Decisions about Feeding after Stroke

Thesis submitted in accordance with the requirements of the University of Liverpool for the degree of Doctor in Philosophy by Heulwen Lisa Sheldrick.

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DECLARATION

This thesis is the result of my own work. The material contained in the thesis has not been presented, nor is currently being presented, either wholly or in part for any other degree or other qualification.

Abstract

Decisions about Feeding after Stroke

Heulwen Lisa Sheldrick

In the acute stages of stroke where the patient experiences dysphagia or reduced levels of consciousness, clinicians make decisions on how a patient's food and fluid needs will be met. These decisions include whether the patient should take oral diet, or whether nutrition should be administered via a Nasogastric (NG) or Percutaneous Endoscopic Gastrostomy (PEG) tube. This qualitative study investigates the process by which clinicians make decisions over the timing and mode of nutrition or hydration interventions available to them.

Data were collected from twenty patient participants and twenty-four clinicians from two NHS Trusts. The patient data comprised both clinical case note data and observational data taken from clinical discussions on the ward during their admission. In-depth interviews were undertaken with clinicians to explore their experiences and views on decision making for nutrition and hydration. The data were analysed to generate substantive theory following the principles of grounded theory.

The findings suggest that the decision making process follows a normative pathway of 'not to feed' the patient which is based on three key beliefs. These were that; nutrition and hydration were viewed as distinct and different interventions, with nutrition not being considered essential to recovery after stroke; the risk of pulmonary aspiration was perceived to outweigh the benefits of providing nutrition; and, that nutritional interventions could prolong a poor Quality of Life for a patient.

Deviation from this normative pathway by clinicians was influenced by four key themes; views about the patient's prognosis; beliefs about the nutrition and hydration interventions available; perceived responsibilities of those involved; and, personal conscience issues. The findings from the study are discussed in the context of clinical practice and the implications for future research.

Acknowledgments

I am indebted to so many people for supporting me through this process. It's been a marathon, and the training and support team must be acknowledged.

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The last word of thanks is the most important and goes to the main inspiration - all of the participants in this study. Thanks to the patients and relatives who allowed insights into their experiences at an extremely difficult time in their lives and to the clinicians who contributed both their time and honesty throughout.

‘Grub first, then ethics….’

Bertolt Brecht

German Communist & dramatist (1898 - 1956)

The origins of the research question

It was a day like any other.
Eight new referrals had come through to the Speech and Language Therapy department, and I was on the wards, steadily working my way through seeing the new patients who had been referred for a swallowing assessment.
Two cases, one after the other increased my frustration, but also my curiosity.

Mrs F – was a 73 year old woman
Admitted to hospital with a suspected stroke six days previously. She had a marked right sided hemiparesis, difficulty communicating and reduced consciousness. Mrs F was lying in bed, drowsy, but intermittently alert. Medical staff had advised that non-oral feeding would not be appropriate for Mrs F, and advised nursing staff to let Mrs F eat and drink when alert. Nursing staff had requested a formal swallowing assessment before giving her any oral intake.

Mr W – a 69 year old man
Admitted to hospital with a suspected stroke four days previously. He has a marked right sided hemiparesis, difficulty communicating and reduced consciousness. Mr W was lying in bed, drowsy, but intermittently alert. Medical staff had advised that a formal swallowing assessment from Speech and Language Therapy was required, after which a Nasogastric Tube should be placed if he could not take oral diet.

The parallels in these cases were remarkable.
Why were the plans and decisions about feeding so different?
Through the weeks and months that followed, these scenarios were replicated in various forms, with varying outcomes.
The decisions seemed to be taken in an ad hoc and random manner. Was that the case? How were these decisions being made?
These niggling clinical questions shaped the research question.

Section One: Introduction and Context

1. Introduction

This research study investigates decision making by clinicians in an acute hospital setting. The clinical decision under investigation concerns the nature and timing of decisions for nutritional intake for patients admitted with acute signs of stroke. The research was carried out in the UK (United Kingdom) based in hospitals providing National Health Service (NHS) care.

This introductory chapter will begin with setting the scene in terms of the background and rationale for the study. It will also outline the thesis structure, giving a rationale for the presentation of each chapter.

1.1. Background to the study

1.1.1. A local view

The defining moment in the background to this research study has been described in the introductory pages.
As a clinician regularly contributing to the assessment and decision making for patients after stroke, I became increasingly aware of the variability of decisions made, and increasingly confused regarding the nature of the process and outcomes. The options for feeding after stroke are oral diet or non-oral diet, particularly nasogastric or gastrostomy tubes. Given the relatively limited number of intervention options, I was intrigued by the reasons for the variability in the process.
At around the same time, in the hospital where I worked, an informal complaint was made about a patient receiving non-oral feeding against his wishes. The patient had a degenerative disease, and had an advanced directive (a 'living will') stating that he did not want artificial feeding when he reached the point where he could not swallow oral diet. He saw this as 'prolongation' of his life, and he wanted to avoid this. The clinicians involved were unaware of this advanced directive, and we responded to his obvious swallowing difficulty by referring for and initiating tube feeding. The patient's family were legitimately upset on hearing that a tube had been inserted, and requested that the tube feeding should stop. However, the clinicians felt unable

to stop tube feeding, as the patient was clinically benefiting from the nutritional intake. The patient transferred to a nursing home with tube feeding still in place. This situation rightly caused much reflection and concern for the clinical team. We were acutely aware that if we could seemingly get something so 'wrong' in a situation where the patient had expressed his wishes, what were we doing in situations where patients could not contribute to the decisions?

I began to focus on stroke. This is a clinical area where the number of decisions about nutrition is high, often in situations where the patient cannot contribute to the process. I started an informal analysis of factors that appeared to contribute to the decision, and my personal role and feelings about them. To my dismay, this further exacerbated my confusion and concern over the process.

I, therefore, turned to the literature to establish if there were ways to address the problem.

1.1.2. A national view

My initial literature review opened up the complexity of the decision for nutritional intake. It was immediately clear that clinical decision making in this field was not restricted to medicine. Feeding featured in the legal, theological, philosophical and ethical literature.

For example, is Artificial Nutrition and Hydration (ANH) a basic care provision or a medical treatment? Does it improve life for patients, or does it have potential to prolong poor quality lives for patients?

The literature, however, was largely silent on practical guidance for clinicians making these decisions. The most widely referenced guidance documents were published by the British Medical Association (BMA) in 2001 (BMA 2001) and the General Medical Council (GMC) in 2002 (GMC 2002). Both documents acknowledge that ANH is an area that is becoming increasingly problematic within medical decision making due to its multifaceted nature and its challenge to personal and social value systems. For this reason, the BMA set specific guidance and procedural safeguards in relation to decisions for withholding or withdrawing ANH.

> *'Although the BMA welcomes the categorisation of artificial nutrition and hydration as a form of treatment, it accepts that many people perceive there to be an important distinction between this and other treatments. In recognition of this fact and in order to reassure patients, their families and*

society as a whole that decisions to withhold or withdraw artificial nutrition and hydration are taken only in the most extreme cases, where provision would not provide a net benefit to the patient, it is recommended that additional procedural safeguards should be followed' (BMA 2001)

Decision-making for initiating, withholding or withdrawing ANH draws upon a number of different perspectives that create uncertainty and dilemma. Clinicians are making decisions with regard to ANH in a vacuum of clinical evidence about the risks and benefits of ANH interventions and a context of legal and ethical uncertainty due to inconsistent case law.

1.2. Rationale for the study

The majority of the literature to date comprises descriptive or philosophical accounts of the issues. Whilst this is important, it was evident that there has been limited empirical research in this area to date. Where research has been conducted, this has largely been retrospective analysis of the decision making process, or investigation of the outcomes.

The motivation behind this study was to provide a prospective investigation of the content and process of nutritional decisions after stroke. The specific rationale was to elicit the factors taken into account when making these decisions. Until we increase understanding of the factors currently affecting the decision process, we cannot begin to develop insight or awareness into how the process could be improved.

This was the motivation for the research project.

