastases, or something that might be treatable, but said that it was impossible to know right now as he was refusing everything. She told Dr Saffron that they needed to speak to his family.*

Field Notes Ward A, 03/07/14 p4-5

For patients thought to lack mental capacity I observed that doctors tended to involve relatives more quickly. But there were many patients whose capacity was unclear or fluctuated and often it was not clear from observations whether or not these patients' relatives were involved. This issue will be further discussed in sections 7.2 and 7.3. I found it interesting that this was an issue commented on by one of the patients as well. Maureen had mental capacity and was able to be informed and involved in decisions about her care. She told me that she and her son were very close and she told him everything about her treatment. Maureen had been a patient on ward A for a few weeks and had observed other patients in the bay with her, many of whom had been less able to speak for themselves. She made the following comment during an interview:

"So I think the decision-making……….. perhaps families, perhaps could be more involved…… If the patient is not fully aware".

Interview with Maureen Brown, patient on ward A, 17/07/14 p7-8

Having observed the care of other patients in the bay she felt that there should be greater involvement of relatives when patients were less well and less able to express their views.

The analysis of data suggests that the patients I interviewed felt that being informed about their condition and being involved in decisions about their care was important. Decision-making included decisions about medical treatments like medications, but also decisions about their every day care on the ward. Patients gave varying descriptions of their involvement in decision-making but what appeared to be important was the process of discussion and interaction between staff and patients. While patients were generally positive about these aspects of their care, I observed that the approaches to information giving and decision-making by staff varied. It appeared that patients who were less able to quickly express their views were sometimes given less time to do so and therefore may have felt less informed and involved in decision-making. And it was suggested by one patient that for such patients there ought to be greater involvement of relatives. Having considered the perspectives of patients on the wards and my own ideas about what the data shows, in the next section I consider what relatives felt about being informed and involved in decision-making about their loved one's care.

7.2   Relatives' Perspectives on Information and Decision-Making at End-of-Life

Relatives of deteriorating and dying patients felt strongly that it was important for them to be informed about the patient's condition. Yet with few exceptions[30] a consistent theme throughout the data from relatives on both wards was the lack of information that they received from staff. Lisa Cummings, a relative on ward A, described her experience when both her parents were admitted unwell:

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[30] See Section 7.2 Marjorie Pringle's account p146, and Nigel Elmsdale's quote p148, and Sarah Mackinnon's quote p148-9.

"I do think, like obviously, everybody's there at the beginning to say how poorly they are, and that they're not going to make it. But nobody comes back to say, well actually they're still poorly but things have changed, as in, like I've kept asking and saying, has his blood pressure come up? Has…..you know, the blood results, what are they showing and are they a bit better? And it would probably be nice for to be told the following morning, yes he's still very poorly however, this is improved slightly so things are looking up, or…and we've not been told. The last time we spoke to a doctor was, he's not going to make it through the night, you know, and that's the last thing we heard. Understandably, everybody's busy, and it's great that he has made it through the night and he's still here. But that's probably the only, not criticism but the only thing that would've probably been nice to have spoke to somebody to, cos you don't know what's going on"

Interview with Lisa Cummings, relatives on ward A, 30/01/15 p1

Both of Lisa's parents had been patients on ward A on repeated occasions over the preceding years. She felt that being given timely updates about her parents' conditions was a recurring problem. Liz White, a relative on ward A, made similar comments:

"I think maybe sometimes the doctors and nurses might assume you know because they know. Em, they might assume you know because they know sort of how much better he is, but we don't. And I'm sure other relatives would find the same. So, that's been quite difficult to handle."

Interview with Liz White, Relative on ward A, 25/08/14 p2

Liz had no experience of hospital routines and practices and she wondered whether staff made assumptions about how much relatives would understand about their loved one's condition. Furthermore it appeared that on both wards relatives often had to seek out staff members in order to receive information about their loved one. I learned from staff that it was possible for relatives to make an appointment to speak with the consultant, but this was not advertised anywhere on the wards:

BW: Yes, she [nurse] said to me on the Friday night, she says em "what you can do is ring up to make an appointment with his secretary". I says "hold on a minute" I says, em… "he was supposed to be coming to see me! I shouldn't be ringing up!" But I did anyway. I rang up.

NW: You know, can I just say, you know, our parents, mine as well, they've had a relatively, em, they haven't had a lot of time in hospital. My Mam especially. But, Bill's Mam did about four years ago, you know? So, we're not au fait with the hospital systems on maybe what the procedure is. Maybe you do have to ring up to get an appointment with the consultant, you know. So we weren't, kind of up to date with that.

BW:But the way I look at it is, if you're admitted onto a ward, somebody should be telling you what she's here for [NW: Yes, I know] and what the plan is [NW: Yeah, I know] and what the overall outcome is.

Interview with Bill and Norma Walker, relatives on ward A, 24/07/14 p3

Bill questioned whether relatives should have to be pro-active in seeking information when their loved ones were admitted seriously unwell. The importance of making the procedure for speaking to staff explicit seemed especially important given that some relatives were unaware of the normal processes on hospital wards. Furthermore I found that some relatives were reluctant even to ask questions of staff:

"I think because I know how busy people are and what they're doing, and you don't wanna take them away from doing something just to satisfy what you're wanting to know, you know? So I never ask. It's very rare I ask anything. I know my brother's a bit different. Like he'll sometimes ring and say, well I've been and asked this and, you know. But I never do".

Interview with Lisa Cummings, relatives on ward A, 30/01/15 p6

I observed that the opportunities for communication between staff and relatives were often limited. Because visiting time consisted of one hour in the afternoon and one hour in the evening on wards A and B, there was often little time for staff to speak with enquiring relatives:

I noticed several relatives standing around the nursing station looking as though they were waiting for someone or wanted to speak to someone. I asked one man if he was alright, as he looked at me expectantly as if he hoped I was one of the ward doctors. He said that he was here visiting his mother and wondered if he could speak to a staff member for an update................................

He explained that he couldn't get any accurate information from his mother. She kept saying she was going home tomorrow, but she couldn't walk so he knew that couldn't be right. He told me that he hadn't had an update all weekend and was keen to hear what the plan was.

Field Notes Ward B, 11/05/15 p1

However, I found that even patients with mental capacity did not necessarily pass on information to relatives. I observed Dr Purple, consultant on ward A, as he spoke to a patient called Dot Cumberland and her family. Dot had mental capacity and Dr Purple had previously explained to her that she had a diagnosis of cancer. Dot asked Dr Purple to speak to her and her family together. I went to see Dot's family as they were waiting in the day room while Dr Purple went to get Dot:

Dot's daughter explained who everyone was – two daughters, one granddaughter and Dot's partner were present. They chatted amongst themselves and said that Dot didn't seem to know what was going on, or at least they said that was what she told them. Once they were all present, Dr Purple asked Dot if it was okay for him to explain to everyone what was going on. She said she was keen for him to go ahead.

Field Notes ward A, 16/07/14 p5

It appeared that though Dot had mental capacity she hadn't told her family about her condition. She wanted them to know but it appeared that she didn't want to be the one to tell them. It may have been that she felt she didn't understand well enough to explain and answer the questions they might have. She might also have worried about upsetting them. This highlighted that simply because a patient has mental capacity, doesn't mean they will tell their relatives (or what they will tell them), even when they might want their relatives to know too.

For relatives, being kept informed of the patient's condition was hugely important especially when a patient was very unwell and unable to be involved; yet relatives often felt uninformed. Regarding decision-making, I found that relatives described varied experiences and perspectives. Liz White a relative on ward A, described her experience of decision-making on the ward after her father, George White, was admitted seriously unwell:

"And basically I think we got, just told this is what we're going to do. And I mean we don't know any different and we rely on the doctors, and I mean the doctors have obviously made the right decisions because he was on deaths door a couple of weeks ago......."

Interview with Liz White, relative on ward A, 25/08/14 p7

When I asked if she would have wanted to be more involved she replied:

"I don't think that medically I would be, want to be involved in the decisions because I don't know what's best for him personally......................... I think my Mum was very happy with the decisions that the doctors made. I think she just would've liked slightly more frequent updates".

Interview with Liz White, relative on ward A, 25/08/14 p7

Liz suggested that because she had no background in healthcare and because her father's condition improved, she was happy with the decisions the doctors made. She didn't seem to expect to be involved in medical decision-making about her father's

treatments. Yet both Liz and her family did expect to be kept informed about his condition. Furthermore I observed that they wished and expected to be informed and involved with decisions about his general care. After a conversation with Liz's sister-in-law, Sandra and Liz's mum, Mrs White, I made the following notes:

> *Sandra said that they had been told about a plan for rehab [for George White] at the start of the week and they had all been horrified because they felt he wasn't ready for rehab. She said that then the consultant told them he wasn't yet ready. But that day they had heard he might be moving wards so they didn't feel like they knew what was going on.*

> Field Notes Ward A, 21/08/14 p

This family appeared happy to let the doctors make medical decisions but they did want to be kept informed and they did want to be involved in decision-making about his general care.

Marjorie Pringle, a relative on ward B, expressed her thoughts about involvement in medical decision-making on the ward:

> *Marjorie Pringle explained to me clearly that she felt medical decisions should be taken by the doctors and that she didn't feel she should be the one to take these decisions. In terms of being informed about her mum's care, she was happy that she had been kept informed by the staff and had been involved………………*

> *Marjorie said that she and her mum had never had a specific discussion with the doctors about resuscitation. She knew her mum would not want it [resuscitation]. She explained that the doctors said it would not be effective and she and her mum agreed. She said she was happy with that as was her mum. She explained that her mum was elderly and frail and didn't feel she needed to discuss it further.*

> Informal interview with Marjorie Pringle, relative on ward B, 10/10/14 p1

This type of decision-making may sound unilateral or paternalistic, with the doctor making decisions and simply telling the relative what has been decided, but Marjorie said this was what she said that she wanted. Furthermore Marjorie didn't go into detail about what she had been told but she did say that she felt 'informed' and 'involved'. It is possible that Marjorie and her mother were not given the option to be more involved, or it could be that the doctor gave them the chance but respected their desire for less involvement. I observed the care received by Anna and Marjorie on the ward over several days and noted that Marjorie frequently spoke to staff if she was unhappy about her mother's care or if she had queries about her mother's condition. Marjorie may not

have felt she should be involved in medical decisions about care but she clearly involved herself in decisions about her mother's general care on the ward by expressing her views and opinions, which the staff responded to.

Jane Blackwell, a relative on ward A, told me that she and her sister were given the responsibility for making a clinical decision about her mother's treatment. Jane's mother, Juliet Crawley, had come in seriously unwell with pneumonia. Jane told me that the doctors had tried to insert an intravenous line into one of her peripheral veins in order to give IV antibiotics to treat the pneumonia but had been unable to do so. The doctor had explained that the only way to give IV antibiotics was to put a central line into one of the blood vessels in her neck. The doctor gave them two choices: put the line in and give antibiotics or not put the line in and simply focus on keeping their mother comfortable. During the interview I asked Jane if there were any decisions she had disagreed with or thought were the wrong decision:

> *Jane: Maybe the line yeah. Maybe that line afterwards. Me and my sister decided, but we thought after maybe a couple of days we thought, why have we done this, you know what I mean?*
>
> *I: Did you feel that was very much your decision or was it the doctor's…*
>
> *Jane: It was our decision, cos the doctor says it was our decision.*
>
> Interview with Jane Blackwell, relative on Ward A, 26/02/15 p6

Jane felt responsible for the decision because she perceived it as their decision alone. They had not asked to make the decision, but from Jane's account, they had been informed about two treatment options or choices and the decision was left up to them. Yet according to the MCA, this action by the doctor is wrong. Jane's mother lacked capacity and needed a best interests decision, which (in the absence of a lasting power of attorney) should be made by the doctors but informed by the relatives' views and

wishes[31]. Later on when things didn't turn out as they had expected, they both started to question their judgement. While this approach to decision-making by the doctor certainly involved Jane and her sister, it did so without recognition of the longer-term impact of the weight of responsibility borne in decision-making at end-of-life and the potential for guilt and self-blame when things didn't work out as hoped[32].

Nigel and Lucy Elmsdale, the son and daughter-in-law of a patient called Sadie on ward B, described their experience of receiving information and being involved in decision-making very positively. Sadie had been admitted to the ICU after suffering recurrent seizures and was later transferred to ward B. Nigel explained their involvement in her care as follows:

> *"When she was in critical care, before she was moved, em, they did fully involve us in that and asked for our opinions. So…we knew exactly really what was going to happen, what was likely to happen as well".*

Interview with Nigel and Lucy Elmsdale, relatives on ward B, 17/11/14 p1

Nigel described his experience very positively. He had been kept informed at every stage and he and his wife felt involved as Sadie's representatives while she was too unwell to voice her opinion. Sarah, the daughter of a patient on ward B felt similarly about her experience of being informed and involved when her mum was admitted to A&E:

> *Sarah: "They informed me every step of the way. They kept checking on her. They were, it was a calm environment. It was efficiently organised. The staff nurse was superb…………………………… They told me that the bloods would take about an hour*

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[31] This account perhaps goes to highlight the conclusion made by the House of Lords Select Committee following a review of the implementation of the MCA: '*The Act has suffered from a lack of awareness and a lack of understanding. For many who are expected to comply with the Act it appears to be an optional add-on, far from being central to their working lives. The evidence presented to us concerns the health and social care sectors principally. In those sectors the prevailing cultures of paternalism (in health) and risk-aversion (in social care) have prevented the Act from becoming widely known or embedded. The empowering ethos has not been delivered. The rights conferred by the Act have not been widely realised. The duties imposed by the Act are not widely followed*' (Select Committee on the Mental Capacity Act 2005, 2013-14, p. 6).

[32] Mol's (Mol, 2008) ideas seem relevant to Jane's account. Mol argues that when 'choice' is the prioritised value in healthcare, establishing what is good or the right decision becomes solely a matter of weighing and balancing different options and arguments. Therefore, anything that results from that choice is seen as following from it. If things go wrong, the decision-maker has only themselves to blame. Instead she proposes the downgrading of choice so that it is viewed as one of many activities people are involved in and a characteristic of specific situations. Instead she proposes a greater focus on the value of 'care' (Mol, 2008). This idea will be further discussed in Chapter Nine.

and a half, so I knew we were in for quite a long wait. I have to say I couldn't fault them. And when we were moved to the ECU ward, I was even provided with a printed slip to say, this is the number to ring, you know, to enquire.......................

So I was fully informed. I was consulted in the ECU unit by one of the lady doctors, who discussed with me how, how I felt about treatment of my mum if there were further physical deterioration, such as heart problems, and more serious...well I'm saying more serious, em.... [I: If she were to become really unwell?] If she was really unwell, that in their opinion, and if I was agreeable they would, a letter would be drawn up. I'm assuming that they mean do not resuscitate if, or do not take some sort of serious medical process if. And I said I fully endorsed that because she's ninety three, her quality of life is declining at a steady rate now, she very rarely gets out, you know, with the best will in the world it's quite difficult process to get her out................... And so, you know, I agree with what was being suggested, is that, you know, as long as she's content, pain-free, at peace, that's what I want. And that, that's been my aim all along since she started..."

Interview with Sarah and Sue, relatives on Ward B, 25/11/14 p4

Sarah described her involvement in a decision about whether her mother should be resuscitated. This decision was made following discussion about how Sarah felt about future treatments for her mother, her opinions about how her mother should be cared for as well as the doctors opinions. Furthermore, the decision was made at a time when Sarah felt well-informed and well supported by staff.

The analysis of data from relatives suggests that being kept informed about their loved one's condition is very important. However, many relatives felt that such information was often lacking and that there was an expectation that they should seek out information from staff. Getting such information could be difficult for relatives especially when staff were busy and visiting time was short. Analysis also suggests that though patients may keep their relatives informed, assumptions cannot be made about how much information patients will pass on. An interesting question is whether or not patients wish healthcare professionals to speak more with their family. Relatives who were involved in decision-making, described varying experiences: being told about the decision which had already been made, being asked to make decisions and being asked for their views and opinions during the decision-making process. Yet what appeared to be most important was that relatives were informed about their loved one's condition, offered the opportunity to share their views about their loved one's treatment and care and felt listened to. Decisions about treatment were simply the result of the more important process of ongoing dialogue.

7.3 Staff Members' Perspectives on Information and Decision-Making at the End-of-Life

I observed certain inconsistencies in staff members' attitudes towards informing relatives and involving them in decision-making. Though speaking to family members was commended as an important practice on the ward, observations and accounts of everyday practice suggested that it was often not prioritised. Dr White, consultant on ward B, described her own observations of practice on the ward:

> "I think there's a, we really push speaking to the relatives on ward B. And part of our [staff] induction is saying how part of the patient assessment is speaking to the relatives, and that you have information for them, but they have information for you. But, I think there is inevitably a culture of almost hiding from relatives. On that 2-3 [pm] you will rarely see juniors [doctors] patrolling the wards, looking for families to speak to. They will if we explicitly say, 'can you speak to that family?' They'll try and find them. And I think, I was just the same as a junior doctor, there's this culture of you need to get your jobs done, and talking to families is way, way, way down your job list. Whereas actually I think it should be right at the top of the job list. I'd rather they spoke to a family, than they all did an echo, or they did the blood tests, or…..cause speaking to families generally has much more influence on how we're managing them, whether we're managing them appropriately, discharge planning, all those sorts of things. So I think there's more work to do in I guess educating our juniors, and supporting them in, you know, seeing how important speaking to families is, and like you say, at the moment they've only got an hour".

> Interview with Dr White, consultant on ward B, 18/11/14 p3

While Dr White recognised how difficult it was to speak to relatives when visiting lasted for only one hour in the afternoon, she also highlighted an implicit work agenda that prioritised getting 'jobs' done over what was perceived as the secondary task of speaking to relatives. I observed this attitude was not just held by doctors. On one occasion I spent time observing Jamie, one of the staff nurses on ward B:

> It was 3pm and visitors were starting to leave. Jamie told me that the nurses used to stand on the corridor and yell 'time!' But Jamie said that this was no longer considered politically correct. Jamie said that relatives ought to stick to visiting times as the nurses needed time to get on with jobs.

> Field Notes Ward B, 11/10/14 p1-2

In my first week on ward B, I asked two of the physiotherapists, Sarah and Sally, about the routine on the ward in the afternoon:

> *They explained that the nurses will do a medication round after lunch, and that the HCAs check patients' observations, and then the relatives arrive at 2pm. Sarah said, 'and you can't get anything done then'!*

> Field Notes Ward B, 08/10/14 p1

During observation on the wards I found that visiting time was often an extremely busy time on the wards:

> *Relatives were arriving as it was visiting time. Many came to the nursing station to ask about their family member, or to ask to speak to a doctor. I noticed that it was often difficult for staff to find the right person for them to speak to. All of the doctors were busy with patients or other relatives and often the nurses were too.*

> Field Notes Ward B, 22/10/14

I asked Nicola, a staff nurse on ward A, whether she spoke to relatives at visiting time to give them updates on their loved one's condition:

> *"Only if they ask. And I'll be honest, it is only if they, I've never found myself going round saying, right, would you like an update, would you like an update? You haven't got time. Cos every single patient has got a visitor, so to be able to go round. And it's not just, if I could go to somebody and say, this has happened, that's happened, this is gonna happen tomorrow, and move onto the next one. But it's not. They're twenty minute conversations that you have with relatives, and you cannot do that with everybody".*

> Interview with Nicola, staff nurse on ward A, 26/03/15 p9

This account fits with the relatives' descriptions of feeling they were expected to ask staff for information about their loved one[33]. In contrast, Pam, staff nurse on ward B, while acknowledging the difficulties of speaking to relatives described the importance of trying to keep relatives informed:

> *"Sometimes visiting can be quite stressful, because like obviously sometimes if you're short staffed you're like, you're sort of catching up on what you should have done……………………………………*

> *But what I do find is that I try to make myself available to visitors, and I'll try to make myself visible, and sometimes I'll even go up to them and say, 'oh by the way there's*

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[33] See Section 7.2 p143-4 Bill Walker's quote.

been a ward round today and this is what was said' or 'your Mam's been fine today'. So I try a lot of the time to give the information rather than them like ask for the information. But I do know that's, a lot of the time that's where your complaints come if they feel as though they haven't had the communication, or if the communication is lacking. And I'll always say to a patient's relative, I'll say 'well you know', if I've updated them, 'well you know, you can ask anytime that you want, just come and you know, ask, if you want to know anything or if you're not sure or whatever. Just come and ask. We are always here to answer your questions.' And I think it's a two way process. I think that, you know, they've got tongues in their head, and they can ask, you know, we are, well I think we're approachable. And I think that, you know, it's a two-way process, I think they've also got to ask for information. There's no point in coming along later on and going 'oh we never had any information and that'. Because if you don't ask, you know, we are here to be asked as well. And I think it's a two way process sometimes".