1.3. Thesis Structure

The thesis is divided into three main sections as follows:

Section 1

This research investigates the process and factors involved in decision making for nutrition and ANH after stroke. As stated, the clinical decision is complex, drawing from a number of perspectives and disciplines. In order to understand the complexity of the decision process and the value of this research, it is necessary to explain the contextual influences. It is for this reason that section 1 of the thesis (chapters 2-6) outlines the historic and current influences pertinent to the study.

These are: the healthcare context (chapter 2), the clinical context relating to stroke care (chapter 3), the bioethical context (chapter 4), the legal context for ANH decisions (chapter 5), and finally the theoretical basis of decision making (chapter 6). The narrative, will, out of necessity, compartmentalise each of the aspects discussed in order to preserve clarity. This fragmentation does not reflect the reality of decision making in a clinical context where many of the issues overlap and intertwine. Having outlined the context and relevant issues for nutrition and ANH decision making, the thesis is then structured in the following way.

Section 2

Section 2 of the thesis considers the design and methodological basis for the study. This comprises chapter 7, outlining issues relating to the chosen methodology of grounded theory and chapter 8, which explains the methods used for research design, data collection and the process of analysis.

Section 3

This section presents the findings and discussion. Chapter 9 provides an account of how the analytical process identified key themes in the data. Chapter 10 gives a summary of the findings. This is outlined early in this section so that the detailed findings can be seen in context of the overall picture. This is followed by chapters 11 – 13, which give detailed accounts of the findings. The findings are presented with supporting quotes and data transcriptions.

Chapter 14, the discussion, evaluates the research project in terms of its contribution to current knowledge.

Throughout the thesis, the term 'patient' will be used to reflect the study context and terminology used by the participants. It is acknowledged that this use of 'medical' terminology may suggest traditional power imbalances in research, but this choice has been made for clarity of presentation.

2. The Healthcare Context

As indicated, this research study was conducted within NHS acute hospital settings in the UK.

It is important to outline the context of the research in terms of the healthcare environment, organisation and culture. This chapter will, therefore, outline the key thematic changes in healthcare provision, and highlight the implications for the clinical decision under study.

2.1. The National Health Service

The provision of Health Services in the United Kingdom has changed beyond recognition since the creation of the NHS in 1948. From its inception to the current date, the NHS has continuously re-defined its role to reflect political ideologies, global policy, and the socio-economic demands of the country.

Prior to 1948, healthcare was provided either to people who could afford to pay for it, or through charity, voluntary organisations or philanthropic acts. However, it was evident in the post-war period, that the government of the time, a Labour government, had a responsibility for the total welfare of citizens, including free healthcare provision. Aneurin Bevan, the health minister, realised his 'socialist dream' on 5th July 1948. The NHS was set up to provide free healthcare to people on the 'basis of need, not on the ability to pay'. Between 1948 and 1968, however, there were significant financial challenges for the government and the NHS in terms of balancing the conflicting demands in the system. Increasing technological advances and professional demands created a situation that was acknowledged as 'demand exceeding supply'. In 1952, the patient was directly affected as prescription fees were introduced. Through the 1960's, staff and managers were challenged to balance skills and resources across the three divisions: hospitals, general practice and local health authorities. In the decade that followed and up to the late 1980's there was increasing recognition that the NHS had clear financial boundaries, and limits on provision of healthcare had to be applied.

The NHS experienced its most significant cultural shift through the publication of the white paper 'Working for Patients' (DOH 1989). This introduced the concept of financial accountability, and generated the notion of an 'internal market' which

divided the NHS into 'purchasers' and 'providers' of healthcare. Alongside the financial changes, came a tangible shift in power and responsibility for staff and patients alike.

A change in government in 1997, brought a new approach to the NHS. A White paper and a new NHS plan 'The New NHS : Modern. Dependable' (DOH 1997), attempted to adopt the original principles of the NHS, whilst incorporating the needs of modern society. This so-called 'Third way' was based on six key principles

- Fairness and equity of healthcare provision
- Local responsibility for services, with clinicians at the helm
- Breaking down barriers to partnership working – across organisations
- Cutting bureaucracy and increasing efficiency
- Quality and excellence in clinical decision making
- User involvement – to increase public confidence

In setting the scene for this research study, the impact of NHS history and current principles must be acknowledged. The process of clinical decision making at the current time is inevitably 'shaped' through the cultural, political and economical beliefs of those involved.

The influence of these aspects will now be discussed in the context of the current pressures for NHS clinicians and patients when approaching clinical issues.

2.2. Shifting the balance of power

Since 1989, there has been a trend within the NHS to address the 'balance of power' between individuals and organisations involved in healthcare.

2.2.1. Individuals

One major theme over the past two decades, has been the drive to increase the 'voice' and representation of the patient in healthcare policy and provision.

In 1991, The 'Patients Charter' (DOH 1991) was introduced by the Conservative Government with the aim of improving information for the recipients of healthcare and clarifying patient's rights to, and expectations of, the NHS. This encouraged greater transparency in terms of the services offered by clinicians, and defined the early stages of 'patient involvement' in their own healthcare decisions.

The 'NHS Plan' introduced by the Labour party in 2000, (DOH 2000) stated its aim was to create radical reform of the provision of healthcare in the UK. This was to develop

> *'a vision of a health service designed around the patient...working together with social services to increase patient choice, cutting waiting times for treatment and improving health and reducing inequality'*

In 2004, The 'NHS Improvement Plan' (DOH 2004) further developed the increasingly pervasive theme of patient involvement and choice in its vision for

> *'an NHS which is fair to all of us and personal to each of us by offering everyone the same access to, and the power to choose from, a wide range of services of high quality, based on clinical need, not ability to pay'*

In this context, healthcare decision making has received considerable public scrutiny over recent years. The increasing mistrust of clinicians created by high profile legal cases and 'bad publicity' has led to some defensive practice in the NHS. The role and responsibilities of doctors in particular, have been open to challenge, with the previously respected paternalistic role being reinterpreted as a barrier to patient choice. The historical tradition of 'the doctor knows best' is steadily being challenged, and healthcare clinicians are rarely encouraged to make decisions on behalf of patients without their direct involvement. The cultural philosophy in clinical decision making is therefore, moving towards one of creating and encouraging patient autonomy and choice.

2.2.2. Organisations

In 2001, the Department of Health published the document 'Shifting the balance of Power' (DOH 2001), The Human Resources framework. This document aimed to give 'greater authority and decision making power to patients and frontline staff'. In order to do this, the government proposed further organisational change to create Primary Care Trusts (PCT's) having responsibility for local healthcare services. Although the 'purchaser-provider split' had been eradicated, organisational divisions remained in terms of reallocating responsibility, power and influence over strategic healthcare decisions to the PCT's. This study was conducted at a time when these organisational changes were being implemented.

2.3. Evidence Based Practice

Individual healthcare decisions have increased in complexity as the evidence base, knowledge, skills and available technology has evolved.

Research evidence in some fields of healthcare can be inconclusive when attempting to translate findings into the practical measures of clinical 'risk and benefit.' This is further compounded by uncertainties when a patient is not in a position to assert their preferences, hence the responsibility lies with the medical consultant to determine what approach is in the patients 'best interests'. The notion of best interests will be discussed extensively throughout this thesis.

Cochrane provided the original text on Evidence Based Medicine (EBM) and its implications for the NHS in 1972. In his book, Cochrane reflected on his experiences of providing healthcare as a prisoner of war, and within the NHS. He stated that in the NHS

> *'people were dying because of the medical attention they received rather than the lack of it.' (1999)*

Cochrane had a profound influence on raising the profile and value of Randomised Controlled Trials (RCT's) for clinical evidence.

The value of EBM and RCT's broadened, and the NHS developed a culture where Evidence Based Practice (EBP) applied to all clinical services. Although research evidence is now widely acknowledged to be broader than the RCT (Sackett, Rosenberg, Gray, Haynes and Richardson 1996), the challenge to identify and implement evidence in clinical practice remains. Areas of clinical service for which evidence is clear, are encouraged to implement EBP based guidelines, protocols and pathways. Services with limited EBP underpinning clinical practice are encouraged to consider the potential benefits and risks of their interventions. Where there is potential for 'harm', there has been clear guidance by the Department of Health that a 'precautionary' approach should be adopted.