Interview with Pam, staff nurse on ward B, 28/04/15 p6-7

While Pam felt it was important to try and update relatives, she also felt that both relatives *and* staff had responsibility for communicating with each other. This was part of both of their roles. Yet from my observation on both wards, relatives did not receive information which stated how they could arrange to speak to staff or that staff would try to update them but that they should feel free to take the initiative and ask staff members on the ward if they had any questions. It appeared that as with uncertainty around roles when patients needed assistance with feeding, here too, there was a lack of clarity about the roles of staff and relatives when sharing information.

I observed that staff tended to prioritise speaking to the families of patients who were deteriorating in order to speak to them about treatment escalation planning and resuscitation. Often on a ward round the consultant would ask the junior doctor to call the family and ask them to come in so that these issues could be discussed:

Outside in the corridor after reviewing Vera Stock, Dr Peach [consultant] agreed that Vera should not be for resuscitation and needed a TEP. She asked Dr Coral [junior doctor] if she was happy to discuss these decisions with Vera's daughter and Dr Coral agreed.

Field Notes Ward B, 28/04/15 p1

Moira was a relative whose mother had dementia and had deteriorated unexpectedly during her admission to ward B:

Moira said she was aware of how short-staffed the ward was, staff were always dashing to and fro, in a hurry. Moira described being interrupted when talking to

staff members on the ward, so that when her mum was first admitted she never felt she knew what was happening with her mum. Now that her mum was more unwell she saw the doctors frequently.

Field Notes Ward B, 11/12/14 p2

However while staff might try to prioritise speaking with the relatives of the most unwell patients, Dr Navy described difficulties in actually doing this:

"But, the challenge is that you can't really structure your day, or prioritise your activities that well if your time is determined by whichever family member shouts for you first, or shouts for you loudest".

Interview with Dr Navy, junior doctor on ward B, 24/11/14 p6-7

I observed further complexities as staff sought to inform both patients and relatives on the wards. During a ward round Dr Red reviewed an elderly lady called Violet Sumner who had come in with an exacerbation of COPD. Dr Red found that she didn't have a DNAR:

Dr Red took a history from Violet and examined her. He explained what he thought the main issues were, and said that he hoped to get her feeling better. Violet said she wanted to go home, and Dr Red said he thought she needed a bit longer, and worried that if she went home now, she would soon come back in again. Violet nodded. He explained that she had underlying conditions, like her COPD, that would not get better, and therefore it was important to plan for the future in case she did deteriorate at some point. He said he didn't want to scare or upset her, and that he didn't expect her to deteriorate imminently, but he said it was important to think about future care. He asked if anyone had ever discussed resuscitation with her. Violet said no. He asked if she would like him to wait and discuss this with her husband when he came in later. She agreed, and Dr Red said he would pop back in and discuss it with them together.

Field Notes Ward A, 25/02/15 p2

Later that afternoon I observed as Dr Red spoke with Violet Sumner, her husband and son:

We met altogether in Violet's side room. Dr Red explained her current condition and that she was frail but likely to recover. However he explained that her chest was not good, and it would likely not take much to make her very poorly again in the future. Dr Red said that it was therefore important to think about her future care and what would be in her best interests. He explained that he was talking about things like going to intensive care or being put on a ventilator or being resuscitated. He suggested that these treatments would not be helpful. When Dr Red asked Violet what she thought, she simply kept saying that she wanted to get better. Her husband explained that she had dementia and wouldn't understand.

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Violet had not appeared confused when Dr Red had spoken to her earlier that day and it was not immediately obvious that she lacked mental capacity to be involved in decisions about her care. Yet after further discussion in the presence of her husband it became clear that she was not able to understand the situation. After this, Dr Red asked if Violet would mind if he spoke with her husband and son alone. She agreed and he spoke to them in the day room. They agreed with the plan to sign a DNAR. This situation highlighted how difficult it could be for staff to determine what is understood by patients especially when their cognitive impairment fluctuates or is not obvious during a simple conversation. The MCA states that healthcare professionals ought to presume that a patient has mental capacity to be involved in decisions (Department of Health, 2005), yet this examples highlights the potential difficulties for staff in informing patients and involving them in decision-making appropriately when cognitive impairment is not obvious. Given that mental capacity is not always obvious or easy to determine, it seems important for staff to balance the presumption of capacity, clinical suspicion of cognitive impairment, while also asking patients to designate relatives to receive medical information early on in their admission (Witkamp *et al.*, 2016).

The above case highlights important issues around assessing capacity when making decisions. I found that the practice of making resuscitation decisions raised further difficulties for doctors. I now consider the attitudes of staff in relation to the involvement of patients and relatives when making specific decisions about whether or not a patient should be resuscitated in the event of a cardiac arrest.

7.3.1   Decision-making about resuscitation

The Tracey case verdict created a new legal precedent that doctors should involve patients and/or their relatives in decisions about resuscitation. However, the data analysis suggests that following the Tracey verdict doctors had varying perspectives about what such 'involvement' required. Some doctors felt that patients and/or their relatives should be informed of the decision which had already been made by the doctors:

Dr Bronze [junior doctor] said he had no problem with signing it [DNAR form] and then speaking to the family. He commented that it was a medical decision. I asked them both if they thought it should be a medical decision given how strongly patients and family seemed to feel about it. Dr Grey [junior doctor] said yes, because they [patients and families] didn't know enough about it to understand.

Field Notes Ward A, 26/02/15 p2

Both junior doctors suggested that resuscitation was a medical decision to be made by the doctors. The strength with which they presented their views seemed to highlight an implicit tension about whose decision this was: the doctor's or the patient's (or the relative's). Though Dr Grey felt that patients and families were not able to make the decision, his comment implicitly and perhaps unintentionally suggested that if patients and families had more information i.e. were better informed by staff, had access to relevant resources and literature, or perhaps if society as a whole was better informed about resuscitation, they might be able to understand and be more involved in the decision.

In contrast to these two junior doctors, Dr Navy, junior doctor on ward B, felt that confusion about what it meant to properly involve families and the fear of complaints had meant that 'involvement' had sometimes been interpreted by doctors as having to ask the family to make the decision about resuscitation:

Dr Navy said he thought that the doctors were all really afraid of a complaint. They'd been told that if a patient had a DNAR and the family didn't know about it and then the patient arrested, they might complain. Or if a patient went home with a DNAR and the family found out they might complain and even the consultants weren't immune. He said there was a culture of fear and no one wanted to get a complaint. Because of this he said that patients and family members, who may not be adequately informed, end up making the decision about resuscitation.

Field Notes Ward B, 13/10/14 p2

Dr Navy felt that families who were poorly informed of the facts of resuscitation could end up making bad decisions. His comments implied that the result of such practice was poor decision-making and poor care (inappropriate resuscitation) for the patient, but he also implied that if families were properly informed, they could be involved in making good decisions.

Dr Yellow maintained that a correct understanding of the Tracey verdict meant that it was not enough just to tell patients and relatives about a resuscitation decision:

"And the onus now, or my understanding of that court case was the onus now is much more on involvement of patients and relatives rather than the very sort of paternalistic 'I have made this decision'. Cos it's [resuscitation] still a medical decision but you're meant to seek their views. And I think one of the risks of making those decisions, so for example, if relatives aren't around or the patient is too poorly and you make a decision, and then you retrospectively discuss it, I'm not sure that's in keeping with the spirit of the law. You are meant to involve them not tell them. Because you want to seek their views and their opinions and their previously expressed wishes, and all of that stuff. I don't think it fits with if you make the decision and retrospectively discuss it with them, I don't think you are discussing it, I think you are retrospectively telling them".

Interview with Dr Yellow, Consultant on Ward B, 12/05/15, p3

Yet I observed that while doctors often agreed with the importance of involving patients and/or their relatives, due to many of the factors previously discussed in Section 7.3 (such as busy staff, limited visiting time), it could be difficult to 'involve' relatives in such decision-making. Furthermore I observed that doctors were under pressure to have discussions about resuscitation with all patients soon after their admission. Doctors acknowledged what a sensitive topic this could be and the difficulty in having such discussions with patients and relatives they had never met before:

"If somebody is clearly dying it's easy to have that conversation [about resuscitation], it's absolutely right to have that conversation. If somebody is very frail, and you want to put limits of care, it's right to have that conversation, I just find the timing difficult. I would prefer to have that conversation after I've known them for a while, known their relatives for a while".

Interview with Dr Yellow, consultant on ward B, 12/05/15 p1-2

While doctors might prefer to take time to build rapport with the patient, due to the rapid transition of patients through the hospital, this was not always possible. The rapid turnover of patients on the wards was described by both patients and staff:

In one of the bays two patients were chatting. I heard one patient say 'they come in and out fast don't they?' The other patient replied 'seems to be a fast turn-around'......... The junior doctors walked down to the nursing station and made a note of the patients on the ward. They commented that there had been a lot of new patients admitted overnight. Dr Lime, one of the junior doctors, asked the ward clerk where one of the patients had gone as her name was no longer on the board. The ward clerk explained that she had been boarded to another ward last night.

Field Notes Ward A, 21/08/14 p1

Furthermore, I observed that patients could deteriorate rapidly and unexpectedly before decisions had been made. On one occasion an elderly patient called Edith, who had multiple comorbidities, deteriorated and died unexpectedly within an hour on ward B. Dr Carmine, one of the junior doctors spoke to me about the case afterwards:

> *Dr Carmine said that Edith should have had a DNAR form, but then said she should have had one if they had suspected that she would arrest but they didn't ever suspect it, and so it was never discussed with her or her family.*

> Field Notes Ward B, 12/11/14 p1

I learned that fears about complaints could also lead to delays in decision-making:

> *"A lot of us are worried about doing them [DNAR forms] without having conversations with families, and it's not always possible to have those conversations, and if there's any doubt, whereas in the past we probably just would do a DNAR form and that whole thing of it's a medical decision, fine, I'm making a medical decision based on, and justifying it like that has gone. And I think that, for that reason, and because of the fear of it coming back at you, em……in those situations where previously you probably would just do a form, we're now not……………………………*

> Interview with Dr Red, consultant on ward A, 04/03/15 p6

Dr Red felt his practice had changed because of fears about complaints. However, not all doctors felt so constricted by external influences. I observed Dr Emerald, one of the junior doctors, who chose to delay discussing a DNAR form with a patient. He explained that she had already had many discussions that day about her inability to cope at home:

> *Dr Emerald said he had decided not to push discussions about DNAR/TEP because he didn't want her to feel as though everyone was writing her off.*

> Field Notes Ward B, 12/05/15 p1

Dr Yellow also talked about the importance of prioritising the care of the individual over and above making a specific decision at a given time:

> *"I think that some of the stuff that comes out, actually if I disagree with it I won't necessarily toe the line absolutely. So if I think it's wrong to have a discussion with somebody about resuscitation or a TEP because it's the wrong time to do it, I'm not going to be forced into having it at that time. Because that I think, would be I think all of those things have to be done in the context of the person in front of you and the situation that it is".*

> Interview with Dr Yellow, consultant on ward B, 12/05/15 p9

Yet it was apparent that many doctors felt ongoing apprehension and confusion about good practice in the light of the Tracey verdict. Dr Red described the challenge he felt about such decision-making:

I don't know, I go through cycles of thinking, what's right and what's wrong, to be honest. I think, to some extent, just playing devil's advocate, what is wrong with everybody just being for resuscitation? Unless they are clearly palliative..............For everybody else, why do we have to, just call the team. That's why we've got a cardiac arrest team. So, I know that's not the right thing, but just sometimes I think, well why don't you just call the team? Em.....and then make a decision depending on what's happening at that time. Em......I think, I don't know, I think that, I think previously we probably were just filling out too many forms without having the right conversations and talking to patients and families about the implications, em.....and I think that was wrong. And I think it's almost swung too far the other way though".

Interview with Dr Red, consultant on ward A, 04/03/15 p6

Dr Red questioned whether changes in decision-making practice had gone too far, with doctors now feeling unable to make clinical decisions without the permission of relatives.

It appeared that the Tracey case had a profound impact on resuscitation decision-making practice. Doctors were expected to speak with the patient if able, or their relatives prior to making a decision, yet having the time to have these discussions with every patient and/or their relatives posed difficulties for doctors. Their time was limited and due to fixed visiting hours relatives were often not present when resuscitation decisions were being made. Practice appeared to be driven by fear of complaints, which could lead to delays in decision-making. Furthermore, ongoing contention over whose decision this was and therefore how such a decision should be taken led to varied involvement of patients and relatives with the potential to negatively impact on patient care. It appeared that the focus of these accounts was on the resuscitation decision itself and what was required in order to make a resuscitation decision which was in line with the new legal precedent. What seemed to be missing in all of these quotes and accounts about resuscitation was consideration of how staff could best care for the patient and their relatives while making these decisions.

7.4 Conclusion

In this chapter I have explored the perspectives of patients, relatives and staff on the provision of information and decision-making at the end-of-life. I have also described my perspectives on my own observations of practice. The aim has been to understand what it means to care well when giving information and making decisions at the end-of-life and where the challenges in practice lie. From patient and relative accounts, good care involves regular interaction between patients, relatives and healthcare professionals in order to share information, elicit perspectives and provide an opportunity to contribute to decisions about treatment and care. While many staff acknowledged the importance of such interaction and involvement in decision-making, there were many challenges to this practice. For example, the structure and length of visiting time, lack of clarity about how relatives ought to gain information about loved ones, the attitudes of staff members about their role and work priorities and the potential for assumptions to be made about patient understanding and their wishes for involvement of relatives. The question about who information belongs to (patient, relative or both), is a key issue. Decision-making at end-of-life posed particular challenges when the ability and wishes of patients for information and involvement varied. It appeared that no single approach was always the right approach. Rather, the most appropriate approach should depend on the decision in question and the patient's ability and desire to be informed and involved. Yet in order to know this, healthcare professionals have to take the time to communicate with patients at the patient's pace and in a way which will facilitate their understanding.

Resuscitation decisions were found to be an area of difficulty for some doctors. Practice appeared to be driven by fear of complaints which could lead to delays in decision-making and had the potential to negatively impact on patient care. Furthermore, ongoing contention over whose decision resuscitation was and therefore how such a decision could or should be taken led to varied involvement of patients and relatives. The perspectives of patients and relatives showed that the process of receiving information through ongoing dialogue with healthcare professionals was a vitally important part of care. The decisions made about treatment were simply the result of the more important process of shared interaction and understanding. Yet for many staff the resuscitation decision assumed priority and they acted according to their

understanding of what was required to satisfy an external legal precedent or their own beliefs about whose decision it was rather than considerations of how best to care for the individual patient and their relatives in a given situation. Having considered practice around decision-making, in the next chapter I focus on the roles of language and meaning in communication practice.

Chapter 8   Communication: Language and Meaning

In the two preceding results chapters I have explored the concept of care, what it means to care well for patients approaching end-of-life care on hospital wards and more specifically what it means to care well when making decisions at the end-of-life. Communication is necessarily a part of the interactions discussed in previous chapters. In this chapter I further analyse communication at end-of-life, by exploring the more elemental concepts of language and meaning. I examine the use of language and how it is interpreted to form meaning by analysing examples of interactions between patients and staff, relatives and staff, and between staff members. I investigate the challenges in communication at the end-of-life and how these could be understood to ensure good care. Throughout this chapter I consider what it means to care well when communicating (through the use of language and the formation of meaning) at the end-of-life.

8.1   Communication: Language and Meaning

In this chapter I use the data to explore two important aspects of communication: the language used by participants and how such language was interpreted to form meaning. As outlined in Chapter Four, in the past medical communication has been conceptualised as a system which enables knowledge to be transferred between doctor and patient. From this perspective language represents or codes for things encountered in the world. Language, the world and people are separate and language simply mediates between people and the world as a neutral tool (Wetherell, 2001). Therefore, language is viewed as a passive tool. However alternative views perceive language and discourse as social action. From this perspective language is constructive and active. It is not an abstract system in which the meanings of words are fixed, instead words and phrases are accompanied by multiple social associations which create new and individual nuances and connotations (Maybin, 2001). It is from this perspective that I present the analysis of data in this chapter.   By 'language' I mean the processes that participants used to make themselves understood. Language can often be non-verbal in nature (body

language, gestures and facial expressions) however, much of the data here focus on spoken language: the words and phrases used by participants. By 'meaning' I refer to the understanding and interpretation of situations at end-of-life made by participants in response to their interactions with others. In the following three sections I explore the data to show how language was used and interpreted to make meaning: first between patients and staff, second between relatives and staff and third between staff members.

8.2 Language and Meaning: Interactions between Patients and Staff

During data collection I observed that many consultations or interactions consisted of sequences of ordered and often predictable verbal behaviour which has been previously described in the literature[34]. Furthermore I observed that during consultations on the wards, many healthcare professionals used skills and techniques which are considered core components of communications skills teaching[35]. During a ward round on ward A, I observed Dr Purple, consultant, as he met a patient named Theresa Dodd for the first time and broke bad news about her likely prognosis. She had had a CT scan but the results had not yet been explained to her and her condition had deteriorated suddenly earlier that morning. Dr Purple had hoped to speak to Theresa when her son was present but her son lived far away and had said he would not be in until the evening.

> *Dr Purple introduced himself and started by explaining that he was very worried about her. He explained that they had the results of her scan and there were some abnormalities. He asked if she would like to know more. She said no, and that she would like to go home. He explained that that would be difficult because she was*

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[34] Byrne and Long outlined the sequence of events occurring in many consultations between GPs and patients. They divided the sequence into six phases: Phase I, the doctor establishes a relationship with the patient; Phase II, the doctor either attempts to discover or actually discovers the reason for the patient's attendance; Phase III, the doctor conducts a verbal or physical examination or both; Phase IV, the doctors, or the doctor and the patient, or the patient (in that order of probability) consider the condition; Phase V, the doctor, and occasionally the patient, detail treatment or further investigation; Phase VI, the consultation is terminated by the doctor (Byrne and Long, 1976).

[35] Kurtz and Silverman designed a communication model designed alongside a practical teaching tool called the Calgary Cambridge Observation Guides. The Guides were developed to outline effective physician–patient communication skills and provide an evidence-based structure for the analysis and the teaching of these skills. The Guides are now used in healthcare institutions around the world. The structure of the medical interview proposed by the Guides is as follows: 1)Initiate the session, 2)Gathering information, 3)Building the relationship, 4)Providing structure, 5)Explanation and planning, 6)Closing the session (Kurtz and Silverman, 1996; Kurtz *et al.*, 2003).

requiring so much oxygen (100%) and this was impossible at home. He asked if he could tell her a bit more about the scan, but said she should stop him if she didn't want to know. She agreed. He said that they could see a shadow on her lung. Theresa asked what he meant by the word shadow and whether he meant cancer. Dr Purple said he thought it was likely to be a cancer. He explained that she would need to stay on the ward for the time being as she needed so much oxygen. She asked how long he thought she would have, and whether it would be three or six months. He explained that he thought it would actually be much less than that given how quickly she had deteriorated. She gave permission for Dr Purple to phone her son………………

A short time later I spoke with Theresa and asked how she was doing after speaking to Dr Purple. She told me that it was a shock but she was glad to have been told, and wasn't unhappy that her son hadn't been with her. She told me how she had everything in order at home [she had recently cleaned the carpets and curtains], and commented that maybe she knew [the bad news].

Field Notes Ward A, 30/01/15 p2

Dr Purple went through several important steps or processes during this consultation: he introduced himself, he gained information by asking about Theresa's preferences for information, he explained her condition and responded to her questions, he explained his wish to inform her son and after gaining her permission he closed the interview. Dr Purple also used tactics known to be helpful when breaking bad news: he gave her a warning that the news was not good[36] and he negotiated with her in order to inform her in a way that provided necessary information according to her preferences. He was honest and explained his opinion of her prognosis clearly. Despite the severity of the news, from speaking to Theresa alone afterwards it appeared that she had not only grasped the nature of her condition but appreciated the honest and straight-forward way that Dr Purple had explained it to her.