The Department of Health select committee on science and technology advocated a precautionary approach to healthcare and defined the precautionary principle as

> *'where there may be threats of serious damage to human health, lack of full scientific certainty should not be used as a reason for postponing proportional measures to reduce such threats' (DOH 1999).*

In relation to healthcare decisions, clinicians are encouraged to take the 'safest' option to minimise harm, especially in situations where there is limited research evidence.

In the context of the current research study, the area of stroke and nutritional management falls into a category with limited current clinical evidence. This will be detailed further in chapter 3, and the impact of this 'backdrop' is further discussed in the findings and discussion.

2.4. Clinical Governance

The framework for clinical governance was introduced to the NHS in 1999 (through 'The Health Act'(1999)), as a statutory obligation for NHS organisations to account for the quality of their services. Clinical governance is defined by the Department of Health as

> *'a framework through which NHS organisations are accountable for continually improving the quality of their services and safeguarding high standards of care by creating an environment in which excellence in clinical care will flourish' (Scally and Donaldson 1998).*

There are a range of issues within clinical governance, reflecting many of the six key principles in the NHS plan. These include risk management, systems for ensuring transparency and accountability, effective practice, user involvement, information needs and evaluation.

Clinical Governance gained increased prominence within the NHS in 2000 and 2001, largely following the Alder Hey and Bristol hospital inquiries. These events contributed to the publication of the report, 'An organisation with a memory' (DOH 2000). This highlighted the need for risk management strategies, and a culture of learning from previous 'mistakes' or 'near-misses' in the NHS. The report acknowledged that there had been 'little systematic learning from patient safety incidents and service failure in the NHS in the past and drew attention to the scale of the problem of potentially avoidable events that result in unintended harm to patients' (National Patient Safety Agency (NPSA 2002)). The result of these initiatives was the emphasis on patient protection and in turn, a climate that encouraged clinicians to raise awareness of potential risk for patients and other staff in their own clinical fields.

Risk management is standard terminology at the current time for NHS clinicians and administrators. Directives for managing risk are issued through the Department of Health, often through the NHS Litigation Authority (NHSLA).

Whilst having the intention to 'protect' patients and staff, the priority placed on risk management has been criticised by some as generating a blame culture. Ottewill (2003) highlights the individual nature of risk and blame currently seen in the NHS. Personal accountability takes precedence. He argues that a cultural shift is required to consider a 'systems' approach to error. He argues that 'human error is ubiquitous and inevitable and that systems need to be developed with this in mind.' He asserts that the cultural shift follows the procedural changes, and that the NHS needs to adopt such an approach if it is to achieve success in managing risk.

The background culture and philosophy of risk management and accountability are particularly relevant to this research study. These points will be revisited in detail in section 3 of the thesis.

2.5. Modernisation and the NHS

The current NHS plan (The New NHS: Modern and Dependable, 1997) brought with it a strategy for implementation, generally referred to as the 'modernisation agenda'. The modernisation agency for the NHS is responsible for the coordination of five key themes for modernisation. These include themes for clinical services, improvement issues, service and organisation issues, workforce factors and 'cross-cutting' themes that apply to all elements of the system.

In 1998, the Department of Health launched its strategy for modernising priority clinical services – the National Service Frameworks (NSF's). The NSF's set clinical standards within defined areas, and include plans for implementation. A number of NSF's have now been issued. The NSF for older people (DOH 2001) sets the context for this research study, and this is further discussed in chapter 3.

The Modernisation Agency, in developing its themes, acknowledged the highly complex system of the NHS, and signalled another developing approach to healthcare delivery. This is the need for healthcare professionals to employ 'complexity thinking'.

Helen Bevan, Director of the NHS Modernisation Agency stated that

'the emerging field of complexity can help service users, healthcare practitioners and organisations progress and prosper despite the uncertainty and complexity of their worlds' (Bevan 2004).

Having progressed through a phase where Clinical Governance aimed to eradicate risk and increase accountability at an individual level, it is suggested that the next phase in managing risk is to 'live' with uncertainty rather than attempting to manage it (Ottewill, (2003) op cit). This shift in philosophy is evident in the education of clinical professionals. Non-linear teaching methods such as problem-based learning and reflective practice are 'explicitly and implicitly espoused in a series of NHS documents covering continuing professional development' (Fraser and Greenhalgh 2001).

The result of adopting complexity thinking, could signal a fundamental shift in how clinicians deal with clinical uncertainty, and how they make decisions. This is evident in the following interpretation by Plsek and Greenhalgh (2001)

'Our learnt instinct with such issues, based on reductionist thinking, is to troubleshoot and fix things- in essence to break down the ambiguity, resolve any paradox, achieve more certainty and agreement, and move into the simple system zone. But complexity science suggests that it is often better to try multiple approaches and let direction arise by gradually shifting time and attention towards those things that seem to be working best'

Thus, the NHS is currently in a transitional phase in its approaches to clinical problem solving and decision making.

It is, therefore, important to consider these contextual issues when approaching research into clinical decision making at the current time.

2.6. Summary

In summary, this chapter has discussed the key themes in the healthcare context that relate to the current study. There have been significant changes in healthcare provision over recent decades and these have altered the relationship between clinicians and patients. Clinical decision making currently occurs within an uncertain context, despite attempts to standardise practice and reduce risk. The perceptions of the clinicians in this study are, therefore, set within the backdrop of relatively rapid organisational and cultural change.

3. Clinical Context

This chapter will outline the clinical context in which the research study is placed. It is necessary to describe the clinical issues that are relevant to stroke, swallowing disorders, nutritional issues and decision making guidance in order to set the decision process for feeding in context.

3.1. Stroke

From a medical perspective, stroke is classified within the field of Cerebrovascular Diseases. It is caused by one of two basic pathological processes – cerebral infarction (death of brain tissue) due to deprivation of blood supply, or intracranial haemorrhage (bleeding into tissue) (Lishman 1988).

Clinically, both processes fall under the clinical descriptor 'Cerebrovascular Accident' (CVA), or, more commonly, 'stroke'. The World Health Organisation first published a classification of stroke for clinical and research purposes in 1978 and this is cited as:

> *'a clinical syndrome of rapidly developed clinical signs of focal or global disturbance of cerebral function, lasting more than 24 hours or leading to death, with no apparent cause other than vascular origin' (WHO 1978)*

The incidence of first time cerebrovascular accidents has been estimated at 2 per 1000 population in the UK. A quarter of patients are under 65 and the risk for males exceeds that for females by 26% (Bamford, Sandercock, Dennis, Warlow, Jones, McPherson, Vessey, Fowler, Molyneux, Hughes, Burn and Wade 1988, DOH 2001).

The 'National Service Framework (NSF) for Older People' was published by the Department of Health in 2001 (DOH 2001). This document set minimum standards of care for NHS service delivery to older people living in England. In recognition of the fact that there is a higher incidence and prevalence of stroke amongst older people, stroke services are included amongst the targets within this NSF.

> *'each year, 11,000 people in England and Wales have their first stroke, and 30,000 people go on to have further strokes. It is the single biggest cause of severe disability and the third most common cause of death in the UK and other developed countries' (Wolfe, Rudd and Beech 1996)*

These figures sit within epidemiological statistics showing steady increases in the population of older people in the UK. It is estimated that between 1995 and 2025, the number of people over the age of 80 years is likely to rise by almost a half, and the number of people over 90 years of age will double (NSF for Older People 2001). Stroke care is therefore identified as a clinical priority for NHS resources and stroke is highlighted as 'Standard 5' in the NSF for Older People. This states that the aim for stroke care in England is

> *'to reduce the incidence of stroke in the population and ensure those who have had stroke have prompt access to integrated stroke care services' (DOH 2001).*

The Royal College of Physicians (RCP) published National Clinical Guidelines for Stroke in 2000 and 2004. These documents combine clinical evidence with specialist consensus, in order to produce a 'care pathway' for interventions in the acute stages of stroke.

One of the areas acknowledged to be problematic within acute stroke care is the determination of prognosis and eventual outcome for patients. Attempts have been made to link the size and site of the neurological lesion with overall outcome (Dennis, Burn, Sandercock, Bamford, Wade and Warlow 1993; Mead, Lewis, Wardlaw, Dennis and Warlow 2000). Other studies have considered the link between neurological investigation results and eventual outcome (Sharma, Fletcher, Vassallo and Ross 2000; Wohrle, Behrens, Mielke and Hennerici 2004). Age as a predictor of outcome after stroke has been considered in a number of studies, and more recently, Black-Schaffer and Winston (2004) added weight to the view that older people have a poorer eventual outcome than younger patients. Levels of consciousness have also been linked to outcome after stroke with Franke, van Swieten, Algra and van Gijn (1992) and Weir, Bradford and Lees (2003) suggesting a poor outcome associated with lower consciousness states.

The breadth of research data, and anecdotal accounts within the clinical field, highlight the uncertainty of predicting prognosis for both survival and disability after stroke. Changes in stroke care services in the UK have encouraged development of palliative care approaches within acute stroke care, in recognition of the fact that a patient's initial presentation is not indicative of their illness progression (Jack, Jones, Jack, Gambles, Murphy and Ellershaw 2004).

To establish a view of stroke care within the UK, The RCP carries out a national audit, the sentinel audit. The last audit of organisational structures was completed in

2006, with the last clinical audit in 2002. The basis of the audit is the RCP 'National Clinical Guidelines for Stroke' (RCP 2000/2004). These guidelines are evidence based and apply to Healthcare in England, Wales and Northern Ireland. They set out clinical and organisational guidelines from the acute stages of stroke, through to rehabilitative interventions.

The objective of the sentinel stroke audit programme is to assess the quality of care for people who have had a stroke in terms of both organisational issues and clinical care provided across UK Trusts. The initial audit reported in 1999, and stated that

> *'at any one time, there are 25-35 patients with stroke as their primary diagnosis in the average general hospital' (Rudd, Irwin, Rutledge, Lowe, Morris and Pearson 1999)*

The RCP revised their stroke care guidelines in 2004 to update the clinical evidence base for acute and rehabilitative stroke services, whilst highlighting the need for further evidence in many aspects of stroke care.

One area acknowledged in the stroke care guidelines to be lacking in evidence is the use of Artificial Nutritional and Hydration (ANH). Specifically, the RCP suggest that more evidence is needed for the use of nutritional interventions, specifically in relation to the timing of feeding, patient selection, mode of feeding and the risks and benefits associated with each intervention choice.

3.2. Stroke Care services in the NHS

Organisation of stroke care services in the UK received increased attention in the 1990's. The particular focus was directed at the acute stages, as research evidence raised awareness that clinical outcomes for patients may be directly influenced by the way acute services are organised (Langhorne 2000).

One of the main debates in acute stroke care lay in the issue of whether provision in a coordinated 'stroke unit' provided greater benefits for the patient than 'conventional' care in general wards. This culminated in a systematic review (RCP 1999) providing evidence that stroke unit care was superior to conventional hospital care.

A stroke unit approach can be defined as 'the provision of coordinated multidisciplinary care usually provided within a geographically discrete area such as a stroke ward' (Langhorne and Dennis 1998). Typically, these units have a variety of

disciplines involved, including Physiotherapy, Occupational Therapy, Speech and Language Therapy and Dietetics.

Systematic review findings (Langhorne 2000 op cit) revealed that stroke units were organised in a number of different ways, with five organisational types identified. An *Acute* stroke unit, often provided care for the first few days after stroke; A *Rehabilitation* Stroke Unit often accepted patients 1-2 weeks after stroke and provided rehabilitative care for several weeks as necessary; *Comprehensive* Stroke units combined both acute and rehabilitative care for several weeks as necessary; *Dedicated* stroke units provided care exclusively to stroke patients and *Mixed* assessment/rehabilitation units aimed to provide stroke care within a mixed disability setting.

The NSF for Older People (2001) applies to England only, but sets out that all hospitals caring for patients with stroke should have 'specialised stroke service by April 2004'. The definition of stroke unit in this document was adopted by the stroke sentinel audit in (2004). This definition states that a stroke unit is 'a multidisciplinary team including specialised nursing staff based in a discrete ward which has been designated for stroke patients'. The definition acknowledged organisational differences and identified three main sub-divisions, these being *acute* stroke units (accepting patients early, but discharging quickly), *Rehabilitation* units (accepting patients after a delay of seven days or more) and C*ombined* units (having no separation between acute and rehabilitation beds).

The stroke audit organisational review (RCP 2006) reported that England and Northern Ireland had increased access to stroke unit care, although the situation in Wales was unchanged. They concluded by stating that

> *'More hospitals are now offering stroke unit care and the quality of care within the units seems to be improving. .....there is some evidence that standards may be deteriorating for stroke patients being managed on generic rehabilitation units'*

The last audit of clinical care was conducted in 2002 and included issues such as the timing of assessments, and the type of care planning offered. Of relevance to the current study, are issues relating to swallow screening and nutritional assessment after stroke. In 2002, the audit reported that screening for swallowing disorders was 63% compliant with the standard that assessment should be carried out by a Speech and Language Therapist within 72 hours of admission.

The reviewed RCP guidelines (2004) include a standard that 'nutritional status, using a validated method, to be undertaken by appropriately trained personnel within 48 hours of admission'. Compliance with the standard is being assessed through the current cycle of the sentinel audit, due to report in March 2007.
The issues relating to the management of swallowing disorders after stroke will now be further discussed.

3.3. Dysphagia

3.3.1. Dysphagia after stroke

Dysphagia is a disorder of swallowing resulting from neurological or anatomical aetiologies.
Logemann (1983) defines normal swallowing as

> *'a rapid act involving voluntary and involuntary aspects requiring complex neuromotor control'*

There is common agreement in the literature on 'normal' swallowing (Logemann 1983; Groher 1984) that there are four distinct physiological stages. These are (i) the oral preparatory stage, where food and drink is prepared into a 'bolus' for swallowing (ii) the oral stage, where the prepared bolus is moved posteriorly in the mouth (iii) the pharyngeal stage, where the bolus is moved through the pharynx and (iv) the oesophageal stage, where the bolus moves through the oesophagus to the stomach.
A disorder of swallowing (dysphagia or 'deglutition disorder') refers to disruption of the swallowing physiology affecting one or any combination of these stages due to neurological or anatomical impairments.
Given the neurological basis, a large proportion of patients who have a stroke may experience some degree of dysphagia, particularly affecting oral and pharyngeal stages of swallowing. Some studies have reported that up to 50% of stroke patients experience dysphagia in the acute stages of stroke, with a significant minority (8%) experiencing persistent dysphagia (Smithard, O'Neill, England, Park, Wyatt, Martin and Morris 1997). Lawrence, Coshall, Dundas, Stewart, Rudd, Howard and Wolfe (2001) found that the incidence of dysphagia within their sample group of 1259 patients was 44.7% in the acute stages.

Swallowing difficulties can result in a number of perceived clinical risks for a patient. These include risks of choking, pulmonary aspiration (where food or drink enters the trachea and larynx, moves below the level of the true vocal cords, and ultimately into the bronchi) or reduced oral nutritional intake. The potential complications linked to dysphagia are commonly cited as those of aspiration pneumonia (Ramsey, Smithard and Kalra 2003), choking and foreign-body asphyxia (Berzlanovich, Fazeny-Dorner, Waldhoer, Fasching and Keil 2005), and undernutrition or dehydration (Barer 1989; Smithard, O'Neill, Parks and Morris 1996; Leslie 2004). These complications could contribute to potentially serious or fatal outcomes for some patients (Perry and Love 2001).

3.3.2. Assessment and management of Dysphagia

Assessment, identification and treatment of dysphagia are relatively recent clinical interventions. Much of the initial research to identify and classify normal swallowing and dysphagia was conducted in the United States of America in the 1980's. This was largely pioneered by Ear, Nose and Throat (ENT) specialists who were describing anatomical processes and Speech & Language Therapists (SLT's) who were addressing the physiological presentation of swallowing disorders. Having detailed knowledge of the anatomy and neurology for oral and pharyngeal muscles, SLT's in the USA adopted a role to assess the stages of swallowing, and to determine any signs indicative of pulmonary aspiration. This newly acquired role for SLT's had most impact in USA healthcare during the late 1980's and 1990's as outlined by Miller and Groher (1993). SLT's in the UK mirrored this pattern, following the American lead.