In the following example I observed Dr Peach as she broke bad news to a patient named Anne Harper and her niece Margaret. Anne had been admitted to ward B following ongoing symptoms of constipation and vomiting. A CT scan requested had revealed a probable pancreatic cancer and liver metastases:

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[36] See Chapter Four, Section 4.3.1. Maynard has described three strategies for breaking bad news: Forecasting, this involves helping the recipient to anticipate and pre-formulate the bad-news-to-come; Stalling, involves avoidance or delaying telling the news; and Being Blunt, involves disclosing the bad news with little forewarning. Maynard proposes forecasting as the optimal method because it helps the recipient to realise the bad news they are being told and understand its likely impact on their life. In contrast, he suggests that narrative evidence shows that stalling or being blunt can lead to recipients felling incapacitated, exacerbate the disruption to their perceived normality and impede realisation (Maynard, 1996).

Dr Peach asked how she was doing, and if she had thoughts about what might be causing her symptoms. Anne said she had just put her symptoms down to simple constipation and not eating much. I noticed that she kept rubbing her abdomen. Dr Peach mentioned her CT scan and asked if she remembered having it. After a bit of prompting, Anne said she remembered, and she asked what it showed. Dr Peach asked her if she wanted to know the results. Anne asked if it was good news, and Dr Peach said she was afraid that it wasn't. Anne said she wanted to know the results, and so Dr Peach explained that it showed a cancer in a gland in the abdomen called the pancreas and that the cancer had spread to the liver. Anne commented that she had had a good life. Dr Peach said that she planned to ask the GI specialists what they thought. Anne asked if they could treat it, and Dr Peach said that she would ask but in her experience there wouldn't be any treatment that they could offer to get rid of it, and they would likely focus on keeping her symptoms well controlled. Anne got a little weepy. Her niece Margaret said what a great life she had had, reminding her of her travels. Anne seemed to brighten up and told us that she had travelled all over the world with her husband……….. Dr Peach explained that she would ask the GI team to review her case and she said she also wanted the palliative care team to come and review her symptoms. Dr Peach then asked Anne if it would be alright if Dr Peach called her daughter to explain the results. Anne gave her permission.

Field Notes Ward B, 22/04/15 p3

Here again processes of the consultation can be seen as well as skills of forecasting, negotiating and checking of Anne's understanding. Dr Peach's use of language was clear without being blunt and though Anne was upset she seemed able to understand the situation. Both Dr Purple and Dr Peach seemed to be very successful in the above consultations. They followed established consultation patterns and used well-known communication skills to inform the patients, break bad news and make management plans and they used language to do these things. It is clear that appropriate use of language can lead to good and effective communication. But *how* did their language enable such good communication? This may not seem a relevant question given that the consultations appeared to go well yet it seems important to understand how language can enable good communication and shared understanding because as is shown in the literature and in subsequent examples in this chapter, there are many occasions when appropriate language does not result in such successful interactions between patients, relatives and healthcare professionals. Therefore understanding the role and work of language seems very important when considering how healthcare professionals can provide good care when communicating.

It appears that language had a number of roles in establishing a shared understanding. First, both doctors took time to outline explicitly the patient's situation at the patient's

pace and in line with the patients' preferences for information. Their language was making explicit what perhaps Theresa and Anne had previously only had an implicit sense of. Language was also used by the doctors and the patients to formulate their feelings about the situations in a way that had not been done before. The doctors articulated their sense of the patients' likely prognoses. Theresa and Anne articulated their feelings about the news and in doing so they were formulating their own new perspectives. As they spoke a specific formulation of the world came into being in a way that it had not been before (Wetherell, 2001). As the doctors shared their accounts of the patients' situations they became social realities to be dealt with by Theresa and Anne. Therefore language works to make explicit, to formulate and to help create new social realities for patients and relatives.

Second, by articulating such opinions out loud the participants' language worked to set the matter before them, or place it in the 'public space'[37]. The doctors were not simply transferring an objective understanding of the situation to be imprinted on the patients' brains. Their language placed the issues in front of them all, mapping out the situations and defining their boundaries, so that they could consider the issues together. In this way their language worked to build rapport, as this was something for them to think about, consider and manage together.

Third, there is a further way that language involves action which can be seen from these two examples. It involves how the participants formed meanings about the situations. Both Anne and Theresa developed an understanding of their respective situations and this was based on their interpretation of what the doctors told them but also on their past experiences, feelings, thoughts and emotions. Despite her sadness, when prompted by her niece, Anne worked to make sense of her diagnosis in light of past memories of traveling with her husband. Theresa described her condition in relation to her home life and responsibilities there. Meaning was co-created as the participants spoke together, asked questions and responded to one another. The meanings made were formed not

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[37] Taylor explains the concept of 'public space' in the following quote: *'language serves to place some matter out in the open between interlocutors. One might say that language enables us to put things in public space. That something emerges into what I want to call public space means that it is no longer just a matter for me, or for you, or for both of us severally, but is now something for us, that is for us together'* (Taylor, 1985).

simply from the words and phrases spoken at the time, but these words and phrases brought with them their own associations, memories and connotations such that each participant formed their own unique understanding and perspective on the situation.

While staff often used what appeared to be clear and straightforward language, as in the examples above, I observed some occasions when sometimes the language used by staff had the potential to cause confusion. I observed a ward round conversation between Dr Purple, consultant on ward A, and a patient named Emma Taylor who had metastatic cancer. They had met before and prior to the field notes listed below, they had discussed her current symptoms, the irreversible nature of her condition and Dr Purple had arranged to speak with her family. Dr Purple and Emma discussed what would happen if she deteriorated:

> *Dr Purple said they would focus on keeping her comfortable and 'wouldn't go jumping on her chest'. He said that this would not be effective in her case. She agreed. Once back in the corridor Dr Purple and Dr Silver [junior doctor] explained to me that on her last admission the medical team had discussed resuscitation with Emma and then completed a DNAR form. Later her family saw it in the notes and were very upset. Emma had said she didn't remember discussing it.*

Field Notes Ward A, 30/06/14 p3

Having observed Dr Silver completing a DNAR form, it was clear to me that 'jumping on her chest' had been Dr Purple's way of describing chest compressions (a core component of CPR). Dr Purple did not question her understanding of the phrase but I wondered if this had been clear to Emma. I imagined that the phrase could potentially conjure all kinds of ideas and thoughts for a patient who was perhaps unfamiliar with such decisions. Perhaps Emma had simply forgotten to mention it to her family in the past, or hadn't wanted to upset them and so purposely didn't tell them. But it also seemed possible that she might not have understood the decision being made if ambiguous language had been used to explain it to her previously. I did not have the opportunity to ask Emma about her understanding but this episode made me question how she had interpreted and understood his language.

On another occasion, I was surprised by the perspective of a patient as he spoke to me about the treatment options he had been given by healthcare professionals for the

treatment of his lung cancer. I made the following field notes after speaking with Edward Ransom, a patient on ward A:

Regarding the decision about whether to have radiotherapy, Edward said it was radiotherapy, or 'he'd be dead'. So he said it wasn't a hard decision. I asked a bit more, and it became clear that he meant he could have radiotherapy which might shrink the tumour or focus on controlling his symptoms.

Field Notes Ward A, 04/03/15 p2

I wondered what the consultant explaining the treatment had not told him. It seemed unlikely, though not impossible, that the consultant had used the words 'he'd be dead'. Either way his words had contributed to Edward's impression of the two treatment options. Thus through its role in the co-production of meaning, language subsequently has an important influence on the decisions that patients go on to make about treatment[38].   As in the example above with Dr Purple and Emma, it is possible that the words used by the consultants, though clearly representing one thing for them, might have represented and led to quite different ideas in the patients' minds.

In this section I have explored the interactions between staff and patients and considered the different roles of language and how such language may be interpreted by different participants to make meaning. In the next section, I consider how language was used and interpreted to make meaning during interactions between relatives and staff members.

8.3   Language and Meaning: Interactions between Relatives and Staff

When relatives recounted the explanations they had received from doctors, I found that language between staff and relatives also had the potential to confuse and cause misunderstandings. In the following example, Liz White, a relative on ward A, explained

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[38] The literature provides examples of such framing of decisions by healthcare professionals. Koedoot found that if chemotherapy was framed as a positive decision by physicians, while palliative care was described as 'doing nothing', it appeared that patients were much less likely to consider let alone choose palliative care (Koedoot *et al.*, 2003).

her recollection of a doctor's explanation to her family after her father was admitted seriously unwell:

> *"Because this came on him so very suddenly, and he was so very ill, and then the doctors told us to prepare for the worst. You know, em….you know, one of the doctors told me, you know they were doing their best and em, they could only do what they could do, you know, and we'd need a little help from him upstairs. And that just makes you think, right, if you've gotta pray, you know it's real, real bad"*
>
> Interview with Liz White, Relative on Ward A, 25/08/14 p1

According to Liz, the doctor didn't explain what 'the worst' meant. She knew it was 'real bad' and later in the interview Liz explained that she and her family had believed that her father was going to die. The phrase 'need a little help from him upstairs' could have referred to gaining advice from the consultant in ICU on the floor above, or as Liz interpreted it, as an indication that supernatural intervention was needed. Liz did not complain about the use of euphemisms but during the course of the interview it appeared that there were times when she had not felt clear about what the doctors meant about her father's treatment:

> *LW: I mean, but we were quite comfortable to say, you know…*
>
> *I: You wanted him to be resuscitated? [LW: Yeah.] Okay. And, you felt that that's what the doctors were saying, yes we agree with that?*
>
> *LW: I don't know whether they were saying we agree they were just saying, oh well there's been no talk of it. Well it kind of was if you're saying you know, we'll give you something to ease him, I mean it wasn't said. It wasn't said, you know, we're going to shuffle him off but….you know, you have to prepare yourself for the worst, and if it comes to that we will give him something to ease him, means…*
>
> Interview with Liz White, Relative on Ward A, 25/08/14 p8

Liz made clear to me during the interview that both she and her mother both wanted her father George to be resuscitated if he suffered a cardiac arrest, yet they remained uncertain of what the doctor's words had meant. Later on in the interview I asked Liz if she would rather doctors used straight-forward language instead of euphemisms:

> *"I think it would have been harsh, but it would have been easier, than just being told, you know that, that, sort of ambiguous statement, yeah".*
>
> Interview with Liz White, Relative on Ward A, 25/08/14 p9

It is possible that the words Liz recounted were an inaccurate recollection of the discussion and were not the actual words used by the doctor. Either way, her interpretation was one of ambiguous language. Furthermore, my observations of conversations between doctors, patients and relatives suggested that euphemisms *were* used by healthcare professionals to explain end-of-life situations:

> *I went with Dr Amber to speak to the family members of Moira Smith who was thought to be approaching the end of her life. Moira's husband, daughter and son-in-law were at her bedside. Dr Amber said there was a small chance she would improve but that it was most likely that she would deteriorate and pass away. They nodded.*

Field Notes Ward A, 05/02/15 p2

On this occasion the relatives appeared to be aware that Moira was dying. I learned from one of the junior doctors that Moira had dementia and had deteriorated while she was being treated for pneumonia. The junior doctor had spoken to her daughter the day before and her daughter had agreed with the plan to stop NIV and 'keep her comfortable'. While euphemisms may well lack the clarity desired by some relatives, it appeared that relatives did not always object to them. Indeed they might even appreciate euphemisms as a more sensitive approach when speaking about death and dying.

On another occasion I spoke to Dr Ivory, one of the junior doctors on ward B, about a patient who I had been told was deteriorating:

> *I asked Dr Ivory if he thought the patient was dying. He said she was 'fading away but not actively dying'. I wondered what the difference was.*

Field Notes Ward B, 16/04/15 p2

I wondered if Dr Ivory chose the phrase 'fading away' to avoid the potential of being proved wrong if the patient unexpectedly recovered. His use of the phrase may also have been related to his assessment of the speed at which he felt the patient was deteriorating. While healthcare professionals might apply the term 'dying' to the last hours or days of life, this may seem less appropriate for patients who are deteriorating over days, weeks or months. How staff members defined 'dying' was related to the way they spoke about it. End-of-Life can be a very uncertain time and it seemed that staff may use euphemisms as a way of managing their own uncertainty about the patient's likely clinical trajectory. However I observed that even common phrases used by staff

such as 'comfort care' or 'keep her comfortable' could be understood and interpreted differently by relatives and staff members. In the following examples, I highlight some of the varied interpretations of staff and relatives that I observed on the wards.

Marjorie Pringle's mother Anna was receiving end-of-life care on Ward B. I had observed the consultant explaining to Marjorie that he thought her mother was dying and that they should aim to do everything they could to 'keep her comfortable'. He had also explained the purpose of the care of the dying patient document (CDP) and Marjorie had agreed with the goal of care and the use of the CDP. However in an informal interview, Marjorie later described feeling shocked by some of the nurses' practices and attitudes related to end-of-life care particularly with regard to eating and drinking:

> *Marjorie told me that because her mum was now on the dying pathway, they'd stopped recording her food intake, and so Marjorie had no way of knowing how much she was eating. She came in and fed her and gave her drinks but didn't know if anyone else did. She said that some of the nurses didn't seem supportive of feeding her. I asked her what she meant and she explained that some of the nurses didn't offer her mum food or drink. She explained that when she came in that morning, one of the nurses was using the sponge to wet her mouth, but it was clear to her that her mum was thirsty and wanted a drink. Marjorie gave her a beaker of water and she drank the whole cup-full. But Marjorie felt that the nurse wouldn't have given her a drink and was only going to use the sponge in her mouth. Marjorie said that she felt she had to give her a drink as she was thirsty. She told me that the staff ordered food for Anna, but if she was sleeping when it came it just went cold and then they threw it away. Marjorie said that she understood they couldn't re-heat it, but she didn't think anyone ever came back to feed Anna something when she woke up. Marjorie also explained the difficulty with the frequent changeover of nursing staff which meant that they didn't always understand what her mum needed. She felt that some of the nurses thought that once a patient was on the dying pathway, everything else, food and drink and observations, should stop and not be re-started. She felt that some staff might accuse her of prolonging her mum's life by feeding her.*

Informal Interview with Marjorie Pringle, relative on Ward B, 14/10/14 p4

Marjorie had no experience of caring for people at the end of life but when she saw that her mum was thirsty and able to drink, she felt unable to ignore her need. In contrast Marjorie felt that the nurses appeared to have quite different ideas about what was appropriate. From Marjorie's perspective they felt that dying patients only required mouth care and their rigour in sticking to their form of practise led Marjorie to feel under suspicion or somehow incriminated when she helped her mother to eat or drink.

The following day I found Marjorie crying as she sat with her mother in her side room. She explained that none of the nurses were recording her mother's fluid intake and she was really worried that no one was feeding her when she wasn't around. Marjorie was Anna's only relative who lived nearby and who could visit regularly but she worked and could not be present at all mealtimes. A short time later I observed a discussion between two of the ward nurses:

> *Norma (senior staff nurse) walked up to the nursing station and spoke with Lisa the staff nurse who was caring for Anna. She explained that Marjorie had been very upset and in tears because she had seen that no record had been kept of her mum's oral intake and feared that no one was feeding her. Norma had explained to Marjorie that the chart had been stopped when they started using the care of the dying patient document, but had said that they would now keep a record of this…………... Lisa nodded sympathetically, and said she wasn't surprised at Marjorie's concerns and that she understood. She immediately started a new fluid balance chart for Anna.*

> Field Notes, Ward B, 15/10/14 p2

Norma and Lisa recognised and understood Marjorie's concerns and they responded immediately to try and rectify the situation. A few days later I spoke to another staff nurse called Caroline who was looking after Anna. It became apparent that she held a different perspective on the situation:

> *I asked how things were going with Anna and her daughter Marjorie. Caroline said it was difficult and that Marjorie was obsessed with her mum's nutrition. I asked what she meant and she told me that Marjorie was constantly reviewing the food diary and explained that she had spent 45 minutes with Marjorie yesterday, talking about nutrition and her mum's needs. She said she had tried to do some education with Marjorie and explain that often as patients approach the end of their life they don't need as much food and fluid, and that they usually get more sleepy, and therefore are at risk of choking……………………The way that Caroline explained the situation, her facial expressions and language, all seemed to suggest that Marjorie was being rather unreasonable. She said that they gave Anna mouth care four times a day and overnight, and her mouth was lovely and pink and moist. Therefore she said she was not dehydrated.*

> Field Notes Ward B, 17/10/14 p1

For Norma and Lisa, Marjorie's language expressed valid and understandable concerns which they responded to by starting a food and fluid chart. For Caroline, Marjorie's language expressed inappropriate and unreasonable demands which Caroline interpreted as coming from a lack of understanding about appropriate care at the end-

of-life. Therefore for Caroline, the appropriate response was to help to 'educate' Marjorie to see her point of view. These varied responses appeared to arise not only from participants' different interpretations of the situation but also from the values they held about how end-of-life care should be practised. Caroline's comments could be interpreted as alluding to the idea that all patients at end-of-life could be cared for in the same way, implying an ongoing 'pathway mentality' post-LCP. Whereas the perspective held by Marjorie and by Norma and Lisa appeared to be that staff should respond to the felt needs of individual patients and relatives. On the other hand, it could be that Caroline felt that Anna was well hydrated and worried that she might cause distress by over feeding her or by causing her to choke. Marjorie and Caroline interpreted the same situation in different ways due to their different understandings. It appeared that in this situation the conflict between Marjorie and Caroline may not have been so much related to differing values as to a failure to recognise how they were interpreting their values in practice, which has been described as 'values blindness'[39]. I think both would have agreed that the individual felt needs of patients were very important. What might have been helpful for the staff members was a greater awareness and discussion of how their values were being acted out and interpreted in practice.

I observed another example of varied interpretations during observation on ward A. Naomi Peters' father, Andrew Smith, had been deteriorating and she and her family had been told by the doctors that he was dying. I spoke with Naomi on the ward and she described her interpretation of her father's needs as his condition changed:

> *Naomi said that at first her father didn't sleep on the ward because he was terrified he wouldn't wake up. She said he was desperate to keep thinking and stay awake, and so she hadn't wanted him to be sedated. But as his condition deteriorated and he was less alert and increasingly distressed, she said that she changed her mind, and now thought he should be sedated.*

Informal Interview with Naomi Peters, relative on Ward A, 18/02/15 p3

I later spoke with Dr Bronze, the junior doctor caring for Andrew. With slight exasperation he described his interaction with the family:

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[39] Fulford describes this as 'values blindness', which means that '*problems arise in practice not so much from direct conflicts of value as from a failure to recognize values for what they are*' (Fulford, 2004, p. 218).

I saw Dr Bronze go in to review Andrew Smith. When he came out I asked how he got on. He said that it changed every day. Yesterday they wanted to keep him awake and today they wanted him sedated.

Field Notes Ward A, 18/02/15 p3-4

I learned from Dr Bronze that the doctors had felt that Andrew should receive small doses of a sedative earlier in the week but Naomi had been very reluctant and refused to allow it. Dr Bronze did not understand her rationale and her behaviour had seemed irrational and rather uncaring. He had not understood Naomi's perspective of her father's care.

On another occasion I spoke to Moira Brown, a relative whose mother, Maggie, was a patient on ward B. Maggie had dementia and had been admitted for investigation of her symptoms of shortness of breath. Maggie then deteriorated suddenly:

Moira described being shocked when the doctors talked about her mum's deterioration and about resuscitation. She said she couldn't cope, and that it came out of the blue. She had phoned her brother as she didn't know what to do. She said she hated the thought that they were giving up on her mum…………………………

Moira explained that the doctors asked her if she had ever discussed resuscitation with her mum, and she was very surprised. She said to me that maybe some people talk about that but not us. It's not us.

Field Notes Ward B, 10/12/14 p2

It was not clear whether Moira felt the doctors were 'giving up' on her mother or that she and her family were. However it seemed that for her a DNAR implied a withdrawal of support or care for her mother, which she felt was not right. I found that relatives could hold very different understandings about the meaning of language used to describe the patient's care, which could in turn lead to varied reactions and concerns. In these examples, the patients' conditions were changing and evolving over time. I observed that the healthcare professionals were often ahead of the relatives in terms of their understanding and response to the patients' changing condition. This could lead to tensions between staff members and relatives because of varied understanding and expectations of what was happening.

I observed that staff members sometimes recognised the potential for misunderstandings between staff and relatives. After observing Dr Red speak to a

patient and the patient's family about a resuscitation decision we spoke about his experience of such discussions:

> *Dr Red said he found speaking to relatives and patients about resuscitation hard. He said he knew what he had said but had no idea what they had taken from it. He explained that he was so used to having these sorts of conversation, but that didn't stop him thinking what have I done? I don't want to upset them.*

> Field Notes Ward A, 25/02/15 p3

Dr Red was a consultant with many years of experience of speaking to patients and relatives yet he recognised the potential for unintended interpretations of his language and he worried about it. Dr Grey, one of the junior doctors raised similar concerns after speaking to Jane Blackwell, the daughter of one of his patients named Juliet Crawley. Juliet had been seriously unwell when first admitted and the family had been told she might die. However her condition had stabilised and she had remained on the ward:

> *Dr Grey commented that he had just spent over an hour with the family of Juliet Crawley. Dr Grey said that they were not happy about anything. He said that while their mum had a pneumonia and a number of co-morbidities and a hypoactive delirium, he felt she was doing relatively well. However, he said they seemed to be fixated on the idea that she was not getting better and was going to die. They wanted to know if she would definitely get better or not. Dr Grey had explained that he couldn't tell them this, but hoped that she would, but that they would have to take it day by day………………………… Dr Grey said that he had repeated the same answers over and over again but he wasn't sure they had taken any of it in.*

> Field Notes Ward A, 26/02/15 p1

Even though Dr Grey felt that he had taken time to explain and repeat his explanation of the situation, still he felt unsure of what the family had understood. Other staff members also expressed frustration when interacting with Jane and her family. The previous morning I had observed the morning handover on the ward. Nicola, one of the staff nurses told the staff team about Jane and her family:

> *She told us that Juliet Crawley's daughters had stayed overnight with her. Nicola commented that Juliet had been very settled and her daughters hadn't been too bad. She explained that previously they had been asking for pain relief repeatedly, but when the nurses assessed the patient, she denied any pain. Nicola said that it was the granddaughters who were the problem, as they repeatedly asked the nurses for things.*

> Field Notes Ward A, 25/02/15 p1

For Nicola the behaviour of Jane and her family often appeared demanding and rather unreasonable. One staff member suggested to me that they wondered if the family wanted their mother to die because of the way they kept repeatedly asking for morphine. For staff, the family's complaints caused staff members to view the family as a 'problem'. No one appeared to question the possible reasons for their behaviour any further.

After observing this handover and speaking with Dr Grey the following day, I then interviewed Jane Blackwell and I asked her how she had found the communication with the staff:

> *"Well, we ask a lot of questions, put it that way, when the doctors come in. Some doctors, like some doctors I feel like, I don't understand what they're talking about. But, like that doctor who I spoke to today [Dr Grey], he was lovely. I mean I did understand him, he seemed to talk, made it simple to talk to a level to say, it's like obviously your Mum's decision now whether she goes this way or that way. Do you know what I mean? Let nature take its course sorta thing. Cos what we're doing is not making it any better. But we're not making it any worse. So, em and some of the nurses explain everything they're doing to her, but then, some just say, they don't explain they just get on with it, you know?"*

> Interview with Jane Blackwell, relative on ward A, 26/02/15 p3

During her interview Jane explained that the doctors had said her mother might die when she was admitted. It seemed that this message had unsurprisingly remained a concern for Jane and her family. Though the staff recognised clinical improvements in Juliet's condition and described these to her relatives, from Jane's account, it sounded as though she had not always understood explanations from staff or perhaps had not believed them, which led to her continued belief that her mother was dying. After Jane's interview as we were walking back to the ward, she made a comment which she said she wanted me to record. During the interview Jane had explained that when her mum was first admitted she had had an intravenous line inserted into her neck in order to give antibiotics:

> *Jane said that when her Mum's line came out, they [the nurses] didn't phone her. She explained that before she and her sister had left the hospital on the night of her mother's admission, they had asked the nurses to call them if anything, big or small, happened overnight. Jane explained that she had woken a few hours later and worried about her Mum, so had phoned the ward, and that is how she found out the*

line had come out just after they left the hospital. She said this had caused them to worry that they couldn't trust the nurses to ring, or tell them what was going on.

Field Notes made following an interview with Jane Blackwell, relative on ward A, 26/02/15 p7

Jane had understood that the staff would call her should anything happen to her mother. The nurses' lack of action, i.e. the lack of a phone call and communication about the line coming out, was perceived as a lack of care and attention by Jane and her family. It appears that practice and language are closely linked and together influence the perspectives held by relatives as well as their ongoing interpretations about care on the ward. Yet what was considered to be reasonable in terms of expectations about care might vary considerably between relatives and staff members. I found that this was not only the case for Jane and her family. Liz White told me about the experience of her and her mother, when her father, George White, was seriously unwell on the ward:

"We ring up like every night, just before, you know, I put Mam in bed and I'll say "right, we'll call the hospital now". And em, just to see how he is. And obviously there's been a change of staff, and sometimes you get somebody who hasn't looked after him. And they just say, "oh yes, he's doing fine"……………………… what's happened with my Mum, when she's realised that the nurse didn't know who George White was, she's lain awake worrying because she just doesn't trust what they've said, cause they obviously don't know him".

Interview with Liz White, relative on ward A, 25/08/14 p13

The response by the nursing staff led to sleepless nights for Mrs White worrying about what might actually be going on with her loved one on the ward. As demonstrated by the above examples, once relatives felt they were not able to trust the staff, interactions between relatives and staff could become increasingly fraught. In this way previous poor communication and negatively perceived interactions could shape attitudes and impact on the current communication and interaction between relatives and healthcare professionals.

Having considered how language was used and interpreted to make meaning during interactions between patients and staff, and relatives and staff, I now explore the interactions between staff members who made up the healthcare teams working on the wards.

8.4 Language and Meaning: Interactions between Healthcare Professionals

While it might be expected that communication would be more straight-forward between staff members, as they share a background in healthcare and are used to the hospital environment and routines, it appeared that differences in interpretation of clinical situations could occur frequently between staff members too.

I asked Susan, a staff nurse on ward A, about whether she had ever disagreed with the doctor's perspective, or felt that the doctors were continuing active treatment when she felt the patient was dying:

> *"Very rarely. But I have mentioned it to one of the consultants before when I thought that was happening……………………I remember the consultant telling me why he felt it wasn't the right time to stop it, or that we shouldn't stop it right now. And what he said, I hadn't actually thought about, you know what I mean? So there was a medical reason that perhaps as a nurse I hadn't thought of straight away. But the medical reason he gave was, I thought 'oh yeah fine, I didn't think of that', you know? That's fine. So yes, so often I think, and maybe from more junior nurses as well, they don't always think of the medical side of things. Which obviously that's why there's doctors and that's why there's nurses, you know?"*
>
> Interview with Susan, senior staff nurse on ward A, 20/08/14 p3

Susan's account highlights the significance of staff relationships which enable dialogue, sharing of opinions and understanding. On first inspection of the situation she had not understood the doctor's perspective. But once the doctor explained further information about the situation, she agreed with the doctor's management. She suggested that she had simply not had all of the relevant clinical information.

On other occasions it appeared that varying perspectives were not always due to a lack of information alone. Instead varying values underpinning perspectives about how deteriorating patients ought to be managed could be thrown into sharp relief. I asked Anne, one of the staff nurses on ward A, whether she felt able to speak to a consultant if she disagreed with their management of a dying patient. Anne described what she felt was a particularly problematic area - patients approaching end-of-life on NIV:

> *"A lot of the nurses will say to the doctors, you know, you need to either do something about it or the NIV needs to be taken off so that the patient can actually die comfortably. Especially when you know they're going to die. It's not nice having the NIV machine on if you know they're going to die. So I think it's difficult though, because even if we suggest that, nobody stops you suggesting how the patient should*

be cared for, but it's whether you're listened to or not. And a lot of the time I don't think you're listened to as a nurse. In regards to that, anyway. Because the doctors are so passionate about making them better, and doing everything they can to give them the best fighting chance. I don't think they necessarily like to hear us say, we think you should, we think you should withdraw".

Interview with Anne, Staff Nurse, Ward A, 03/03/15 p7

Though Anne did not mention conflicting values as a cause of the difficulty, they were implicit in her account and concerned how staff members recognised 'dying', what appropriate care involved once 'dying' had been recognised and the role of the healthcare professionals in caring for deteriorating patients. Anne implied that at times it was possible to know when patients were going to die and her frustration seemed to spring from her belief that doctors, even when they knew the patient was going to die, would continue invasive treatments. In an interview with Pam, a staff nurse on ward B, she expressed similar concerns and opinions as Anne regarding deteriorating patients:

"I've had a couple where I actually challenge the doctor, and I do because I just think it's absolutely ridiculous to be going on with active treatment, you can see the patient's deteriorating. And yes, I know people have a duty of care to sort of sustain life, but it's when it's, when do you not play God? When do you say, okay this patient is dying, they're coming to the end of their life, enough is enough?"

Interview with Pam, senior staff nurse on ward B, 28/04/15 p3

Yet when I spoke to doctors about patients deteriorating, they spoke of the real difficulty in knowing when a patient might deteriorate and die, or respond and recover:

"I think people who die from non-malignant disease can be tricky. So, for instance, people with COPD. Prognosticating in them is really difficult, and there is no tool to do it. Physician assessment is wildly inaccurate, it's been shown to be wildly inaccurate in studies. So there's no reliable way. You know, if someone's got cancer, you can pretty well judge their prognosis, particularly lung cancer. But people with non-malignant disease is really difficult. So COPD, really difficult. And other conditions like pulmonary fibrosis, heart failure, again, really difficult because the focus is always very medical, very proactive, very much in terms of treating things, eh and I think we miss a trick with these people sometimes, cause often they are dying, at the end of their life, but we find it very difficult to be precise about things like we are with cancer".

Interview with Dr Purple, consultant on ward A, 03/03/15 p4

Dr Purple described the difficulty of making accurate prognoses at end-of-life yet he also implied that often he felt their approach was too medical. It appeared that in these kinds

of situation, there could be both a lack of awareness of the values held by fellow staff, as well as an assumption that other staff members' values would be the same as the participant's. This has been described as both values blindness and values myopia[40]. In Anne's account, she seemed to assume that both she and the doctors could be sure when a patient was dying, yet Dr Purple was not so certain about this. I observed that when conflicting values went unrecognised staff could feel ignored and as though their perspective was undervalued. It seemed that explicit recognition of conflicting values might facilitate team discussion and deliberation about patient care. Indeed this was illustrated to some extent by the following account from Lisa, a staff nurse on ward B. For while Susan and Anne felt able to voice their different perspectives and concerns to doctors, I found that other staff felt less confident to do so. Lisa described her perspective on how she felt when she disagreed with a doctor's perspective:

> *L: I think as well, just being able to say to doctors, sort of now being able to a little bit sort of kind of say, oh why are we still doing this? But I don't think I'd have the guts to say it to a consultant yet, who would be the one who would make the decision. But we say it to the junior doctors now, but I then wouldn't say it to the consultant, well I don't think we're doing the right thing. But again I don't know if that comes with experience, or if it's just not something nurses would say, but then I think we're the ones who are in and out [of the patient's room] for a longer stretch of time, that our opinion [I: what stops you saying it to the consultant?]. Cause they're scary, and they're consultants. I'm just a nurse. They're a consultant. So it's kind of like, oh they know best, they know best in everything.*
>
> *I: What do you think they might do?*
>
> *L: I don't know. Cause like especially on this ward, our consultants are all really lovely. But I just think that my opinion wouldn't be that valid, cos they're like a consultant, and I shouldn't like say anything, I should just do what I'm told to do [L laughs].*
>
> Interview with Lisa, Staff Nurse on Ward B, 21/11/14 p10-11

Lisa was a relatively junior nurse on the ward and though she got on well with the consultants she lacked the confidence to share her opinion with them. Lisa perceived a hierarchy of perspectives on the ward, with the opinions of consultants of greatest importance, while hers were much less important. This implicit hierarchy stopped her from sharing her concerns with consultants perhaps for fear of looking stupid or

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[40] Fulford refers to this as 'values myopia', which is the idea that people may assume that other people's values are the same as their own (Fulford, 2004).

impertinent. I asked Lisa about what had happened when she had shared her concerns about patients with the junior doctors on the ward:

> *"They're actually generally really understanding, they, like cause we're the ones who are in and out of, if they're in a side room, in and out all the time. And we're seeing how distressing doing hourly obs can be for the patient, and then how for us it's a losing battle, cos we're doing them but then you don't want us to do anything with the obs, so why should I disturb that patient? I want to go in and see that patient, but I don't necessarily want to make them uncomfortable, and bother them. So they [junior doctors] generally are really understanding and they sort of take a step back and reassess the situation and kind of reflect on what we are doing and what the plan is".*

> Interview with Lisa, Staff Nurse on Ward B, 21/11/14, p3

Though Lisa did not mention values her language implied them. She felt that when a patient was dying they should not continue to perform regular observations which were not being acted upon and could be uncomfortable for the patient. The doctors may well have agreed with her or they may have believed that the patient was not dying and did require ongoing observations. Either way, Lisa explained that by raising her concern the doctors stopped to consider her perspective and their management of the situation afresh. When Lisa spoke her concerns out loud to her medical colleagues it was no longer just a matter for her but something for them to consider together as a team.

However, I also observed situations when for varied reasons, staff members did not speak with each other to share information and perspectives.

> *Dr Pearl [junior doctor] told me about a patient who had been transferred up to the ward in the early hours of the morning. He had acute leukaemia and he had been receiving chemotherapy. He had been very unwell and the consultant, Dr Cobalt, had spoken to the patient and his family. Dr Pearl said that she had been on a ward round with another consultant when Dr Cobalt went to speak to them. She said she wished he had asked her to go with him because later on she had to go in and introduce herself and ask how they were not really knowing what had been said. Dr Pearl said the patient's wife was really upset because he was agitated and in pain and nothing had been sorted out. Dr Pearl explained to me that the management plan was to give him platelets, which she felt were useless given that he was dying. Dr Pearl said she reviewed the patient and told his wife she would try and get him more comfortable. She called Dr Cobalt and he said he was happy for her to prescribe prn drugs for end-of-life care. However, Dr Pearl said that they gave the patient medication for his symptoms and then about half an hour later he died. She felt bad that he had died so quickly, but was happy that his family had seen him settled before he died. She said that she felt there were loads of gaps in communication.*

Dr Pearl and Dr Cobalt reviewed the same patient and family but appeared to interpret the situation differently such that they formed very different management plans. Dr Cobalt was keen to treat the patient's low platelet count, while Dr Pearl felt he was dying and wanted to focus on keeping him comfortable. Because they had not reviewed him together there had been no opportunity to discuss their varied opinions and later on Dr Pearl explained that she felt that this had delayed the initiation of good symptom control. Furthermore she felt that it made it much harder for her to establish a rapport with the patient and family when she didn't know what they had been told.

Just as Dr Cobalt and Dr Pearl interpreted the above situation differently, I observed that staff often held differing opinions about when to use the term 'dying'. On the wards patients described as 'dying' were those who were felt by staff to be deteriorating due to conditions no longer reversible or treatable, which would inevitably lead to their death. Yet the way staff members interpreted patients' clinical conditions varied. One of the junior doctors on ward B, Dr Coral, told me about Emily Brown, a patient who she thought was dying:

> *Dr Coral explained that she was a very frail, elderly lady who was dying of frailty, but had deteriorated overnight and was now dying of something.*

Field Notes Ward B, 10/04/15 p1

A few minutes later I observed her conversation with another junior doctor who had just reviewed Emily:

> *Dr Coral asked him what he thought. Dr Ivory had written his impression in the notes and I listened as he explained that Emily was septic, had acute kidney injury, faecal impaction and overflow diarrhoea, low phosphate and low magnesium levels. But he said that mostly she was just incredibly frail............................ I asked Dr Ivory if he thought Emily was dying. He replied that she was not yet dying, but was right on the edge. I noticed that Dr Coral frowned at this as if in disagreement. She then commented that she had thought Emily was dying yesterday.*

Field Notes Ward B, 10/04/15 p1

Dr Ivory listed many serious medical problems but from his perspective these did not equate with 'dying', whereas Dr Coral had interpreted the patient's gradual deterioration as part of the dying process. A short time later the consultant, Dr Yellow,

arrived to do his ward round and he reviewed Emily Brown. Afterwards I made the following field notes:

Emily responded when Dr Yellow said hello and said no, when he asked if she had any pain. But she then started groaning and mumbling and seemed to be delirious. After examining her and explaining that she had a very severe chest infection, Dr Yellow left the bay and we followed. Outside the bay he commented that she was clearly dying. He read through her notes again and commented that she had chest sepsis and evidence of multi-organ failure……………….

Dr Yellow advised that they continue the IV fluids and antibiotics until the afternoon, so that she had had 24 hours of treatment. He felt it was highly likely she would deteriorate and then they would change their management to palliate her symptoms and focus on keeping her comfortable. In the meantime, if her cannula came out he said not to replace it. He prescribed some Midazolam for her distress and agreed that she should be moved to a side room.

Field Notes Ward B, 10/14/15 p2

When Dr Yellow described Emily as dying his management strategy for her care changed. His words created a new reality which provided a new direction for treatment. The focus became keeping her comfortable and active treatments were gradually withdrawn. A few days later I saw Dr Ivory again and I asked what had happened to Emily Brown:

Dr Ivory told me that he had reviewed her again early in the evening. He said she was much worse, and was unresponsive, so they palliated her. I asked him if he thought she was dying when he saw her in the evening. Dr Ivory said yes, and that it was obvious then because she was unconscious.

Field Notes Ward B, 13/04/15 p2

Dr Ivory seemed reluctant to label Emily as 'dying' until she was unconscious and it was beyond all clinical doubt that she would indeed die. Though clinical terms like 'dying' or 'deteriorating' can appear to be objective descriptions of patients, I observed that these descriptions were staff members' interpretations of reality. In this sense, making meaning is a subjective process through which people use their experiences, feelings, understanding, language and interactions with others to form meaning about the world around them.

8.5   Conclusion

In this chapter I have considered the role and work of language and meaning in communication during end-of-life care. From the data it appears that language has many roles: first, it works to make explicit the details of a situation and help to formulate the perspectives of participants as they speak their thoughts and feelings out loud. Second, by expressing their thoughts, opinions and views out loud, language can place matters in the 'public space' where they can be openly reflected upon by participants. This shared language can work to establish relationships and build rapport between participants. Third, language provides a medium through which participants express their perspectives and understandings about situations. While participants often agreed on the processes and practices of care on the ward, when conflicts of opinion occurred, another role of language could be seen, that is, to express participants' values and moral concerns. Yet even when seemingly appropriate language was used misunderstandings could still occur. In order to investigate this further, I considered how meanings are formed by participants.

The analysis of data shows that information is not simply transferred between participants like an object and how language is understood has to do with how participants form meaning about situations. Participants form meaning through their experiences, thoughts, feelings and values as they interacted on the wards. Patients and relatives do not always interpret or understand information as intended by staff and vice versa. The same is true of interactions between staff. Differences in perspectives and values when unrecognised and unchecked, can lead to confusion, conflict and distress. Data analysis suggests that to 'care well' at end-of-life involves staff actively seeking to recognise and understand the perspectives of patients, relatives and fellow staff in given situations. While appropriate language and good communication is very important, the emphasis in healthcare should be on establishing a shared understanding between patients, relatives and healthcare professionals.

Chapter 9   Discussion

In the three preceding data chapters I have presented a detailed analysis of the practice and complexities of end-of-life care on hospital wards. The data analysis has highlighted the perspectives of patients thought to be approaching the end-of-life, their relatives and the staff involved in caring for them as well as my own observations of end-of-life care practice. It has also described some of the clinical and ethical challenges related to the provision of end-of-life care. For simplicity the analysis has been organised under three themes set out in the three data chapters (Chapters Six, Seven and Eight). However, it was clear from the data that these three themes were not discrete but rather they often overlapped and were interconnected. In this chapter I further unpack these themes by discussing them together and present an integrated analysis of the study findings in light of the wider literature. I build on the literature by applying both practical and philosophical approaches to the data, further demonstrating the complexity of care between the patient, relatives and healthcare professionals on hospital wards.