Prior to this time, it was not uncommon for aspiration pneumonia, co-existing with a range of neurological disorders, to be seen as natural and unavoidable consequence following a stroke. In some cases, aspiration pneumonia was felt to be a positive aspect to 'saving' the patient from a life-time of disability, or facilitating death in a chronic terminal illness. In this context, aspiration pneumonia was colloquially termed 'the old man's friend' by medical clinicians when it resulted in the person's death (Brancati, Chow, Wagener, Vacarello and Yu 1993).

The increase in awareness of dysphagia and aspiration prompted a dramatic increase in requests for swallowing assessments. The role of the SLT in post-stroke care developed greater prominence than had been seen previously, as medical

clinicians referred to SLT for assessment and advice for dysphagia following stroke. This newly adopted role was supported by the Royal College of Speech and Language Therapists (RCSLT) in professional standards issued in 1996

> *'Speech & Language Therapists as a professional group are ideally equipped to take a central role within the multidisciplinary team in the assessment and remediation of swallowing disorders' (RCSLT 1996).*

However, there remains a divided view within the SLT profession over the level of involvement for SLT's in dysphagia, particularly in view of the resulting re-profiling of services to allocate resource to dysphagia that would have previously been available to patients with communication disorders.

From an educational point of view, dysphagia is now taught at a basic level at undergraduate training for all SLT's. This was introduced in 1999, (RCSLT 1999) reinforcing the RCSLT's stance that dysphagia should be considered a core role and responsibility for SLT's.

The SLT assessment comprises a subjective 'bedside' assessment of the oral and pharyngeal stages of swallowing where the SLT identifies the physiological level of difficulty and highlights any possible risks of pulmonary aspiration.

Recommendations may be given to continue with oral diet, or to take a modified texture diet (eg pureed diet or thickening fluids) or to adopt swallow routines to facilitate swallowing. In some cases, the SLT may conclude that there is a high level of risk for pulmonary aspiration, and in these cases, the advice given by the SLT may be to maintain Nil By Mouth (NBM). In the clinical context, NBM can relate to either a short term recommendation (routinely adopted prior to surgical or other 'invasive' interventions) or, in this case, an indefinite time period where it is felt that eating and drinking orally poses a risk to the patient.

Given the relative infancy of both research into dysphagia and the clinical role for SLT's, there has been a relatively fast evolution of approaches to patients with dysphagia within the NHS. There is some recognition nationally that the current profile of roles and responsibilities for dysphagia management warrants review. SLT's have been the core professional group for undertaking assessments, but the profession does not work on a shift basis, and generally does not cover weekends and Bank Holidays. This creates difficulties in terms of response times for assessments and in some cases, leaves patients who are NBM 'waiting' for Speech and Language Therapy assessments. In recognition of this, the National Patient Safety Agency (NPSA) commissioned a study in 2004 to identify clinical

competencies for dysphagia screening, assessment and management. This preliminary work 'will allow other professionals with similar skills to adopt the role' (NPSA 2004). In addition, the revised RCP guidelines for stroke care (2004) state that the swallow screen should be carried out by an 'appropriately trained specialist', rather than specifically by SLT.

These issues highlight the rapidly evolving nature of dysphagia management after stroke, and the changing context in which this research study is placed.

3.3.3. Risk and Dysphagia

Within the context described above, the SLT profession has, by necessity, responded to the management of dysphagia in a reactive way. From my own clinical experience, in the 'early days' of dysphagia management, identification of aspiration risk often resulted in a firm recommendation of NBM by SLT. This was attributable to the widespread belief by SLT's at the time that a recommendation of NBM was the 'safest' position if the clinician was uncertain over swallowing safety. The risks of aspiration and aspiration pneumonia were acknowledged to increase after stroke hence great attention was placed on a preventative approach to avoid aspiration. These issues are further discussed in section 3.4.

Levenson and Crecelius (2003) acknowledge the risk of aspiration in terms of its impact on professional practice. They state that

> *'Effective speech therapists recognize that their evaluations and conclusions must be considered in the context of the entire patient. But others may focus on swallowing and overlook or fail to understand the broader context. They may feel compelled to recommend the "least risky" diet.'*

This is reflected in many of the swallow screening procedures adopted in the UK whereby the guidance is to keep the patient NBM until assessed, and maintain NBM if uncertain. This position is echoed in many local guidelines drawn up by SLT departments for the management of dysphagia, and is evident in the Scottish Intercollegiate Guidelines Network (SIGN 2004) recommendations. This document states that 'all patients should be screened for dysphagia before being given food or drink'. This was the position in the study sites over the period of this study.

The RCSLT clinical guidelines for dysphagia (RCSLT 1998), state that the Speech and Language Therapist has responsibility to 'assess for aspiration'. Further, this document suggests that

' where a doctor chooses a course of action contrary to the opinion of the Speech and Language Therapist, and the therapist believes that such an action may be inappropriate or cause the client harm, the therapist is advised to record his/her opinion in writing.....in some cases it may be necessary to withdraw involvement.'

This highlights the issue of accountability for risk, and over the decade of the 1990's, many SLT's in reality were forced by professional standards to adopt a 'non-negotiable' risk management approach.

This conflicts with the developing culture of patient choice and the more pragmatic approach to assessing risks and benefits in the NHS at the current time. As a result, there remains some confusion and divided opinion within the profession regarding the role of the SLT's in managing the risks of aspiration, and the authority attached to the SLT's recommendations.

Dysphagia identification and management is an area that has seen rapid development and change in terms of evidence and practice over recent years. In clinical areas where evidence follows practice, it is not uncommon for approaches to evolve over time. As such, many of the issues raised here are 'anecdotal' or based on the reality of personal experience rather than formal policy.

It is important however, to recognise the contributions of the historical perspective on 'safety' and risk associated with dysphagia, in order to understand some of the current practices and beliefs that will be discussed in later chapters.

3.3.4. The Impact of Dysphagia

The impact of dysphagia for a patient who is in the acute stages of stroke falls largely into two categories.

The first issue relates to respiratory issues and the 'safety' of the swallow itself. In particular, this links to the risks of choking or pulmonary aspiration. These issues will be covered in section 3.4.

The second issue is that of achieving satisfactory nutritional intake. The nutritional issues after stroke will be considered in section 3.5.

3.4. Respiratory Issues

3.4.1. Pulmonary Aspiration

In the context of dysphagia, 'aspiration' generally refers to the event where ingested food or fluid enters the larynx and moves below this into the trachea and potentially the lungs during the process of swallowing. This definition is distinct from that of 'laryngeal penetration' where material enters the larynx, but remains above the vocal cords. The definition of aspiration as given by Logemann (1983, op cit) is

'entry of material into the airway below the true vocal cords'

This definition encompasses aspiration of saliva, stomach content reflux, or any other foreign substance that is not intentionally swallowed, hence may occur at any time outside of the physiological process of swallowing (Perry et al 2001, op cit). Pulmonary aspiration therefore refers to the situation where material enters the lungs.

Research literature into aspiration assumes this broad definition, and has addressed issues relating to causes of aspiration and effects of aspiration in humans.

Aspiration is seen to be a common and regular occurrence in all humans. About half of normal adults and 70% of patients with reduced levels of consciousness have been reported to aspirate saliva into the lungs during sleep (Huxley, Viroslav, Gray and Pierce 1978). Among elderly people, swallowing abnormalities are reported to be very common, and have no adverse effect on health (Linden and Siebens 1983; Ekberg and Feinberg 1991).

Aspiration is associated with dysphagia leading to the view that patients who have swallowing problems will be more likely to experience further complications assumed to be the result of aspiration, such as chest infections or lung abscesses (Perry et al 2001, op cit).

In general, many patients who aspirate have overt signs of having done so. This might include changes in voice quality, or coughing (Smithard, O'Neill, Park, England, Renwick and Wyatt 1998). According to the literature however, a significant proportion of people, particularly after stroke, are seen to 'silently' aspirate. Smith, Logemann, Colangelo, Rademaker and Pauloski (1999) carried out videofluoroscopy assessments of swallowing and identified that 25% of their study population were seen to silently aspirate.

Research into localising the site of neurological lesion in stroke linked to prevalence of aspiration has received increasing attention. Daniels and Foundas (1999) suggested that the site of lesion is more critical than hemisphere or lesion size in predicting patients at risk of aspiration. They found that patients with anterior or subcortical lesions were at higher risk of aspiration than those patients with posterior lesions. In a later study, Daniels, Corey, Barnes, Faucheaux, Priestly and Foundas (2002) presented results to offer partial support for a bilateral hemisphere representation of swallowing with the left hemispheric contribution being more significant for swallowing.

3.4.2. Aspiration Pneumonia

Aspiration pneumonia is a term that refers to:

> *' the entry of pharyngeal contents with infectious material into the lower airways' (Finucane and Bynum 1996).*

This definition suggests that all infectious material, including diseases such as tuberculosis, would be included within the classification of aspiration pneumonia. Finucane and Bynum (1996, op cit) highlight the misuse of the term aspiration pneumonia as an all inclusive classification for chest infections attributable to foreign substances in the lungs. They cite the account of chemical pneumonitis by Mendelsohn (1946) as a distinct presentation from that of bacterial pneumonia. In Mendelsohn's account, women who aspirated liquid gastric contents while undergoing ether anaesthesia were seen to experience respiratory problems such as cyanosis, tachypnoea, and dyspnoea. These symptoms were short-lived, and did not result in longstanding bacterial changes. However, these cases are often referred to under an 'umbrella term' of pneumonia in both clinical practice and research literature. Descriptions of aspiration pneumonia by DePaso (1991) and others often lack consistency and definition over the exact nature of aspiration and the subsequent effects.

Research evidence on the clinical impact of aspirating food or drink after a stroke is sparse. Marik (2001) proposed that the key factor for pneumonia is not *whether* a patient aspirates but *what* they aspirate. There is some literature to support the view that pneumonia will occur if large volumes of material are aspirated (Holas, DePippo and Reding 1994). Others suggest that pneumonia results from aspiration of hazardous material (Marik 2001, op cit).

McClave and Dryden (2003) suggest that poor oral hygiene is a major determinant for developing aspiration pneumonia. This is given some support by the work of Feinberg, Knebl and Tully (1996) who found that maintaining Nil by Mouth for patients did not reduce the incidence of aspiration. There is some criticism of this finding in that some of the patients were receiving tube feeding, and the possibility of reflux aspiration was not accounted for. However, the evidence supporting the implications of poor oral hygiene for aspiration is gaining support from other authors (Terpenning, Taylor, Lopatin, Kerr, Dominguez and Loesche 2001; Oh, Weintraub and Dhanani 2004).

In the clinical context of stroke, the exact nature of the respiratory problem observed can be vague and indeterminable. It is not uncommon for a diagnosis of aspiration pneumonia to be given based on the clinical symptoms of an increase in temperature and changes in breathing after recent stroke rather than definitive diagnostic tests. Where videofluoroscopy swallow X-Rays identify aspiration, it is clear that this does not always lead to pneumonia (Johnson, McKenzie and Sievers 1993). The difficulties with identifying aspiration pneumonia and giving a differential diagnosis compared to other clinical respiratory symptoms is acknowledged by some authors as evident throughout general medicine (Marik 2001; Mylotte, Goodnough and Naughton 2003). However, despite the lack of concrete research evidence to support causal links between aspiration of food and drink and aspiration pneumonia and, in the absence of clinical diagnostic detail, the impact of chest infections and pneumonia after stroke is a widely cited 'risk' requiring a cautious approach. Pneumonia is linked more commonly to patients who are unconscious, (Huxley, Viroslav et al. 1978; Adnet and Baud 1996) and although this is not conclusively linked to aspiration, the relative vulnerability of the unconscious patient drives a preventative approach to aspiration in clinical care.

In summary, therefore, the impact of aspiration after stroke is debatable, but is often reported to be linked to risks of developing pneumonia. The literature remains inconclusive in this area.

Langmore, Terpenning, Schork, Chen, Murray, Lopatin and Loesche (1998) acknowledge the paucity of evidence and state that 'dysphagia is linked to aspiration risk but in isolation it is not enough to cause pneumonia'.

In clinical practice however, the risk of aspiration is strongly associated with pneumonia, as evidenced in the Scottish Intercollegiate Guidelines Network (SIGN) advice ((2004) op cit). These state that 'the relationship between aspiration and

pneumonia is complex, but aspiration is a risk factor and must be identified as a priority'.

3.5. Nutrition

3.5.1. Oral nutrition

Nutrition has long been recognised as a major contributor to health, illness and recovery. Hippocrates' primary rule is recorded to be

"Let food be your medicine, and medicine be your food." (460-377BC)

Nutrition and particularly the high incidence of malnutrition in older people, has received considerable attention in the UK over recent years.

In 2001, the Malnutrition Advisory Group (MAG 2001) for the UK reported that one in seven people aged over 65 years was malnourished and this has generated attention from the media and charitable organisations. In a recent survey, the charity Age Concern (2004) revealed factors such as inability to prepare food affecting 15% of over-85s with 38% of these receiving insufficient help or access to hot food. Disability and poverty were also contributory factors to malnutrition in the elderly population.

The effects of malnutrition have been extensively researched and the detrimental effects on health and illness recovery are widely acknowledged (Barton 1994; Pingleton 2001). Malnutrition effects have been reported in terms of the biochemical changes (McFarlane, Ogbeide, Reddy, Adcock, Adeshina, Gurney, Cooke, Taylor and Mordie 1969), the health and illness impacts (Barton, 1994 op cit) and the sociological/economical impact (Correia and Waitzberg 2003; Perez de la Cruz, Lobo Tamer, Orduna Espinosa, Mellado Pastor, Aguayo de Hoyos and Ruiz Lopez 2004).

As stroke illness is most common amongst the older population, it has been reported that onset of a stroke may occur in patient groups for whom the nutritional baseline is already poor (Guigoz, Lauque and Vellas 2002; Ramos Martinez, Asensio Vegas, Nunez Palomo and Millan Santos 2004). Studies have shown that malnutrition after stroke onset, is a risk factor for poor overall outcome (Finestone, Greene-Finestone, Wilson and Teasell 1995; Davalos, Ricart, Gonzalez-Huix, Soler, Marrugat, Molins, Suner and Genis 1996; Pennington 1998) and that improving nutrition can improve outcomes for stroke patients (Gariballa 2001).

A number of research studies have highlighted the poor nutritional state of older patients on admission to hospital and have further presented the incidence of malnutrition in hospitals (McWhirter and Pennington 1994), with 71% of malnourished patients reportedly having their nutritional needs overlooked during the hospital admission (MAG 2001 op cit).

The Royal College of Physicians stroke care guidelines (2004), report that of all new stroke admissions, 15% are already malnourished, and this deteriorates to 30% over the initial week.

Hospital malnutrition has received sufficient interest and attention to encourage a UK governmental drive to improve the quality and provision of nutrition in hospitals – 'Better Hospital Food' (DOH 2001).This directive aimed to improve quality, access, choice and delivery of the hospital menu and oral diet.

The issue of hospital malnutrition has been discussed in a wider context by the Council of Europe, (COE 2003) (Resolution AP 2003(3) on Food and Nutritional Care in Hospitals). This acknowledged the similarities in incidence and prevalence of both community malnutrition and hospital malnutrition across Europe. This resulted in guidelines on best practice for all forms of hospital nutrition, including ANH.

Recently, the National Institute of Health and Clinical Excellence (NIHCE) published comprehensive evidence and guidance on nutrition support for adults (2006). It is clear therefore that oral diet and nutrition is an area that raises some concern in the UK, particularly for older people. In this context, patients admitted to hospital with acute stroke may be nutritionally vulnerable, whether or not they have a swallowing disorder. This sets the backdrop for the decision making issue under investigation in this study.

3.5.2. Artificial Nutrition and Hydration (ANH)

When patients are admitted to hospital after stroke, they may have a swallowing disorder, or may present with variable levels of consciousness. Both of these factors can create further nutritional vulnerabilities for patients. In some cases, patients will be unable to take sufficient oral intake, and in these instances, ANH requires consideration.