This research study set out to explore end-of-life care in a hospital setting, by observing how end-of-life care and decision-making happen in practice; by exploring the perspectives of patients thought to be approaching end-of-life, their relatives and the healthcare professionals caring for them in order to uncover their underlying values; and to identify areas of ethical difficulty within end-of-life care practice. The data analysis suggests the following four points: first, both the objective and the more subjective aspects of care need to recognised and made explicit on hospital wards in order that such care is not simply assumed but actively planned for and prioritised by healthcare teams; second, the important role of relatives in helping to advocate for and represent patients' wishes at end-of-life must be acknowledged by healthcare professionals as something of both practical and ethical significance and processes must be designed to facilitate ongoing discussion and dialogue between patients, relatives and staff; third, the multiple and nuanced roles of language (in creating and maintaining relationships, enabling shared perspectives and the recognition of the values held by others) should be taught and acknowledged on the wards such that communication between patients, relatives and healthcare professionals is given appropriate time and priority; fourth, there is a need for healthcare professionals to commit to care and

decision-making that seeks to involve the patient (and/or relatives where appropriate) as far as possible, without unduly burdening them or their relatives. In this chapter I discuss the data with reference to the literature and highlight the significance of this study's findings for practice, policy and future research.

9.1   What is Care?

In Chapter Six I discussed the concept of care at end-of-life. Participants gave varying accounts of the care they received. For example, it involved competent physical care, gentleness when providing personal care, as well as treating patients like human beings[41]. The data suggested that good care involves seeking to meet physical, psychological, social and spiritual needs. The care patients described as important included how staff members interacted with them and their manner which could cause patients to feel that staff were not just doing things to them but that they were there for them[42]. The writings of Wolff and Saunders chime with aspects of the data from patients, relatives and staff. They described care as being about more than competent physical care; it included taking the time to listen and understand the patient, seeking to relate to them as a fellow human being[43]. Care is about recognising and attending to the multiple and varied aspects of human need. Mol (2002) highlights this in her ethnography of the body and disease: '*the humane does not reside exclusively in psychosocial matters. However important feelings and interpretations may be, they are not alone in making up what life is all about. Day-to-day reality, the life we live, is also a fleshy affair*' (Mol, 2002, p. 27).

From the data analysis it became clear that care is constituted by many component parts rather than having one essential essence[44]. But as could be seen from the data there is no one thing that care *is*. Rather, good care considers both the physical and

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[41] See Chapter Six, Sections 6.2, 6.3.

[42] See Chapter Six, Section 6.2, p112, quote from Brian Cook.

[43] See Chapter Six, Section 6.3, p119 account from Marjorie Pringle.

[44] An 'essence' can be defined as 'The fundamental nature of anything' (Frame, 2015, p. 751).

metaphysical and the objective and the subjective aspects of patient need. It is about competent medical interventions and treatment, but of equal importance is how staff members behave with the patient and relate to them. It is composed of many things and these component parts may vary depending on the patient and the situation. Maureen Brown described how important it was for her care that the nurses provided for her needs while also allowing her to be as independent as should could be[45]. Yet she also recognised and called for greater attention and assistance for patients who were less physically able[46]. Healthcare policy and practice focuses on the practical and rational aspects of end-of-life care, while the more personal, subjective, relational and existential aspects of care are often unacknowledged. Yet as seen from the data and the literature, such aspects of care are important for patients and their families in their experience of care on hospital wards.

The issue about care not being an essence is important for a number of reasons which I will now consider. First, because the components of care may change according to a given situation, care cannot be limited to a specific set of characteristics, routines or policies. It needs to be perceptive and responsive to the needs of the patient at the time. Second, because the components of care may vary from patient to patient, it is important for staff members to be aware of this and to discuss openly the important components of care required in different situations. This is in contrast to the assumption, for example, that patients with the same condition will require the same kind of care. Third, certain threads or components may not be immediately obvious to staff members, as in the example of Jane Blackwell and her family[47]. They feared that their mother would not be well cared for and needed clear explanations and consistent care to reassure them. Yet the nurses didn't appear to recognise the basis of the family's concerns and so perceived their behaviour as 'being difficult'. Fourth, as Hughes et al. have highlighted, components of care may appear to contrast or even contradict each other (Hughes *et al.*, 2008). For example, the important principle of patient autonomy may appear to be under threat when patients' relatives seek involvement in the patient's care. Yet

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[45] See Chapter Six, Section 6.2 p112.

[46] See Chapter Six, Section 6.3.1 p123.

[47] See Chapter Eight, section 8.3, p175-6.

conceptions of relational autonomy[48] provide a basis for understanding and reconciling such apparent contrasts in practice (Ells *et al.*, 2011; Wilson *et al.*, 2014). Fifth, care is not an intrinsic quality inherent within healthcare professionals, rather it requires the development of many different qualities and virtues. Certain healthcare professionals will be better able or more skilled at providing some aspects of care than others and for this reason good care requires teamwork with different staff members playing different parts just like the overlapping threads in Wittgenstein's example[49]. This was exemplified on ward B by staff nurse Lisa who carefully planned her work and delegated tasks in order to meet the needs of all of her patients while also providing care for a patient who was approaching the end of their life as well as their family members[50]. It was not only the nurses who provided care on the wards, the data gives examples of doctors and allied healthcare professionals who recognised and described their varied caring roles[51].

These insights into care provided by the data are especially important in light of the 'appalling suffering' found to have occurred at the Mid-Staffordshire Hospital (Francis, 2013). In 2013 Robert Francis QC published his inquiry into the poor standards of care at the Mid Staffordshire NHS Foundation Trust and listed 290 recommendations for NHS organisations and staff members (Francis, 2013). The nursing-specific recommendations appear to suggest certain perspectives on 'care' and what is required to ensure that such care is provided to a high standard on hospital wards. First, the recommendations imply that it is simply nurses (as opposed to all healthcare professionals) who need more training in 'caring'. Second, the idea of introducing aptitude tests for caring suggests that care has an essence, an intrinsic quality which can

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[48] Christman (2003) has described the concept of relational autonomy as: 'an alternative conception of what it means to be a free, self-governing agent who is also socially constituted and who possibly defines her basic value commitments in terms of inter- personal relations and mutual dependencies. Relational views of the autonomous person, then, valuably underscore the social embeddedness of selves while not forsaking the basic value commitments of (for the most part, liberal) justice. These conceptions underscore the social components of our self-concepts as well as emphasize the role that background social dynamics and power structures play in the enjoyment and development of autonomy' (Christman, 2003). This concept will be discussed in greater detail in Section 9.2.2.

[49] See Chapter Four, Section 4.1, p37

[50] See Chapter Six, Section 6.4, p129

[51] See Chapter Six, Section 6.4, p128 and p130

be tested for. Third, these recommendations suggest that compassionate care is not distributed between healthcare professionals (as described in my first point), but also that it is not distributed between organisational levels (individual, ward, hospital, Trust, regional and national levels). These organisational levels were seen in the data. For example: caring involves how individual staff relate with patients and provide for their varying needs in different situations; it includes the ways in which organisations respond (the procedures and processes they carry out) when there is concern about patient safety due to short staffing[52]; it includes how staff teams work to improve care in light of poor feedback from patients[53]; and therefore it necessarily includes management decisions about finance, governance, and organisational structure which all work to ensure that patients approaching the end of life receive good care. Good care is composed of many different component parts which may operate at all levels within the NHS, from individual to ward teams, to NHS trusts and to the wider NHS. If good care at end-of-life is to be provided consistently, care must be recognised and improved at all of these levels. Fourth, these recommendations do not take into account the ways that care must vary and adapt depending on the situation in question. For example, care may involve doing something (an intervention for example) to a patient, but it may also involve the way that staff care when they spend time with a patient.

The debate in the national press following the Francis Report described the need to reduce the *'compassion deficit'* in nursing (Lobl, 2013). Yet Paley (Paley, 2014) expresses scepticism about the idea of a compassion deficit (a problem with the attitudes and values) among the nurses in the hospital, which can be righted by emphasising compassion in nurse training and recruitment. Instead he argues that the problems stemmed from interlocking contextual factors related to the hospital organisation and environment (Paley, 2014). He maintains that such factors cannot be changed or righted by focusing on the teaching of ethics, compassion and empathy.

The analysis of data in this study highlighted the influences that short staffing, ward structure and organisation can have on care just as Paley acknowledges above. However, it also demonstrated the importance of a compassionate manner and attitude

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[52] See Chapter Six, Section 6.2, p108-9 staff nurse Pam's account.

[53] See Chapter Six, Section 6.2, p110 Dr Auburn's account.

in all staff and showed that whether healthcare professionals recognise it or not, their practice (actions and language) embodies their values and ethical stances. For example, the behaviour of staff members on ward A unintentionally led to the concern by Jane Blackwell and her family that they could not trust the nurses[54]. A further example, was seen when Marjorie Pringle understood from the behaviour and communication from some of the nurses on ward B that it was wrong for her to try and feed her mother even though she appeared to be hungry[55]. Therefore the importance of ethics, compassion and empathy in training and practice cannot be denied. This must be accompanied by recognition from staff members of the importance of unambiguous communication, clarifying the perspectives of patients and relatives and seeking a shared understanding with them in any given situation. For as the data has highlighted, it is possible for poor care and misunderstandings to occur even when the wards are well-staffed. Staffing levels therefore are only one component of good care. Adequate staffing levels *and* the embodiment of appropriate values and practices are both needed if good care is to be provided. However, in an increasingly stretched healthcare system where staffing levels are unlikely to increase, the importance of values and attitudes (and the behaviours they lead to) become even more important. However for Francis to press the importance of care and compassion on nurses alone appears to deny the importance of care and compassion embodied by the whole healthcare team (clinical and non-clinical). As van Heijst (van Heijst, 2011) proposes, organisations cannot change themselves but need people to do so, and it is the values embodied by people that work to establish the norms and standards upon which healthcare organisations function. In the next section I will consider how language works to express and embody different values.

9.2 Language and the Expression and Embodiment of Values

In Chapter Eight I discussed the role of language and meaning in end-of-life care communication. Data analysis showed that language has many roles in end-of-life care and highlighted that meaning is not simply received knowledge but is created by every

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[54] See Chapter Eight, Section 8.3, p175-6

[55] See Chapter Eight, Section 8.3, p170

individual according to their own experiences, emotions and understanding. Language can be seen to express peoples' values on moral concerns about the world though they may not describe them in this way. I observed this on the ward as relatives spoke about their concerns to staff members and sometimes explicitly, though more often implicitly, suggested that the current practice was wrong in some way or in need of re-assessment[56]. Though participants did not routinely use what might be termed ethical language, or refer to moral principles or theories, they clearly expressed opinions about what they felt was good and bad, as well as uncertainty over the rightness or wrongness of everyday actions. In Chapter Eight section 8.4, I explored examples in the data in which staff members unconsciously expressed their values through language as they explained their views and experiences to me.

In healthcare culture today notions of 'goodness' and 'badness' have come to be seen as those determined and directed by the values stated in professional guidance and the law. Professional and legal guidelines outline the practical action and behaviour required to ensure 'good' end-of-life care. Such guidelines are based on ethical principles and implicitly underpinned by moral norms such as dignity, autonomy, rights and justice. However, how such principles are defined and where their justification comes from is rarely (if ever) expanded on in professional guidance, let alone discussed on medical wards. It is possible that healthcare professionals feel there is no need to discuss such issues as to provide good care one can simply follow the guidelines. As van Heijst (van Heijst, 2011) proposed, when a moral approach to care is replaced by legal discourse alone, the result is likely to be a reduction in the participation of healthcare professionals. Furthermore, in a time-pressed healthcare system, discussing the principles underlying reasons for action and behaviour may be seen as an inefficient and an irresponsible use of time. However, Fulford (Fulford, 2004) has proposed that values are of vital importance in clinical medicine. He advocates for a theory called Values-Based Medicine (VBM) which acts as the counterpart to Evidence Based Medicine (EBM) and recognises the growing complexity of different values in healthcare today. Indeed he highlights that scientific progress and the rise of technological interventions is increasingly leading to more diverse human values in all areas of healthcare (Fulford,

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[56] See Chapter Six, Section 6.3 p116-117, Bill Walker's quotes.

2004). The increasing complexity of values was seen in the data with relation to the treatment of deteriorating patients with NIV[57] and in relation to DNAR decisions[58]. Whereas in the past, before the development of NIV and CPR, differing opinions and values were not present because such choices did not exist.

VBM provides practical principles for theory and practice in clinical decision-making, which can be seen in Figure 7. The sixth principle of VBM draws attention to the potential for 'values blindness', which is the potential for values to become invisible to healthcare professionals when they are shared by healthcare professionals. This principle is closely aligned with the seventh principle which involves 'values myopia'; the idea that healthcare professionals have a tendency to assume that other people hold the same values as they do (Fulford, 2004). VBM emphasises the important role of language in the identification of values in practice and emphasises the importance of 'good process' (rather than rigidly obeying rules without heed to the circumstances) in clinical decision-making (Fulford, 2004). It seemed clear from my own observation and from the data that language also had a key role in the formation of meaning and of caring relationships on the wards and I will discuss these key roles of language in the following section.

Figure 7 Ten Principles of Values-Based Medicine (VBM)

1.	All decisions stand on two feet, on values as well as on facts, including decisions about diagnosis (the "two-feet" principle).
2.	We tend to notice values only when they are diverse or conflicting and hence are likely to be problematic (the "squeaky wheel" principle)
3.	Scientific progress, in opening up choices, is increasingly bringing the full diversity of human values into play in all areas of health care (the "science-driven" principle).
4.	VBMs "first call" for information is the perspective of the patient or patient group concerned in a given decision (the "patient-perspective" principle).

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[57] See Chapter Eight, Section 8.4 p177-8, staff nurse Anne's quote.

[58] See Chapter Seven, Section 7.3.1.

5.	In VBM, conflicts of values are resolves primarily, not by reference to a rule prescribing a "right" outcome but by a process designed to support a balance of legitimately different perspectives (the "multi-perspective" principle).
6.	Careful attention to language use in a given context is one of a range of powerful methods for raising awareness of values (the "values-blindness" principle).
7.	A rich resource of both empirical and philosophical methods is available for improving our knowledge of other people's values (the "values-myopia" principle).
8.	Ethical reasoning is employed in VBM primarily to explore differences of values, not, as in quasi-legal bioethics, to determine "what is right" (the "space of values" principle).
9.	In VBM, communication skills have a substantive rather than (as in quasi-legal ethics) a merely executive role in clinical decision making (the "how it's done" principle).
10.	VBM, though involving a partnership with ethicists and lawyers (equivalent to the partnership with scientists and statisticians in EBM), puts decision making back where it belongs, with users and providers at the clinical coal-face (the "who decides" principle).

9.3 Language, Relationships and Care

As patients sought to make sense of their terminal diagnoses in light of their past history and current responsibilities[59], I saw that language worked to create the reality of whether a patient was deemed to be 'dying' or not. When a doctor expressed that a patient was dying this led to a change in their management as active treatments were withdrawn and the focus of care was changed to keeping the patient comfortable[60]. I observed the way that language articulated during ward handover meetings could shape the way staff viewed patients and relatives, sometimes as 'problems' to be dealt with[61].

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[59] See Chapter Eight, Section 8.2 p162-4, interactions involving Theresa Dodd and Anne Harper.

[60] Chapter Eight, Section 8.4 p182, account of Dr Yellow's management of a dying patient.

[61] See Chapter Eight, Section 8.3 p174, staff nurse Nicola's account at morning handover.

The language used by participants worked to determine how they perceived one another. When staff members took time to explain situations clearly and sensitively they were viewed positively by patients and relatives. In contrast, when they gave what appeared to be generic answers, they were perceived as potentially untrustworthy[62]. Therefore, as described in Chapter Four by Taylor and others[63], language was active and at work on the ward, formulating realities, building and maintaining relationships.

The PLC approach to care acknowledges the importance of building and maintaining relationships and appears to be consistent with the care needs described earlier by both patients and relatives. PLC aims to see and respond to the needs of each individual and to ensure that those being cared for feel supported and valued. It also recognises that care is not a unilateral concept but is in many ways reciprocal and acknowledges the worth and value of all people (patients, relatives and healthcare professionals) as unique individuals (van Heijst, 2011). From a PLC perspective relationships are vital for providing and maintaining care. On wards A and B interactions between patients and healthcare professionals were seen to be essential for the practical provision of care, but the companionship and friendship provided within such relationships were also an important component of care itself. Care was enabled and maintained through relationships on the wards. The philosophy of PLC emphasises the importance of relationships and '*calls for a high-quality interpersonal relationship between professional and client; this is considered a necessary for quality care*' (Hermsen *et al.*, 2014, p. 222). This was seen in the data as patients described the importance of relationships between staff when providing their care, but also in the friendship and comradery they had with staff members[64]. A PLC approach does not deny or ignore the asymmetry of dependency in the doctor-patient relationship but is acknowledged as being of central importance. Patients *are* needy in a way that healthcare professionals are not. Yet despite their differences, doctors and patients are both of equal worth and such asymmetry can be managed through caring relationships, enabling patients to be both dependent on others for care while maintaining their dignity as persons (van Heijst, 2011). Brian Cook, a

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[62] See Chapter Eight, Section 8.3 p176, account from Liz White and Mrs White.

[63] See Chapter Four, Section 4.3.2

[64] See Chapter Six, Section 6.2 p113 Sue Webster's comments and Brian Cook's comments

patient on ward A, described how important it was for staff to see his need for care while also treating him as an individual: "*And I feel…. I'm not just a number, I'm not just a thing that's occupying a bed, I am a person …That's not very well…. And I need looking after. And it makes the world of a difference when you feel, you're not just another, another body lying there"*[65]. The provision of this kind of care on busy hospital wards requires teamwork and good relationships between staff members in order to encourage an approach to care which prioritises both the objective and subjective needs of patients.

Relationships were seen to be important both for patient care and for the care of staff members as they worked together in often difficult situations at end-of-life[66]. Despite the fundamental importance of relationships on the wards, I observed that their value was not something that was openly discussed or prioritised by staff. And despite the recognition of the importance of relational and emotional factors in providing good care there remains little acknowledgement of these issues in policy or in the practice I observed on hospital wards. The important relationships between patients and relatives and between relatives and healthcare professionals will be discussed in the following section.

9.4 Care and the Role of Relatives

A critique of modern healthcare decision-making is its failure to recognise the importance of involving those close to the patient in decision-making about appropriate treatment and goals of care. As the literature in Chapter Four highlighted, patients rarely make decisions as isolated and autonomous individuals. Lloyd argues that the inter-relatedness of people and importance of their narrative and context has been overlooked by the current societal and political focus on individual rights and autonomy (Lloyd, 2004, p. 247). The analysis of data from relatives suggests that being kept informed about their loved one's condition is very important. However, many relatives

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[65] See Chapter Six, Section 6.2, p112

[66] See Chapter Six, Section 6.2, p113 quotes from Sue Webster and Brian Cook.

felt that such information was often lacking and that there was an expectation that they should seek out information from staff[67]. Getting such information could be difficult for relatives especially when staff were busy and visiting time was short. Analysis also suggests that though patients may keep their relatives informed, assumptions cannot be made about how much information patients will pass on. These findings are in keeping with the literature which consistently reports on the dissatisfaction of relatives with the information they receive from healthcare professionals (Parker *et al.*, 2007; Caswell *et al.*, 2015; Witkamp *et al.*, 2016).

Relatives on wards A and B who were involved in decision-making described varying experiences, for example: being told about a decision which had already been made, being asked to make a decision and being asked for their views and opinions during the decision-making process. What appeared to be most important was that relatives were informed about their loved one's condition, offered the opportunity to share their views about their loved one's treatment and care and felt listened to. Witkamp et al. call for healthcare professionals to acknowledge the interdependence of the human condition and to recognise the important role that relatives play in the care of patients at end-of-life. They propose that the concept of relational autonomy is more appropriate at end-of-life, whereby: '*the patient and the relatives are seen as interdependent…… where the involvement of relatives is important in preserving or restoring an overall sense of patients' identity, agency, and selfhood*' (Witkamp *et al.*, 2016, p. 7).