The British Medical Association defines ANH as

'those techniques for providing nutrition or hydration which are used to bypass a pathology in the swallowing process. It includes the use of Nasogastric tubes, Percutaneous Endoscopic Gastrostomy (PEG feeding) and total parenteral nutrition.' (BMA 2001)

As is evident in this definition, ANH is a term encompassing both nutrition and hydration, and the majority of literature on ANH makes no distinction between food and fluid provision. Finucane and Christmas (2003) however, highlight that the two interventions may be perceived differently in clinical practice, particularly in relation to withholding or withdrawing nutrition or hydration.

Where Nil by Mouth (NBM) is advised in stroke care, usually as a result of an outcome of swallow screening or SLT assessment of swallowing, the clinical team are required to make decisions about whether to intervene with artificial nutrition. Where there are concerns over aspiration risk, options include interventions whereby nutrition is given in a way that bypasses the oral and pharyngeal stages of swallowing.

The British Association for Parenteral and Enteral Nutrition (BAPEN) is the key national organisation in the UK for providing guidance on ANH. In most local hospital services, BAPEN guidelines have been the main information source, with their literature adopted and adapted to produce locally relevant nutritional screens and pathways (BAPEN 1994; BAPEN 1996; BAPEN 2000).

BAPEN guidelines cover issues relating to the following forms of ANH

3.5.2.1. Subcutaneous fluids.

This relates to short-term fluid supplementation that is given through a needle into the subcutaneous tissues. This approach is not routinely used as the primary intervention, but may be used in cases where intravenous methods are not possible.

3.5.2.2. Intravenous Fluid Infusions (IVI)

Intravenous (IV) fluids are given through a needle into the vein when the patient needs supplementary fluid intake. In the case of stroke, it may be that an IV fluid regime is commenced on admission, and certainly within 12 hours (RCP guidelines) where a person's oral intake is compromised. IV fluids can be continued for an indefinite period and although dextrose can be added, this approach in isolation does not meet a patient's full nutritional needs.

3.5.2.3. NasoGastric Tube (NGT) Feeding

This is an *enteral* method of feeding, where the nutrition is given directly into the intestinal system. The NGT is inserted through the nose and into the stomach. Once placed (generally by the nurse on the ward), the position is checked either by X-Ray or by aspirating liquid from the tube using a syringe, and checking for pH levels to confirm stomach placement. According to BAPEN guidelines, NGT's should be considered when the person has been NBM for no longer than 5 days. In the clinical arena, NGT's are considered to be most beneficial in cases of short term feeding, and are often used in the early days after a stroke when the decision has been made that enteral feeding is appropriate.

The disadvantages of this approach are reported to include a risk of aspiration pneumonia (Nakajoh, Nakagawa, Sekizawa, Matsui, Arai and Sasaki 2000; Dziewas, Ritter, Schilling, Konrad, Oelenberg, Nabavi, Stogbauer, Ringelstein and Ludemann 2004) discomfort, and difficulty in maintaining the tube *in situ* (Ciocon, Silverstone, Graver and Foley 1988).

3.5.2.4. Gastrostomy Feeding

This is an *enteral* method of feeding with the nutrition being given through a tube directly through the stomach wall and into the stomach. Gastrostomy tubes can be inserted surgically, radiologically or endoscopically. The latter of these is the most common method of placement, and this is referred to as a Percutaneous Endoscopic Gastrostomy (PEG).

PEG insertion was introduced into clinical practice by Gauderer, Ponsky and Izant (1980). PEG placement has been reported to resolve many of the problems presented by NG tube feeding in terms of maintaining placement and continuity of feeding (Park, Allison, Lang, Spence, Morris, Danesh, Russell and Mills 1992). Although studies have cited complications with PEG tubes such as chest infections, (Hassett, Sunby and Flint 1988) local infection around the insertion site and similar difficulties in maintenance *in situ* (Wanklyn, Cox and Belfield 1995; Santos and McDonald 1999), the relative simplicity of the procedure has resulted in a continued and significant increase in PEG placement (Nicholson, Korman and Richardson 2000).

PEG is currently regarded as the preferred method of treatment for dysphagia in cases where long-term non-oral feeding is required, as described by Rabeneck, Wray and Petersen (1996). According to BAPEN guidelines, PEG feeding should be considered if the dysphagia is likely to persist beyond 21 days.

In some cases, patients need to have tubes inserted into their abdomen, and these are named according to the site of placement – for example Percutaneous Endoscopic Jejunostomy (PEJ) is performed when the tube is inserted directly into the jejunum. These procedures are not routine, but are carried out when there are contraindications to feeding directly into the stomach.

3.5.2.5. Total Parenteral Nutrition (TPN)

This feeding intervention is *parenteral* as it does not use the enteral tract, but provides nutrition directly into the bloodstream. TPN is not routinely used for patients following a stroke, unless they have co-existing gastrointestinal problems such that enteral feeding is not possible.

3.5.2.6. Selection Issues for ANH

There is currently insufficient evidence to give concrete recommendations on when to initiate non-oral methods, and which type of ANH should be used in each clinical situation. The issues as they relate to stroke care will be discussed further in section 3.5.4.

It also remains uncertain in the literature regarding the clinical outcomes associated with ANH. There is deeply divided opinion over whether ANH sustains or prolongs life, and in which clinical situations (Graham 1999; Gillick 2001; Somogyi-Zalud, Zhong, Hamel and Lynn 2002).

The issue of 'life-prolonging' medical treatments, (of which ANH is included according the BMA, 2001, op cit), is controversial. Medical advances have led to the situation where technological devices allow life to be sustained or prolonged through artificial means. Where life is sustained for a temporary period such that the body can recover and regain functioning, there is less controversy relating to whether these technological interventions are positive and beneficial to the patient.

Where the intervention sustains life with debatable 'quality', the issue of 'best interests' becomes complex and controversial. In some cases, it is argued that technological advances prolong the dying process as opposed to sustaining life.

Some authors, such as Capron (1986) refer to this as the 'medicalisation of death' whereby death is prolonged, or characterised by attempts to prevent its inevitability.

3.5.3. Economic aspects of nutrition

The economic impact of nutrition on society is unclear. In order to explore this, health economists often attempt to compare the relative costs associated with malnutrition - both 'under' nutrition and 'over' nutrition. In addition, there are costs associated with ANH for some individuals in terms of whether the treatment costs exceed the benefits. Cost benefit analyses, however, are rarely undertaken.

The first of these issues relates to undernutrition and the effects on society. The Council of Europe Resolution (2003, op cit) identifies the health economic impact associated with undernutrition

> *'undernutrition among hospital patients leads to extended hospital stays, prolonged rehabilitation, diminished quality of life and unnecessary costs to health care'*

This concern was echoed by Barna (2002) who reviewed the role of nutritional care in hospitals and concluded that 'nutrition is the most cost effective measure to prevent the complications of diseases'.

Health promotion initiatives to tackle malnutrition have multiplied over recent years, with acknowledgment of the wide-reaching detrimental effects for health and economy of poor nutrition. Solomons (2005), amongst others, highlights the socio-economic impact of childhood malnutrition to later disease incidence and management. Two notable health promotion policies in the UK include direct advice to individuals (The '5 a day' initiative by the department of health in 2003) (DOH 2003) and campaigns to improve institutional food (School fruit and vegetable scheme, (DOH 2004)).

When considering ANH, the issues are further complicated by the standards used to measure effectiveness. Alvarez, Monereo, Ortiz and Salido (2004) considered the role of management on the issue of clinical nutrition, recognizing that it is an expensive service requiring scrutiny. In recognition that evidence based medicine and cost effective medicine are both relevant to these decisions, they reached the conclusion that economic analysis is too simplistic to be of use to the ANH debate. Waitzberg and Baxter (2004) highlight that 'hospital malnutrition burdens the system financially by provoking a higher rate of surgical complications, mortality and longer

hospital stays; Investment in nutritional therapy provides economic returns.' They suggest that a clinician should consider other factors in decision making, such as 'quality, efficiency and effectiveness' of the treatment, often in a wider context than for one individual patient.

The literature provides inconsistent views over the economic impact of various forms of ANH. For example, Hedberg, Lairson, Aday, Chow, Suki, Houston and Wolf (1999) identified that early enteral feeding after surgery proved cost-effective, where as Lucha, ,Butler, Plichta, and Francis, (2005) revealed that early enteral feeding reduced peri-operative mortality, but with increased costs.