On wards A and B, many of the accounts from staff acknowledged the importance of informing relatives and involving them in decision-making. However, staff and relatives highlighted many challenges to this practice: the structure and length of visiting time, lack of clarity about how relatives ought to gain information about loved ones and the attitudes of staff members about their role and work priorities. Furthermore, I observed that there was potential for assumptions to be made about patient understanding and their wishes for involvement of relatives. For many relatives with loved one's approaching end-of-life, information about their changing condition and involvement in their care is extremely important. Rather than detracting from the patient's autonomy, the involvement of relatives in accordance with the patient's wishes, can demonstrate an

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[67] See Chapter Seven, Section 7.2, p173-4 Bill Walker's quote.

understanding of the shared and distributed nature of decision-making and can help to preserve a sense of the patient's identity. Therefore, it is important to acknowledge the role of relatives and recognise their need for clear and explicit information about their loved one.

If the notion of relational autonomy is to be worked out in practice, staff need both awareness of the principle and organisational support to facilitate its practice. Staff need a shared and explicit understanding about what is expected of their role in informing relatives and an understanding of the values underpinning such care. Furthermore given the busyness and pressure of the ward environment, they will need organisational support in prioritising these aspects of care. It seems vital that staff also ask patients about who (relatives and/or close friends) they wish to receive information about their condition and care, and who should be involved in decisions about their care. This should be done early on in their admission and throughout their admission to ensure that the appropriate people are kept informed and involved according to the patient's wishes. Yet even when healthcare professionals discussed key information with patients and relatives I observed that at times they still held very different understandings of the same situation. How meaning is formed by patients, relatives and healthcare professionals will be further discussed in the next section.

9.5 Enabling a Shared Understanding

As outlined previously in Chapter Four, modern communication training focuses on skills attainment but often says little about how participants in a consultation come to understand information or form meanings about the situation in question. Yet as can be seen from the data in Chapter Eight, meanings of words are not fixed and making meaning is a dynamic social process involving subjective experiences, emotions and understanding. Differences in perspective of what equated to good care could vary, and when disagreements arose a failure by staff to see the perspective of patients or relatives could lead to conflict and distress[68]. Data analysis suggests that to care well at

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[68] See Chapter Eight, Section 8.3 p170-2, example of Marjorie and Anna Pringle.

end-of-life involves recognition of the perspectives of patients and relatives – their understanding, interpretation and values in a given situation.

It is apparent from the data in my research study and from the literature that communication involves subjective interpretations of language, situations and experience which leads to the formation of meaning. This helps to explain why it is possible for participants to have different understandings following participation in the same discussion (Haidet *et al.*, 1998; Fried *et al.*, 2003; Hancock *et al.*, 2007b). This was exemplified in the data on several occasions, for example on ward A when the doctors could not understand why Naomi Peters would not want her father to have medication to calm his distress[69]. On another occasion, a lack of shared understanding between the nurses on ward B and Marjorie Pringle, caused Marjorie to be very concerned about the care given to her mother at the end-of-life[70]. These examples highlight the importance of checking understanding on both sides. But they also emphasise the need to realise the potential for different perspectives and to try to empathise with others and see as others see in order to promote shared understanding. The formation of meaning is an active and ongoing process leading to the varied perspectives of patients, relatives and staff. Failure by staff to see the perspective of patients or relatives can lead to conflict and distress. Current practice, communication education and end-of-life care guidelines emphasise the importance of good communication. I argue that good communication is simply the means to achieving the real goal of shared understanding. It is a shared understanding that should be emphasised and sought after by healthcare professionals.

As has been suggested previously, language is not simply a neutral tool for describing different perspectives (Wetherell, 2001). Rather it has many roles in the formation of shared understanding: it works to formulate realities, it works to build rapport and relationships, it provides a medium for expressing moral concerns and values and it involves work (Taylor, 1985). However, awareness and discussion of these roles appears to go unrecognised in clinical practice. The skill and vital work of communication can be taken for granted or go completely unrecognised and unacknowledged. The time required for interactions with patients and relatives can be

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[69] See Chapter Eight, Section 8.3, p172-3

[70] See Chapter Eight, Section 8.3, p170

the source of frustration for staff working on busy hospital wards when the necessary communication is viewed as a 'quick update'. Communication between healthcare professionals, patients and relatives has both practical and ethical outputs. It is not simply the transfer of knowledge and information but demonstrates the values underpinning care. The data suggest that what is needed is behaviour and language that embodies the values that underpin good care. This will be further discussed in the next section.

9.6 Values Underpinning Resuscitation Decision-Making

In Chapter Seven I discussed the practice of decision-making at end-of-life. Resuscitation decisions were found to be a current area of difficulty for doctors. The fact that long-standing professional guidance is not always in step with the most recent legal rulings can make for challenges in the practice of medicine and this was clearly apparent in relation to resuscitation decisions. Practice often appeared to be driven by a fear of complaints, leading to delays in decision-making and had the potential to impact negatively on patient care[71]. Ongoing contention over whose decision resuscitation was and therefore how such a decision could or should be taken led to varied involvement of patients and relatives[72]. I found that staff often appeared to act according to their understanding of what was required to satisfy an external legal precedent or according to their own beliefs about whose decision it was rather than in line with considerations about how best to care for the patient.

While the Tracey verdict impacts on healthcare in the UK, van Heijst proposes that in modern healthcare in general, a '*procedural understanding of responsibility'* is increasing and that legal discourse is becoming more pronounced in practice (van Heijst, 2011, p. 751). She argues that because of this, moral and ethical discourse has diminished in significance: '*When the moral approach to dealing with conflicts is replaced by judicial interaction, the nature of communication changes profoundly. Professionals are forced to*

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[71] See Chapter Seven, Section 7.3.1, p155

[72] See Chapter Seven, Section 7.3.1., p155

take a defensive stance' (van Heijst, 2011, p. 154). Van Heijst suggests that in practice this can lead to a reluctance by healthcare professionals to be involved in the difficult and challenging aspects of patient care. This was seen to occur in the data. Though some doctors' accounts suggested that they continued to act according to their beliefs about what was best for the patient, others openly acknowledged that fear of complaints led them to delay decisions they would have otherwise made. In this way they did take a defensive stance, acting in order *not* to get a complaint[73]. On some occasions it appeared that moral debate and discussion about the right course of action were replaced by guidelines and legal precedents and the rationale for practice focused on how choices and decisions could be made with the least risk of complaint. While the defensive stance taken by some staff is understandable, it did not always lead to good care and on some occasions led to delayed decision-making and the potential for poor care. So how can healthcare professionals act to help ensure the provision of good care when making decisions at the end of life? This question will be discussed and unpacked in the following section.

9.7 Commitment to the Values Underpinning Good Care

Analysis of my own observations and patient and relative accounts suggest that good care involves regular interaction between patients, relatives and healthcare professionals in order to share information, elicit perspectives and provide an opportunity to contribute to decisions about treatment and care[74]. The analysis of data confirms what is shown by the literature: that being informed about their condition and being involved in decisions about their care is highly valued by many patients. And for patients, important decision-making includes decisions about medical treatments like medications and also decisions about their every day care on the ward. Patients gave varying descriptions of their involvement in decision-making but what appeared to be important was the process of discussion and interaction between staff and patients. This finding correlates with previous studies analysing patient perspectives on hospital

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[73] Chapter Seven, Section 7.3.1, p155 Dr Navy's account, p141 Dr Red's quote.

[74] See Chapter Seven, Sections 7.1, 7.2.

care at end-of-life, in which communication and decision-making are repeatedly mentioned as important aspects of care (Hancock *et al.*, 2007b; Parker *et al.*, 2007; Robinson *et al.*, 2014; Virdun *et al.*, 2015; Virdun *et al.*, 2016).

On wards A and B patients were generally positive about the information they received and their involvement in decision-making; however, I observed that the approaches to information giving and decision-making by staff varied as did patients' ability to receive and understand information. This highlighted the challenge faced by staff caring for patients at end-of-life whose desires and ability to be informed and involved in decision-making may fluctuate[75]. While less information from healthcare staff may appear paternalistic, it may also represent the acknowledgement by staff that too much information can be burdensome and that if this is the case, routine decisions should perhaps appropriately entail less discussion and involvement than complex ones. Yet sometimes the data suggested a lack of understanding and implementation of the principles of the MCA by staff[76]. What is key is that healthcare professionals work with patients to achieve a level of information-sharing and involvement in decision-making which is accord with their wishes and ability. Yet it appeared that patients who were less able to quickly express their views were sometimes given less time to do so and therefore may have felt less informed and involved in decision-making. This is perhaps one of the reasons that decision-making can be so challenging in the acute ward setting, where patients' conditions may change rapidly and there is pressure to get patients 'sorted out' quickly. This is a very difficult area to study as patients who are unwell and have fluctuating capacity are often unable to consent to participate in research. However, it is these patients who potentially receive the least information or involvement in their care. At end of their life patients' ability and desire for information and involvement in the decision-making process may vary. Therefore it is important for doctors to be committed to decision-making which will not unduly burden and tire patients, yet also seeks their involvement as far as possible and aims to keep central the patient's wishes.

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[75] See Chapter Seven, Section 7.1, p137 Sue Webster's quote.

[76] See Chapter 7, Section 7.1, p139 field notes about Enid and Dr Indigo, Section 7.2, p147 Jane Blackwell's quote.

The literature suggests that the information received by patients is often felt to be insufficient (Gaston and Mitchell, 2005; Hancock *et al.*, 2007b; Parker *et al.*, 2007). Yet some research suggests that a patient's need for information may change as their condition progresses, with a desire for less information while their relatives may want more (Parker *et al.*, 2007). The results of this study also suggest that a patient's preference for or ability to be involved in decision-making may be difficult to predict and may change over time. Sue Webster, a patient on ward A, described her own difficulty in taking part in decision-making because she felt 'spaced-out'[77]. On another occasion, the experience of Dr Red highlighted that it is not always clear how much a patient is able to understand[78]. Therefore, it is important for doctors to continually check patients' preferences, or attempt to do so. Even though their mental capacity may fluctuate, they may continue to be able to describe their preferences for information and involvement; and their preferences may change as their condition deteriorates.

The process of ongoing dialogue between patients, relatives and staff members is vitally important for the provision of good care. In healthcare today, we are obsessed with decisions, who makes them and how they are made. This thesis shows that the crucial thing for patients and relatives is involvement in ongoing dialogue. When this happens, the actual decisions do not take precedence and are made in the context of ongoing dialogue and shared understanding. When the dialogue is absent, the decision making process and individual decisions become the focus. Decision-making should be viewed as part of an ongoing dialogue in line with the patient's goals of care, rather than a response to a choice.

9.8   Study Limitations

The data in this thesis provides an in-depth account of end-of-life care on two acute medical wards in an English hospital. The process of observation combined with interview accounts from patients, relatives and staff provides a unique and detailed

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[77] See Chapter Seven, Section 7.1, p137

[78] See Chapter Seven, Section 7.3, p153-4

understanding of the realities and difficulties of end-of-life care in practice, as well as the values underpinning perspectives and practice. My role as clinician-researcher allowed me to understand the complex clinical discussions which took place on the ward. It also enabled me access to the wards, staff teams and to be part of formal and informal interviews with participants which may have been more frank and open because of my background as a doctor.

In Chapter Five I discussed the quality and value as well as the limitations of the qualitative approach used for this study. However, the methods of data collection and sampling in this study in particular have limitations which need to be acknowledged. First, with respect to data collection and sampling, this thesis highlights the difficulties of involving and gaining the perspectives of patients who are approaching the end-of-life. Patients who were physically well enough were usually happy to take part. However, patients who struggled with troublesome symptoms were often less willing and those with fluctuating mental capacity were more difficult to involve because of difficulties in ensuring informed consent. As has already been suggested in Chapter Four, prospective research with patients at end-of-life may be fundamentally biased because of the difficulty in capturing the perspectives of very unwell and dying patients. Because of this I tried to make myself available to speak informally with patients on the ward who wished to be involved but felt too unwell to participate in a formal interview. However, I acknowledge that I was unable to capture the perspectives of all patients approaching end-of-life, especially those who were most unwell. In regard to consent, throughout the process of data collection I was continually aware of the difficulty in determining how best to inform patients and gain consent in order to give them the opportunity to be involved without over-burdening them with excessive information. Though I used formal patient-information sheets, I found that each patient required an individual approach. Despite the clear potential for a bias in perspectives with this type of research, the perspectives and care of patients at end-of-life remain an important and needed area of study. By carrying out ward observation I was able to gain insights into the care received by patients who were too unwell to interview or share their perspectives informally.

While it was sometimes difficult to access the views of patients thought to be dying, I found that it could also be difficult to determine which patients were dying. As

previously discussed in this thesis, I found that healthcare professionals varied in their opinions about whether patients were or were not thought to be approaching the end-of-life. Furthermore, I found that it was not uncommon for patients who were thought to be dying to recover to eventually be discharged. In practice, I relied on the accounts of doctors as well as my own clinical experience and the willingness of patients when selecting who to interview. Therefore, though all patients interviewed had incurable conditions and were thought to be approaching the end-of-life, in reality they were at varying stages of their trajectory towards death and often did not die during their admission. Nonetheless they were involved in decisions about end-of-life care and provided their perspectives on the care received as they neared the end-of-life.

Finally this study included only two wards in one hospital in England. While it could be presumed that other acute medical wards in hospitals throughout England will face similar issues related to end-of-life care this cannot be assumed. Thus, some of the issues explored in this thesis may not be relevant on other wards, or may be different to those encountered on other wards.

9.9 Conclusion

In this chapter I have unpacked the concept of 'care' by discussing the main findings in light of the wider literature. I have built on the literature by applying both practical and philosophical approaches to the data, further demonstrating the complexity of care between the patient, relatives and healthcare team members on hospital wards. Here I present the main conclusions of the thesis. First, the data in this study particularly illuminates the challenges of delivering end-of-life care on hospital wards. Wards are busy places and may be inadequately staffed at times which can make it very difficult to provide good end-of-life care. It is here that the importance of teamwork and good relationships can be seen in facilitating care in the face of challenging circumstances. Yet the data also highlights that external influences (such as legal precedents, organisational structures, availability of resources) also have a weighty influence on the care received by patients at the end-of-life on hospital wards. This has helped to clarify a conception of care which in composed of many parts but also functions at all levels from the individual, to staff teams, to the wider NHS. This means that solutions required to

ensure good care will also have to focus on many different aspects of care and at all organisational levels (from individual ward staff members to NHS Trusts).

Second, the data in this study highlight the importance of values underpinning care. This was particularly illuminated by the practice of decision-making where varying values were evidenced about how a decision ought to be taken, whose decision it is and who ought to be informed and involved. The data suggest a potential conflict for staff in providing care, between respecting a patient's autonomy while also responding to relatives' need to be involved. I propose that the value of autonomy be complemented by that of relational autonomy at end-of-life and that this value can be embodied through the actions of staff in many varied ways on hospital wards. The data also highlights the importance of a healthcare rationale or value which prioritised 'care' over 'choice' and viewed decision-making as a process of ongoing dialogue rather than a single transaction. This is especially important for decision-making at end-of-life when patients' thinking may be impaired by medications, difficult symptoms such as pain, nausea and fatigue, yet they retain the ability and desire to be involved to some degree in the decision-making process. Knowing how much information and involvement is enough without being too much is extremely difficult and requires commitment to an ongoing process of discussion and dialogue which keeps the focus on the care of the patient rather than specific decisions.

Third, communication is a key component of care and therefore awareness of how language and meaning may work to enable shared understandings between patients, relatives and staff is extremely important. The data analysis describes interactions between participants and illuminates the complex reality of the roles of language as well as the work involved in making meaning in order to create a shared understanding. I propose the goal of discussion and dialogue in healthcare is not simply described as 'good communication'. Rather, good communication is recognised as that which seeks to establish and maintain a shared understanding between patients, relatives and healthcare professionals.

Finally, I have described the three main themes of this thesis, however, the data and discussion of the data has also been represented in the following three layers. First, discussion of the relevant philosophical positions and arguments provides a

philosophical basis for the rationale and values behind healthcare practice and recommendations for future practice. Second, the data provides a clear view of how end-of-life care actually happens in practice: the challenges and successes of clinical care on two acute hospital wards in England. Third, the data points to the importance of organisational structure and political issues which also work to influence and determine the care received by patients and their relatives. Recognition of each of these layers highlights the complexity behind the provision of good end-of-life care and also helps to identify potential solutions for managing current difficulties in end of life care.

Chapter 10   Recommendations from the Research

This research project has achieved the original aims and objectives set out at the start of this thesis. It aimed to explore end-of-life care in a hospital setting by achieving the following objectives: to observe and describe how end-of-life care and decision-making happen in practice; to explore the perspectives of patients approaching end-of-life, and the family members and/or close friends of patients approaching end-of-life in order to uncover their underlying values; to explore the perspectives of healthcare professionals providing end-of-life care in order to uncover their underlying values; and to identify areas of ethical difficulty within end-of-life care practice.

In the previous chapters the research findings and how they relate to relevant literature have been presented and discussed and conclusions made. However, both the data and discussion of the data raise further thoughts, ideas and questions about how end-of-life care on acute hospital wards can be improved. Here I present my own thoughts and recommendations about how the findings of this research project could be applied to clinical practice, policy and future research.

10.1.1 Recommendations for Clinical Practice

- While the environment and staffing levels are both key determinants of good care, the attitudes and values of staff remain vital. Core underpinning values such as relational autonomy and seeing the patient as a person, which were highlighted by patients and relatives as important for care, need to be explained to staff and modelled by senior clinicians on the wards. Drawing on philosophical and sociological literature, this thesis highlights that care must be effected in practice; it is not enough to simply tell someone to be more caring. Such values and good practice might best be taught to staff members through ward team simulation teaching sessions. Patient experience stories could be re-enacted (using actors or role play) in a training setting as a form of simulated teaching on values and caring in practice. Multidisciplinary team members could work together to consider how best to respond to the patient and relatives or indeed how they might feel if they were the patient or relative. Team reflection on this sort of training might provide greater

clarity and understanding of the key challenges faced by patients, relatives and staff in practice.

- There should be opportunities for staff to discuss the emotional impact of the care they provide. Schwartz rounds provide one example of how this kind of practice might be encouraged (The Point of Care Foundation, 2016). These events provide a structured way of discussing the emotional and social aspects and challenges of working in a healthcare setting.

- On some occasions there was clearly a need for greater numbers of staff on the wards. However, as highlighted by patients and relatives, these need not necessarily be trained staff nurses. At the end-of-life, a patient without relatives may need someone to help feed them or to simply sit with them. There is a need for extra help on the wards and this help could come from employing extra HCAs, from other staff members like nutritionists, or from trained volunteers. Having a clear policy on relatives coming in to assist patients would also enable relatives who wished, to provide their help. If patients approaching the end of their life need one-to-one care for any reason, and relatives do not wish to or are not able to provide the needed assistance, perhaps there is a need for a special care package for the patient while on the ward. Care packages are usually organised for patients with ongoing care needs on discharge and can include twenty four hour care where necessary. Sometimes when patients with intensive care needs are admitted to hospital, their carer comes too to maintain their provision of care. In reality, it is absurd for a patient in need of twenty four hour care to be admitted to a ward with two staff nurses for thirty patients. Perhaps such thoughts need to be considered for patients approaching end-of-life who require prolonged assistance and one-to-one care.

- Dialogue between patients, relatives and healthcare professionals must be prioritised in clinical practice. This must be modelled by senior clinical staff to their junior colleagues. But an environment that supports ongoing dialogue is also needed. Ideas include: longer visiting times, clinical diaries for patients and relatives to complete each day if they wish outlining their thoughts, concerns and questions about the care (McEvoy *et al.*, 2012), a booking system which relatives are made aware of and can use to make appointments to speak with senior staff.

- Communication training for healthcare professionals and students, which includes recognition of meaning as a dynamic process, may help to encourage good care at the

end-of-life by making staff and students aware of the importance of understanding the changing perspectives of patients and relatives, which may be very different from their own.

10.1.2 Recommendations for Policy and Professional Guidelines

- While I have highlighted some of the difficulties and limitations in collecting feedback from patients and relatives earlier in the thesis, the importance of gaining the perspectives of those receiving care is vital if care is to continually be improved. At the hospital where data collection took place a patient experience team were employed to carry out real-time patient experience surveys on the wards and feedback results to staff teams. This initiative provided timely feedback and the opportunity for staff teams to reflect on their own practice and make appropriate changes to improve care. However, this type of initiative is not consistent in other Trusts across the country. There is a need for a comprehensive, ongoing data collection programme which looks at the experiences of patients and relatives. It should be run by those unrelated to the clinical teams on the wards and collect anonymous data about the experiences of patients and their relatives. They should not simply be asked if they are satisfied with care, or whether they would recommend the ward to friends or family, but about their experiences on the ward, including: symptom control, personal care, staff attitudes (including respect and dignity), delivery of medication and treatments and communication and understanding between patients, relatives and staff. This feedback should be collected regularly and frequently (such as once per month) with rapid feedback to clinical teams. When feedback is poor or certain areas are consistently rated poorly, there should be opportunities for clinical teams to consider the causes of poor feedback and to develop their own strategies within the team for improving care. This type of service of course requires funding, yet I argue that such an investment is worthwhile if it can be shown to lead to sustained improvements in the experiences of patients and relatives. Therefore, evaluation of this type of initiative is also essential to provide data on its effectiveness.
- While current literature and professional guidelines emphasise the importance of SDM and communication, I argue instead that ongoing dialogue and establishing and

maintaining a shared understanding are the real priorities of end-of-life care. When dialogue is ongoing between patients, relatives and healthcare professionals, decisions become less stressful and occur more naturally. In contrast, when dialogue is absent, healthcare professionals focus on the decision-making process and the 'decision' as the end-point of that process becomes the most important thing. I recommend that professional guidelines change their emphasis so that while they encourage communication and SDM, they also acknowledge these as important components of ongoing dialogue, the purpose of which is to establish and maintain a shared understanding between patients, relatives and healthcare professionals.

10.1.3 Recommendations for Future Research

- Following on from the recommendations for policy and professional guidelines about collecting patient and relative experience data, future research could focus on evaluation of patient and relative experience surveys, how ward teams respond to feedback, and the longer term impact on patient care on the wards.

- The data repeatedly highlighted the importance of ongoing dialogue between patients, relatives and healthcare professionals. Future research could explore the attitudes of healthcare professionals to this finding and consider how such practice might best be encouraged and maintained on busy hospital wards.

- Too often professional guidelines and new legal precedents are out of step and clinical practice and understanding lag behind the most current legal precedents. External influences such as new legal precedents have important impacts on practice which deserve examination and analysis through ongoing evaluation and research.

Chapter 11   Conclusion

The history of end-of-Life care in the UK highlights the diverse influences that have worked to shape and determine how patients are cared for when dying in hospital today. The UK is regarded as the birthplace of modern day palliative care, an approach to care which has gained priority in governmental healthcare policy, healthcare funding and within NHS hospitals. Internationally, the UK is renowned for its provision of excellent end-of-life care (The Economist Intelligence Unit, 2015). Yet in recent years, complaints to the NHS Parliamentary Ombudsman, accounts from bereaved relatives and articles in the national press have highlighted concerns about the provision of end-of-life care on hospital wards (Office for National Statistics, 2014; PHSO, 2015).   Indeed concern in the national press about the LCP grew to such an extent that in 2013 it prompted an independent review of the document. This led to subsequent withdrawal of the LCP and new guidance on the practice of end-of-life care. Furthermore, concerns about resuscitation decision-making at end-of-life led to two Court of Appeal cases and new legal precedents related to resuscitation decisions. However, the perspectives of those directly involved in this care and how such practice actually occurs in light of the recent changes in policy remains unexplored.

This thesis has unpacked the concept of 'care' at the end-of-life. 'Care' is composed of many different component parts including the physical and metaphysical, objective and subjective aspects of patient need, which will vary for each individual and cannot be presumed. While barriers do exist to this kind of care on hospital wards, such care is facilitated when prioritised by staff who work as a team to provide it.

Decision-making at the end-of-life is an important component of care. The barriers to informing relatives include system-barriers as well as attitudinal barriers of staff members. The data suggest that choice and decisions *per se* are not the priority of patients and relatives. Rather the crucial thing for patients and relatives is involvement in ongoing dialogue. When this happens, the actual decisions do not take precedence and are made in the context of ongoing dialogue and shared understanding. When the dialogue is absent, the decision making process and individual decisions become the

focus. Decision-making should be viewed as part of an ongoing dialogue in line with the patient's goals of care rather than a response to a choice.

Communication is widely acknowledged to be an essential part of end-of-life care. Yet this term encompasses so many things and has been used so frequently that calls for better communication training often ring hollow. Language and meaning represent two important constituents of communication and the data was analysed in light of these concepts. Language has many roles: it works to help create realities, to build rapport and relationships, to provide a medium for expressing moral concerns and it involves work. Further effort is required in the formation of meaning - an active and ongoing process which leads to varied perspectives. Given the increasingly technologically complex world of clinical practice, careful use of language is essential for the identification and communication of the widely differing values present today. While current literature and professional guidelines emphasise the importance of SDM and communication, the data from this thesis suggests that ongoing dialogue and establishing and maintaining a shared understanding are the real priorities for patients and relatives.

This thesis presents new data on end-of-life care from the acute hospital setting by means of an ethnographic study. It encompasses both practical and philosophical approaches and thus provides a unique perspective on this area of care. It highlights current challenges in the provision of end-of-life care on hospital wards and considers how these can be understood. It demonstrates that care is composed of many parts, which require different types of interaction and engagement between patients, relatives and staff and that these components operate at many levels: from individual staff members, to wards, to NHS Trusts and to the wider NHS. If end-of-life care in hospitals is to be improved, strategies must consider the views of those directly involved (patients, relatives and healthcare professionals), the challenges of current end-of-life care provision, as well as the different components of care and the varied levels at which they operate.

Appendix A Glossary

A&E – The Accident and Emergency Department

BMA – British Medical Association

Bronchoscopy - an investigation used to visualise the main airways in the lungs in order to diagnose and treat certain lung conditions.

CCF – Congestive Cardiac Failure

CCG – Clinical Commissioning Group

CDP - Care of the Dying Patient document

COPD – Chronic Obstructive Pulmonary Disease

CPR - Cardiopulmonary Resuscitation

CT scan – Computed tomography scan

Diuretic – a drug to promote the production of urine

DNAR – Do Not Attempt Resuscitation

EBM – Evidence-Based Medicine

ECHR – European Convention on Human Rights

ECTP – Emergency Care and Treatment Plan

ECU – Emergency Care Unit

GI – Gastro-intestinal

GMC – General Medical Council

HCA – Healthcare Assistant

HCP – Healthcare professional

HDU – High Dependency Unit

ICU – Intensive Care Unit

Inotropes - Drugs to increase the strength of heart muscle contraction.

ITU – Intensive Care Unit

IV – intra-venous. In to the vein.

IVT – Intra-venous therapy. This means that IV fluid is given into the vein.

LACDP - Leadership Alliance for the Care of Dying People

LCP - Liverpool Care Pathway

MCA – Mental Capacity Act

MDT – Multi-disciplinary Team

Midazolam – A sedative Medication, a sedative medication commonly used for symptom control at end-of-life when patients appear distressed and agitated

NEWS – National Early Warning Score. Six physiological parameters form the basis of the score. These include the patient's respiratory rate, oxygen saturation level, temperature, blood pressure, pulse rate and level of consciousness.

NG Tube – Naso-gastric tube. A tube which runs from the nose to the stomach and can be used to feed patients with swallowing difficulties.

NHS – National Health Service

NICE – National Institute for Health and Care Excellence (Previously known as the National Institute for Clinical Excellence).

NIV - Non-Invasive Ventilation

NMC – Nursing and Midwifery Council

Obs – Observations. This refers to the routine checks that nurses conduct to measure a patient's blood pressure, heart rate, respiratory rate, temperature, level of consciousness, and oxygen level.

OT – Occupational Therapist

PCU – Palliative Care Unit

PHSO - the Parliamentary Health Service Ombudsman

PRN – As required

S/C – Sub-cutaneous

SDM – Shared decision-making

TEP – Treatment Escalation Plan

UFTO – Universal Form of Treatment Options

VBM – Values-Based Medicine

VOICES – National Survey of bereaved people in the UK

Appendix B Ward Poster

HOSPITAL WARD OBSERVATION STUDY

There is currently a research study taking place on this ward

What is the purpose of the research?

The researcher is interested in learning about how patients are cared for on this ward and how decisions are made about patient care.

The researcher is interested in learning about the perspectives of patients, their close family and friends and the healthcare staff.

What is the researcher doing?

The researcher will be present on the ward, observing the healthcare team in different situations. She may observe ward rounds, medication rounds or discussions between you and the team. The team will ask your permission before the researcher observes any aspect of your care. If you do not wish to be observed, please inform your healthcare team (the doctors and nurses looking after you).

The project specifically looks to see how decisions are made about patients' care.

The researcher may want to talk with you, or one of your close family members or friends as part of the study. In this case a member of the team looking after you will ask you whether the researcher may speak to you about this. You should feel entirely free to say no, in which case you would hear no more about it.

Further information and contact details

If you would like further information or would like to discuss any aspects of the study please contact the researcher (Dr Fiona MacCormick) whose contact details are listed below:

Dr Fiona MacCormick , Researcher

Institute of Health & Society, Newcastle University

Baddiley-Clark Building, Richardson Road,

Newcastle upon Tyne, NE2 4AX

Telephone: 07598854984

Email: f.maccormick@newcastle.ac.uk

Thank you in anticipation of any help you can give in this study!

Hospital Ward Observation Study v4 – 21/03/14

Appendix C General Information Sheet for Patients

Newcastle University

GENERAL INFORMATION SHEET FOR PATIENTS

HOSPITAL WARD OBSERVATION STUDY

Introduction:

There is currently a research project taking place on this ward. This information sheet is to let you know that there will be a researcher on the ward and what she will be doing. The researcher is interested in learning about how patients are cared for on this ward. As part of the project, the researcher will be spending time with the healthcare team (such as the doctors and nurses) who are looking after you. One of the important parts of the project is to learn more about how decisions are made when a patient's clinical condition is unstable. By watching how the team make decisions, we can learn more about how patients are cared for on the ward.

What is the researcher doing?

The researcher will be present on the ward, observing the healthcare team in different situations, such as ward rounds. The clinical team will ask your permission before the researcher observes any aspect of your care. The researcher may observe your care, and make notes about her observations. The project is particularly interested in how decisions are made about patient care on the ward. The researcher may want to talk with you as part of the study. In this case a member of the team looking after you would ask you whether the researcher may speak to you about this.

Do I have to take part?

If you do not wish to be observed, please feel free to inform your healthcare team (the doctors and nurses looking after you). One of your family members or friends can also speak to the healthcare team on your behalf. If you initially agree to take part, and then then take back your permission, the researcher will destroy any information she has collected related to that episode of observation. You should feel entirely free to say no, in which case you would hear no more about it. If you do not wish to take part in the study the researcher will not approach you. She might hear about your case, but will not record anything she hears. Any personal information will be kept confidential in the same way as it is by doctors and nurses.

Will my taking part be kept confidential?

The researcher will take written notes about the situations and discussions she sees while observing the team on the ward. When observing on the ward, the researcher will only record her own thoughts and observations. This data will be anonymised so that there will be no way of tracing the data back to you.

Can the researcher break confidentiality?

There are certain situations in which the researcher would break confidentiality. This would only take place if there was a criminal disclosure or if the researcher felt your safety or the safety of other people was at risk. She would only reveal the information necessary to prevent harm. We feel that breaking confidentiality is serious and it would only be done if absolutely necessary. The researcher would tell you why and what action she planned to take. Because this decision is important she would also speak to other members of the research team.

Can I speak to the researcher?

Yes. If you would like to know more about this research project, please contact the researcher. She will be on the ward frequently. The healthcare team can contact her for you or you can contact her directly as follows below:

Dr Fiona MacCormick, Researcher

Institute of Health & Society, Newcastle University, Baddiley-Clark Building, Richardson Road, Newcastle upon Tyne, NE2 4AX

Telephone: 07598854984

Email: f.maccormick@newcastle.ac.uk

You can also contact the Patient Advice and Liaison Service (PALS) if you have any questions or concerns about this study: Telephone: 0800 032 0202

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General Information Sheet for Patients v5 – 26/04/14

Appendix D Information Sheet for Family Members & Friends about an Individual Interview

Newcastle University

INFORMATION SHEET FOR FAMILY & FRIENDS ABOUT AN INDIVIDUAL INTERVIEW

HOSPITAL WARD OBSERVATION STUDY

Introduction

We wish to invite to you to take part in a research study. The study is looking at how patients are cared for on the ward. Before you decide whether to take part, you need to understand what the research is about and what it would mean for you to be involved. Please take some time to read the following information. Ask others about the research if you would like to.

Part 1: tells you some details about the study, why we have invited you to be involved and what would happen to you if you do take part.

Part 2: gives you some more details about the conduct of the study. Please ask the researcher if there is anything that is not clear in this information sheet. Take your time to decide whether or not you would like to take part.

Part 1

What is the purpose of the study?

The purpose of this research is to gain a deeper understanding of how decisions are made in practice when patients are being cared for on the ward. One of the important parts of the project is to learn more about how decisions are made when a patient's clinical condition is unstable. It aims to explore the perspectives of patients, their family members and close friends, and staff members; and to identify any areas of confusion and difficulty in the care of patients. We hope that this research will help us to better understand how to meet the needs of patients.

Why have I been invited?

You have been invited to participate because you are a family member or close friend of a patient on one of the wards selected for the research project.

Do I have to take part?

No, your participation is completely voluntary. If you do not wish to take part, please feel free to inform the researcher or a member of the healthcare team. If you do decide to take part, you are still free to withdraw at any time without giving reasons. A decision not to take part or to withdraw will not affect your legal rights or the medical care of your family member or friend on the ward. If you do decide to take part, you will be given this information sheet to keep.

What will happen if I take part?

The researcher will ask you to take part in an individual interview and will give you this information sheet to read through. If you decide you would like to take part, the researcher will ask you when you

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would like to have the interview, and will plan a convenient time with you. When you next meet the researcher, you will be asked to sign a consent form. The researcher will then interview you about your experience of care on the ward. The interview is designed to ask you about how treatment decisions have been made, how involved you felt and how things could be improved. You can say as much or a little as you would like. The interview will last about an hour. The interview will be audio recorded and typed up word for word, but participant identifiable information (such as your name) will be removed. Written notes will also be taken at the time. The recording will be erased once it is typed up. All the information collected will be kept strictly confidential. Computerised data will be stored on password protected computers and written data will be stored in a locked filling cabinet in a locked office.

What are the possible disadvantages of taking part?

Taking part in this study will not affect your loved ones care in any way. You are being asked to give about an hour (or less) of your time. It is possible that you will find talking about these issues to be upsetting. If you feel like this you may wish to stop the interview.

What are the possible benefits of taking part?

There are no direct benefits to you of taking part, but we hope the findings from the study will help us to get a better understanding of how best to care for patients in hospital, which may lead to improved patient care in the future.

What if there is a problem?

If you have any complaint about the way you have been treated during the study or are upset in any way please inform the researcher and this will be addressed. Detailed information about this is given in Part 2.

Will my taking part in this study be kept confidential?

Yes. All of the information about you will be kept confidential to the study team. The details are included in Part 2.

If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

Part 2

What will happen if I don't want to carry on with the study?

If you want to stop taking part in the study, you can do this at any time and it will not affect the care of your loved one. You don't have to give a reason for wanting to stop taking part. The information that we have collected will still be used, unless you ask us not to use it.

More information about what you can do if there is a problem.

If you have a concern or complaint about any aspect of this study you should contact Dr Fiona MacCormick (researcher) or one of the research team via the contact details below. The NHS operated Patient Advice and Liaison Service (PALS) can also provide guidance with any complaints or

Information Sheet for Family & Friends about an Individual Interview v5 – 26/04/14

concerns by phone on 0800 032 0202, Text/SMS: 01670511098 or by email northoftynepals@nhct.nhs.uk

More information about confidentiality

Any information which is collected about you during the interview will be kept strictly confidential, and will have details such as your name removed. Your comments cannot be identified or traced back to you personally. The research data may be looked at only by members of the research team or by representatives of regulatory authorities - to check that the study is being carried out correctly. All share the same duty of confidentiality to you as a research participant.

Can the researcher break confidentiality?

There are certain situations in which the researcher would break confidentiality. This would only take place if there was a criminal disclosure or if the researcher felt your safety or the safety of other people was at risk. She would only reveal the information necessary to prevent harm. We feel that breaking confidentiality is serious and it would only be done if absolutely necessary. The researcher would tell you why and what action she planned to take. Because this decision is important she would also speak to other members of the research team. Any detection of poor clinical practice would be dealt with according to standard procedures.

What will happen to the results of the study?

The data will be used towards a PhD qualification for the researcher and may be presented and published in academic journals. Published work may contain summary information or quotes, but no names or initials will be used so that you cannot be identified.

Who is organising and funding the research?

The study is being undertaken as part of Dr Fiona MacCormick's PhD at Newcastle University. The funding is from Northumbria Healthcare NHS Foundation Trust.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people called a Research Ethics Committee. This ensures that your safety, rights, wellbeing and dignity are protected. This study has been reviewed and approved by the Newcastle & North Tyneside 1 Ethics Committee.

Further information and contact details

If you would like further information or would like to discuss any aspects of the study please contact the researcher (Fiona MacCormick) or the other members of the research team whose contact details are listed overleaf:

Dr Fiona MacCormick, Researcher

Institute of Health & Society, Newcastle University, Baddiley-Clark Building, Richardson Road, Newcastle upon Tyne, NE2 4AX

Telephone: 07598854984   Email: f.maccormick@newcastle.ac.uk

Dr Paul Paes, Consultant in Palliative Medicine and Honorary Senior Lecturer

Palliative Care Unit, North Tyneside General Hospital, North Shields, Tyne and Wear

Telephone: 0191 235 4904   Email: Paul.Paes@newcastle.ac.uk

Professor Julian Hughes, Consultant in Old Age Psychiatry and Honorary Professor

North Tyneside General Hospital, North Shields, Tyne and Wear, NE29 8NH

Telephone: 0191 293 4057   Email: Julian.Hughes@newcastle.ac.uk

Dr Catherine Exley, Senior Lecturer in Medical Sociology

Institute of Health and Society, Newcastle University, Baddiley-Clark Building, Richardson Road, Newcastle upon Tyne, NE2 4AX

Telephone: 0191 222 7045   Email: Catherine.Exley@newcastle.ac.uk

You can also contact the Patient Advice and Liaison Service (PALS) if you have any questions or concerns about this study: Telephone: 0800 032 0202

Thank you in anticipation of any help you can give in this study.

Appendix E Information Sheet for Patients about Individual Observation and an Individual Interview

![Newcastle University logo]

INFORMATION SHEET FOR PATIENTS ABOUT INDIVIDUAL OBSERVATION AND AN INDIVIDUAL INTERVIEW

HOSPITAL WARD OBSERVATION STUDY

Introduction

We wish to invite to you to take part in a research study. The study is looking at how treatment decisions are made about your care while you are on the ward. Before you decide whether to take part, you need to understand what the research is about and what it would mean for you to be involved. Please take some time to read the following information. Ask others about the research if you would like to.

Part 1: tells you some details about the study, why we have invited you to be involved and what would happen to you if you do take part.

Part 2: gives you some more details about the conduct of the study. Please ask the researcher if there is anything that is not clear in this information sheet. Take your time to decide whether or not you would like to take part.

Part 1

What is the purpose of the study?

The purpose of this research is to gain a deeper understanding of how decisions are made in practice when patients are being cared for on the ward. One of the important parts of the project is to learn more about how decisions are made when a patient's clinical condition is unstable. It aims to explore the perspectives of patients, their family members and close friends, and staff members; and to identify any areas of confusion and difficulty in the care of patients. We hope that this research will help us to better understand how to meet the needs of patients.

Why have I been invited?

You have been invited to participate because you are a patient on one of the wards selected for the research project.

Do I have to take part?

No, your participation is completely voluntary. If you do not wish to take part, please feel free to inform your healthcare team (the doctors and nurses looking after you). One of your family members or friends can also speak to the healthcare team on your behalf. If you do decide to take part, you are still free to withdraw at any time without giving reasons. A decision not to take part or to withdraw will not affect your legal rights or medical care on the ward. If you do decide to take part, you will be given this information sheet to keep and read through.

What will happen if I take part?

The researcher will ask you if you would be willing to take part in this research project. You can

Information Sheet for Patients about Individual Observation and an Individual Interview v5 – 26/04/14

participate in this research in two ways as outlined below:

First, the researcher will ask your permission for her to more closely observe your care on the ward. For example, she may wish to observe your discussions with the doctors or nurses. If you agree to this individual observation, the researcher will ask you to sign a consent form. Even if you agree to this, the researcher will always seek your permission before any observation on the ward, and you would be completely free to withdraw your permission at any time.

Second, the researcher will ask you to take part in an individual interview. If you decide you would like to take part, the researcher will ask you when you would like to have the interview, and will plan a convenient time with you. When you next meet the researcher, you will be asked to sign a consent form. The researcher will then interview you about your experience of care on the ward and your decisions about your treatment. The interview is designed to ask you about the treatment decisions that have been made, how involved you felt and how things could be improved. You can say as much or a little as you would like. The interview will last about an hour. The interview will be audio recorded and typed up word for word. Written notes will also be taken at the time. All participant-identifiable information will be removed from the transcript. The recording will be erased once it has been analysed. All the information collected will be kept strictly confidential. Computerised data will be stored on password protected computers and written data will be stored in a locked filling cabinet in a locked office.

It is possible simply to take part in the observation part of the study even if you do not wish to take part in an interview.

What are the possible disadvantages of taking part?

Taking part in this study will not affect your care in any way. You are being asked to allow the researcher to observe your care and to give about an hour (or less) of your time for an interview. It is possible that you will find talking about your care and treatment decisions to be upsetting. If you feel like this you may wish to stop the interview.

What are the possible benefits of taking part?

There are no direct benefits to you of taking part, but the findings from the study will help us to get a better understanding of how to care for patients in hospital, which may lead to improved patient care in the future.

What if there is a problem?

If you have any complaint about the way you have been treated during the study or are upset in any way please inform the researcher and this will be addressed. Detailed information about this is given in Part 2.

Will my taking part in this study be kept confidential?

Yes. All of the information about you will be kept confidential to the study team. The details are included in Part 2. If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

Information Sheet for Patients about Individual Observation and an Individual Interview v5 – 26/04/14

Part 2

What will happen if I don't want to carry on with the study?

If you want to stop taking part in the study, you can do this at any time and it will not affect the standard of care that you receive. You don't have to give a reason for wanting to stop taking part. The information that we have collected will still be used, unless you ask us not to use it.

More information about what you can do if there is a problem.

If you have a concern or complaint about any aspect of this study you should contact Dr Fiona MacCormick (researcher) or one of the research team via the contact details below. The NHS operated Patient Advice and Liaison Service (PALS) can also provide guidance with any complaints or concerns by phone on 0800 032 0202, Text/SMS: 01670 511098 or by email northoftynepals@nhct.nhs.uk

More information about confidentiality

Any information which is collected about you during the observation or interview will be kept strictly confidential, and will have details such as your name removed. Your comments cannot be identified or traced back to you personally. The research data may be looked at only by members of the research team or by representatives of regulatory authorities - to check that the study is being carried out correctly. All share the same duty of confidentiality to you as a research participant.

Can the researcher break confidentiality?

There are certain situations in which the researcher would break confidentiality. This would only take place if there was a criminal disclosure or if the researcher felt your safety or the safety of other people was at risk. She would only reveal the information necessary to prevent harm. We feel that breaking confidentiality is serious and it would only be done if absolutely necessary. The researcher would tell you why and what action she planned to take. Because this decision is important she would also speak to other members of the research team. Any detection of poor clinical practice would be dealt with according to standard procedures.

Do I need to tell my General Practitioner (GP) if I decide to take part?

No, this will not be necessary as your involvement simply requires ward observation and/or an interview. Your treatment will not be affected in any way by taking part in the study.

What will happen to the results of the study?

The data will be used towards a PhD qualification for the researcher and may be presented and published in academic journals. Published work may contain summary information or quotes, but no names or initials will be used so that you cannot be identified.

Who is organising and funding the research?

The study is being undertaken as part of Dr Fiona MacCormick's PhD at Newcastle University. The funding is from Northumbria Healthcare NHS Foundation Trust.

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Who has reviewed the study?

Ethical review of this study has been conducted by the Newcastle & North Tyneside 1 Research Ethics Committee.

Further information and contact details

If you would like further information or would like to discuss any aspects of the study please contact the researcher (Fiona MacCormick) or the other members of the research team whose contact details are listed below:

Dr Fiona MacCormick, Researcher

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Dr Catherine Exley, Senior Lecturer in Medical Sociology

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Telephone: 0191 222 7045   Email: Catherine.Exley@newcastle.ac.uk

You can also contact the Patient Advice and Liaison Service (PALS) if you have any questions or concerns about this study: Telephone: 0800 032 0202

Thank you in anticipation of any help you can give in this study.

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Information Sheet for Patients about Individual Observation and an Individual Interview v5 – 26/04/14

Appendix F Information Sheet for Staff Members

INFORMATION SHEET FOR STAFF MEMBERS

HOSPITAL WARD OBSERVATION STUDY

Introduction:

We would like to invite you to take part in a research project on this ward. In order to decide if you want to take part it is important that you understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. You can ask the researcher questions and talk it over with others if you wish.

Background:

A research project will be taking place to observe how decisions are made and care is delivered on the ward. The researcher is particularly interested in the care of patients whose clinical condition is unstable. The researcher hopes to learn about the views of clinical staff members, patients, and their family members and close friends. During this research project, the researcher (Dr Fiona MacCormick) will spend time on the ward observing different episodes of care such as ward rounds, MDTs, staff handovers and drug rounds. The researcher may also invite certain patients, their family members and/or close friends, and staff members to be interviewed.

What is the purpose of this study?

The purpose of this research is to gain a deeper understanding of how decisions are made in practice when patients are deteriorating and may not improve. It aims to explore the perspectives of patients, their significant others and staff members; and to identify any areas of confusion and difficulty in the care of patients. We hope that this research will help us to better understand how to meet the needs of patients who may be approaching end of life.

What will the researcher be doing?

Observation

The researcher will be present on the ward and hopes to observe different clinical activities such as ward rounds, MDTs, drug rounds and staff handovers. She is not present to criticise or praise the way the team make decisions, rather she hopes to observe what takes place on the ward while causing

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minimal interference or distraction to the team. The researcher will ask permission from a member of the team prior to observing any ward activity. She may also ask you if you think a patient would be appropriate to participate in part of the study, such as an individual interview. If you felt a patient would be well enough to take part in an interview, the researcher may ask you to approach the patient and ask if she could talk to them about the interview.

The only circumstance in which the researcher would offer any opinion about patient care would be if she felt there was a risk of harm to a patient.

During the ward observation, the researcher may make notes about how the team make decisions. She will not record any person identifiable information about patients, their family members or close friends, or staff. She may record her thoughts and impressions in a note pad.

If any staff member does not wish to be observed during a specific activity, the researcher will refrain from observing that specific activity and will not make any notes about the staff member in question. If a staff member does not wish to have any involvement in the research project, the researcher will refrain from observing their actions on the ward, will not make notes about their activity on the ward, and will not approach the staff member with queries related to the research project.

Individual Interviews

The researcher will seek to interview patients who may be approaching end of life. The purpose of these interviews is to explore the patient's thoughts and feelings about their condition and their experience on the ward. She may also seek to interview the family members or close friends of patients. The interviews will take place on the ward or another room in the hospital, wherever was the most appropriate for the participant. Each patient and family member or friend would only be interviewed once during their in-patient stay.

The researcher may also seek to interview you if you are involved in caring for a patient who is deteriorating and may not recover. She would be keen to hear about your thoughts and opinions about how decisions had been made while caring for this patient. She may also ask you about your experiences of caring for patients who may be approaching end of life. Participation in an interview is not compulsory, and you are under no obligation to participate. If you did wish to consider taking part in an interview, full details would be provided to you.

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Do I have to take part?

No. You do not have to take part in the ward observation or in an individual interview. If you do not wish to take part, please inform the researcher or a senior staff member. If the researcher asks you to take part in an interview you are under no obligation to agree. Prior to an interview, the researcher would need your full written and verbal consent before the interview could go ahead.

If you have any concerns about this research project please inform the researcher or the ward manager, who would then inform a member of the research team. Raising concerns or wishing not to participate will not affect the terms of your employment or your relationship with the Trust in any way. You have a right to do this.

Who can I discuss the project with?

We are keen to hear your thoughts about this research project. If you would like to speak to a member of the research team please contact them on the details provided in this information sheet.

What if there is a problem?

We want to conduct this research in the best way possible and we are keen to hear any suggestions you may have. If you are unhappy about any aspect of the research please contact the research team and this will be addressed. Please feel free to contact a member of the research team via the contact details provided in this information sheet.

What will happen to the information gathered through observation and interviews?

The data gathered will be analysed by the researcher and members of the research team. Some of the data may include comments made by patients, their family members and close friends, and staff. However, all data will be anonymised so that individuals will not be identifiable from the results. The data will be anonymised and written down word for word (transcribed) and the recording will be erased once it has been analysed. All the information collected will be kept strictly confidential. Computerised data will be stored on password protected computers and written data will be stored in a locked filling cabinet in a locked office.

What will happen to the results of the research study?

The data will be used towards a PhD qualification for the researcher and may be presented and

published in academic journals. Published work may contain summary information or quotes, but no names or initials will be used so that you cannot be identified.

Will my taking part be kept confidential?

The researcher will take written notes about the situations and discussions she sees while observing the team on the ward. When observing on the ward, the researcher will only record her own thoughts and observations. This data will be anonymised so that there will be no way of tracing the data back to you.

Can the researcher break confidentiality?

There are certain situations in which the researcher would break confidentiality. This would only take place if there was a criminal disclosure or if the researcher felt your safety or the safety of other people was at risk. She would only reveal the information necessary to prevent harm. We feel that breaking confidentiality is serious and it would only be done if absolutely necessary. The researcher would tell you why and what action she planned to take. Because this decision is important she would also speak to other members of the research team. Any detection of poor clinical practice would be dealt with according to standard procedures.

Who is organising and funding the research?

The study is being undertaken as part of Dr Fiona MacCormick's PhD at Newcastle University. The funding is from Northumbria Healthcare NHS Foundation Trust.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people called a Research Ethics Committee. This ensures that your safety, rights, wellbeing and dignity are protected. This study has been reviewed and approved by the Newcastle & North Tyneside 1 Ethics Committee.

Further information and contact details:

If you would like further information or would like to discuss any aspects of the study please contact the researcher (Dr Fiona MacCormick) or the other members of the research team whose contact details are listed overleaf:

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Dr Fiona MacCormick, Researcher

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Thank you in anticipation of any help you can give in this study.

Appendix G Information Sheet for Staff Members about an Individual Interview

INFORMATION SHEET FOR STAFF MEMBERS ABOUT AN INDIVIDUAL INTERVIEW

HOSPITAL WARD OBSERVATION STUDY

Introduction

We wish to invite to you to take part in a research study. The study is looking at how treatment decisions are made for patients whose clinical condition is unstable. Before you decide whether you would like to take part, you need to understand what the research is about and what it would mean for you to be involved. Please take some time to read the following information. Ask others about the research if you would like to.

Part 1: tells you some details about the study, why we have invited you to be involved and what would happen to you if you do take part.

Part 2: gives you some more details about the conduct of the study. Please ask the researcher if there is anything that is not clear in this information sheet. Take your time to decide whether or not you would like to take part.

Part 1

What is the purpose of the study?

The purpose of this research is to gain a deeper understanding of how decisions are made in practice when a patient's clinical condition is unstable. It aims to explore the perspectives of patients, their family members and close friends, and staff members; and to identify any areas of confusion and difficulty in the care of patients. We hope that this research will help us to better understand how to meet the needs of patients.

Why have I been invited?

You have been invited to take part in an individual interview because you have been involved in caring for patients on the ward whose clinical condition has been unstable.

Do I have to take part?

No, your participation is completely voluntary. If you do not wish to take part, please feel free to speak to the researcher or inform a senior member of staff. If you do decide to take part, you are still free to withdraw at any time without giving reasons. A decision not to take part or to withdraw will not affect your legal rights or employment on the ward. If you do decide to take part, you will be given this information sheet to keep.

What will happen if I take part?

The researcher will ask you to take part in an individual interview and you will be given this information sheet about the interview. When you meet the researcher, you will be asked to sign a consent form. The researcher will then interview you about your experience of caring for patients on

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the ward and your involvement in decisions about treatment. The interview is designed to ask you about the treatment decisions that have been made, how involved you felt and how things could be improved. You can say as much or a little as you would like. The interview will last about an hour. The interview will be audio recorded and typed up word for word, but participant identifiable information (such as your name) will be removed. Written notes will also be taken at the time. The recording will be erased once it has been analysed. All the information collected will be kept strictly confidential. Computerised data will be stored on password protected computers and written data will be stored in a locked filling cabinet in a locked office.

What are the possible disadvantages of taking part?

Taking part in this study will not affect your role on the ward in any way. You are being asked to give about an hour (or less) of your time. It is possible that you will find talking about your experiences of caring for unwell patients to be upsetting. If you feel like this you may wish to stop the interview.

What are the possible benefits of taking part?

There are no direct benefits to you of taking part, but we hope that the findings from the study will help us to get a better understanding of how best to care for patients in hospital, which may lead to improved patient care in the future.

What if there is a problem?

If you have any complaint about the way you have been treated during the study or are upset in any way please speak to the researcher and this will be addressed. Detailed information about this is given in Part 2.

Will my taking part in this study be kept confidential?

Yes. All of the information about you will be kept confidential to the study team. The details are included in Part 2. If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

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Part 2

What will happen if I don't want to carry on with the study?

If you want to stop taking part in the study, you can do this at any time and it will not affect the standard of care that you receive. You don't have to give a reason for wanting to stop taking part. The information that we have collected will still be used, unless you ask us not to use it.

More information about what you can do if there is a problem.

If you have a concern or complaint about any aspect of this study you should contact Dr Fiona MacCormick or a member of the research team by telephone or in writing via the contact details below.

More information about confidentiality

Any information which is collected about you in the form of interview transcriptions will be kept strictly confidential, and will have details such as your name removed. Your comments cannot be identified or traced back to you personally. The research data may be looked at only by members of the research team or by representatives of regulatory authorities - to check that the study is being carried out correctly. All share the same duty of confidentiality to you as a research participant.

Can the researcher break confidentiality?

There are certain situations in which the researcher would break confidentiality. This would only take place if there was a criminal disclosure or if the researcher felt your safety or the safety of other people was at risk. She would only reveal the information necessary to prevent harm. We feel that breaking confidentiality is serious and it would only be done if absolutely necessary. The researcher would tell you why and what action she planned to take. Because this decision is important she would also speak to other members of the research team. Any detection of poor clinical practice will be dealt with according to standard procedures.

What will happen to the results of the study?

The data will be used towards a PhD qualification for the researcher and may be presented and published in academic journals. Published work may contain summary information or quotes, but no names or initials will be used so that you cannot be identified.

Who is organising and funding the research?

The study is being undertaken as part of Dr Fiona MacCormick's PhD at Newcastle University. The funding is from Northumbria Healthcare NHS Foundation Trust.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people called a Research Ethics Committee. This ensures that your safety, rights, wellbeing and dignity are protected. This study has been reviewed and approved by the Newcastle & North Tyneside 1 Ethics Committee.

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Information Sheet for Staff Members about an Individual Interview v5 – 26/04/14

Further information and contact details

If you would like further information or would like to discuss any aspects of the study please contact the researcher (Fiona MacCormick) or the other members of the research team whose contact details are listed below:

Dr Fiona MacCormick (researcher)

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Dr Paul Paes, Consultant in Palliative Medicine and Honorary Senior Lecturer

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Professor Julian Hughes, Consultant in Old Age Psychiatry and Honorary Professor

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Telephone: 0191 293 4057   Email: Julian.Hughes@newcastle.ac.uk

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Thank you in anticipation of any help you can give in this study.

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Appendix H Topic Guide for Individual Interviews with Patients, Family Members and Friends

Note: The topic guide is developmental. The questions will need to be tailored to the specific answers of each interviewee. The topic guide given here is therefore a general guide for the individual qualitative interviews.

1. Introduction
- Introduce self
- Explain purpose of the study and this interview:
    - We're interested in people's views and experience of care on the ward
    - How decisions are made
    - No right or wrong answers – not a test of your knowledge
- Consent – written, because this is extra to standard care.
- Explain interview recorded but details will be confidential. If the interview raises any issues of concern regarding health and safety these will be raised with senior ward staff and the research supervisory team.
- Questions or concerns?

2. Care on the ward
- What do you think of the **experience** you/your (partner/relative/friend) have/has had on the ward?
    - Communication
    - Eating and drinking
    - Personal care
    - Medication
- What was done well?
- What could have been done better?
- What are the key aspects of care that were important to you and/or your spouse/friend/relative?
- Are there any other aspects of care you would like to talk about?
- Do you have any concerns, problems or difficulties about the care here?

3. Decisions about care
- Have you been involved in decisions about your care or the care of your partner/relative/friend on the ward?
- If not, would you have liked to be?
- If yes, which decisions have you been involved in?
- Were there any decisions you found particularly difficult?
- What made these decisions [specify individual decisions if possible] difficult?
- [If ethical decisions not identified as such]: What made the decisions worrying?
- [If ethical decisions not identified as such]: Were they decisions about what might be the right thing or the wrong thing to do? Or, were they decisions about what was good or bad about what was happening or what was planned?
- How did you feel having to make decisions about what was right or wrong, good or bad?
- Were the decisions made in a way that you thought was right/good? Or were they made in a way that seemed wrong or bad?
- Were the decisions themselves good or bad, right or wrong?
- Do you have any concerns about decisions that might be taken in the near future?

4. Current needs
- How are you doing?

- Is there anything that you're finding particularly difficult at the moment?
  - Is that something you've tried to get help with?
  - If yes, what happened?
  - If not, why haven't you tried to get help?

5. Any further questions/comments and conclude interview
- Thank participant
- Check they are still happy for their information to be used in the study

Appendix I   Topic Guide for Individual Interviews with Staff Members

Note: The topic guide is developmental. The questions will need to be tailored to the specific answers of each interviewee. The topic guide given here is therefore a general guide for the individual qualitative interviews.

1. Introduction
- Introduce self
- Explain purpose of the study and this interview:
  - We're interested in the views staff members about the care of patients who have unstable clinical conditions
  - How decisions are made
  - No right or wrong answers – not a test of your knowledge
- Consent – written, because this is extra to standard care.
- Explain interview recorded but details will be confidential. If the interview raises any issues of concern regarding health and safety, these will be raised with senior staff and the research supervisory team.
- Questions or concerns?

2. Care on the ward
- Have you experience of caring for unstable patients who may be dying? If yes, can you tell me about it?
- Do you feel prepared to care for patients who may be dying?
- Can you recall any particular people or events that have influenced the way you care for people who are dying? What did you learn from this?
- How did this change/inform your practice?
- How do you find caring for patients who are unstable?
- What is done well?
- What could be done better?
- Are there any aspects of the care you provide that you find particularly difficult?
- Are there any other aspects of your role you would like to talk about?

3. Decisions about care
- How are decisions made in patients with unstable clinical conditions?
- Are you involved in the decision making process?
- If no, would you like to be?
- If yes, which decisions have you been involved in?
- Were there any decisions you found particularly difficult?
- What made these decisions [specify individual decisions if possible] difficult?
- [If ethical decisions not identified as such]: What made the decisions worrying?
- [If ethical decisions not identified as such]: Were they decisions about what might be the right thing or the wrong thing to do? Or, were they decisions about what was good or bad about what was happening or what was planned?
- How did you feel having to make decisions about what was right or wrong, good or bad?
- Were the decisions made in a way that you thought was right/good? Or were they made in a way that seemed wrong or bad?
- Were the decisions themselves good or bad, right or wrong?
- Do you have any concerns about decisions that might be taken in the near future?

4. Current needs
- Is there anything that you find particularly difficult when caring for unstable patients?
  - Is that something you've tried to get help with?
  - If yes, what happened?

      o   If not, why haven't you tried to get help?

5. Any further questions/comments and conclude interview
- Thank participant
- Check they are still happy for their information to be used in the study

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