Hull, Rawlings, Murray, Field, McIntyre, Mahida, Hawkey and Allison (1993) identified the value of a specialised enteral feeding team in facilitating early hospital discharge and, therefore, reducing costs associated with length of hospital stay after stroke.

Despite the economic impact remaining unclear, it is evident that an evaluation of the economic perspective is significant for those responsible for policy development. The following examples highlight the significant impact of the economic perspective when considering ANH as a 'life-sustaining treatment'. Baroness Warnock sat on the Lords select committee on euthanasia in 1993, and remains a highly respected contributor to health and social policy. She recently stated her personal view that keeping an older person alive is 'an awful drain on public resources,' (Templeton 2004).

Similarly, Dr Tim Howe, the doctor who gave evidence in the case of Tony Bland (see chapter 5 for further details of this case) stated that 'Some press reports said the decision (to withdraw feeding) was a financial one. In a sense it was because every penny spent on keeping someone alive who cannot benefit is a penny that is not being spent on someone who could' (Alert 1999).

The tension between developing technological advances and the ability for a society to support their use economically is becoming an increasing issue for government policy and practice.

Having considered the economic context of ANH, the issues as they relate to stroke care will now be discussed.

3.5.4. ANH use in Stroke Care

With regard to ANH, there is a paucity of research or guidelines that focus specifically on stroke.

Some authors have reported studies comparing the nutritional efficacy of PEG feeding compared to NGT feeding after stroke. These studies have suggested that PEG feeding should be considered to be the 'nutritional treatment of choice' (Norton, Homer-Ward, Donnelly, Long and Holmes 1996). Other studies have addressed the issue of patient selection for PEG feeding after stroke in the context of the clinical outcomes of both survival and disability (Wanklyn, 1995 op cit). However, most studies to date have been small scale, hence difficult to generalize to the entire stroke population.

There are limited figures available for the incidence of gastrostomy tube placement in the UK. In an epidemiological review of ANH interventions, Cummins, Marshall and Burls (1999) reported figures from the West Midlands region of England such that 66% of the total PEG's performed in the region were for patients following stroke. However, as outlined in the British Association of Nutritional Survey (BANS) (BAPEN 1998), caution is necessary if attempting to extrapolate regional findings to national prevalence figures, due to the large variation reported in prevalence data for enteral feeding. In relation to Home Enteral Tube Feeding (HETF), BANS reported a high growth figure for HETF of 20% per annum. Data suggested that diseases of the Central Nervous System accounted for 64% of the increase per annum, with stroke being the most common diagnosis. It is acknowledged by BANS however, that whilst the use of enteral feeding is increasing annually for stroke patients in the UK, data sets are variable and standardised terminology for comparison is unreliable.

In the USA, Grant (1998) reported 'an estimated 1% of the US population aged over 85 years was discharged from a hospital in 1990 with a gastrostomy'

In relation to stroke care, Blackmer (2001) reports that the percentage of patients with stroke who might require ANH varies widely in the literature, with figures ranging from 8.5 to 29%.

More recently, the Scottish Intercollegiate Guidelines Network (2004, op cit) produced a document giving a comprehensive account of available evidence for feeding interventions after stroke. For NGT and PEG decisions, these guidelines

highlight the lack of available evidence in determining the optimum method for feeding stroke patients.

In an attempt to address the lack of clinical evidence for ANH feeding after stroke, the F.O.O.D (Food or Ordinary Diet) trial (Dennis 2004; Dennis 2004; Dennis, Lewis and Warlow 2005; Dennis, Lewis and Warlow 2005) was developed as a large international trial evaluating various approaches to nutrition after stroke. The study involved in excess of 5,000 patients, with the patients being randomised to different groups. Amongst the study aims were those of establishing the optimum time to start ANH, and comparing the outcomes of patients who had NGT or PEG feeding. In respect of these aims, the results were largely inconclusive. With regard to the timing of ANH, early tube-feeding was associated with a 5.8% reduction in death but a 1.2% increase in poor outcomes compared with delayed tube-feeding. Hence it is concluded that early tube-feeding may reduce case fatality but this may be at the expense of increasing the proportion of patients surviving with poor outcomes. With reference to NGT and PEG comparisons, the NG tube was associated with a marginally significant 7.8% reduction in poor outcomes and a non-significant 1.0% reduction in death when compared to PEG feeding. The trial concluded that NGT feeding should be used in preference to PEG in the first three weeks after stroke.

In summary, therefore, there remains limited clinical evidence with regard the ANH selection, timing or efficacy after stroke, resulting in clinicians making decisions in an uncertain clinical context.

The decisions for ANH are further complicated by the uncertain benefit relating to aims of intervention.

There is divided opinion amongst the literature and clinicians over whether ANH should be viewed as life 'prolonging' (with the implication that death will be inevitable and probably imminent) or life 'sustaining' (having a more ambiguous link to a temporary arrangement to allow recovery). The clinical evidence is inconclusive, reinforcing the problematic nature of predicting prognosis and the aims of treatment. Mcfie (2001) acknowledges this dilemma, and suggests the concept of a 'time-limited trial' of artificial feeding when prognosis is unclear. He argues that this would need to be explicit, with a review date set to consider possible withdrawal of ANH if felt appropriate at a later stage when prognosis might be more evident. This is supported by the BMA in their guidelines for decision making in 2001.

Blackmer (2001, op cit) provided a review of issues in ANH decision making after stroke in recognition of the fact that incidence of PEG placement in stroke patients is

high despite a dearth of clinical advice or evidence regarding its efficacy. Blackmer states that 'the percentage of stroke patients who require tube feeding for nutritional support varies quite widely, with studies quoting rates in the acute phase from 8.5% to 29%.' He states that the decision process for ANH after stroke is complex and 'likely to involve medical, ethical and legal considerations.'

3.6. Decision making for ANH

Approaches to decision making in healthcare are to be discussed further in chapter 6.

With specific reference to ANH, the literature provides accounts of decision making for ANH in a variety of clinical settings and scenarios.

This covers a vast field and considers decisions, current practice and guidance along the spectrum of initiating, withholding and withdrawing ANH.

A main focus of the research literature to date relates to decision making for PEG tubes, with relatively little attention given to the decision process for NGT feeding.

The literature relating to withholding or withdrawal of IV or subcutaneous fluids is largely developed in the context of palliative care, rather than relating to general medical or surgical perspectives.

There is a body of research developing within the field of Mental Health, and specifically in dementia care which addresses the process and factors involved in ANH decision making. The issues raised relate to the intent of the intervention with a progressive condition, and the implications of withholding and withdrawal in different care institutions. Gillick (2000) for example, raises issues over the efficacy of tube feeding in this client group. She challenges the emotional impact of withholding feeding, and focuses instead on the clinical risks and benefits associated with a degenerative condition. She therefore suggests that ANH is not beneficial for patients with dementia. However, she maintains that cases must be considered individually and that 'decisions should reflect the preferences of the patient and should arise from a clear determination of the overall goals of care'

Mitchell, Kiely, and Gillick (2003) considered the financial and economic implications of ANH with patients with dementia. In the USA, they found a perverse financial incentive to tube-feed residents with advanced dementia in nursing homes arising from the additional income generated through private medical care. The

authors propose further research is needed to determine whether these potential financial incentives influence tube-feeding decisions in practice.

The, Pasman, Onwuteaka-Philipsen, Ribbe, and van der Wal (2002) conducted a qualitative ethnographic study to examine the practice of withholding the artificial administration of fluids and food from elderly patients with dementia in nursing homes. They found that doctors' decisions about withholding the artificial administration of fluids and food from elderly patients with dementia are less influenced by advanced directives, and more by the clinical course of the illness and the anticipated 'quality of life'.

This study is remarkable in the literature on ANH decisions in that it is a prospective study based on naturalistic data. The vast majority of research in this field to date has been conducted retrospectively, or via hypothetical decision making methods.

One other prospective study that attempted to study the decision making process for long-term tube feeding was that by Van Rosendaal, Verhoef and Kinsella (1999). They addressed the perspective of both the patient and carer and used semi-structured questionnaires to establish the information given and the process of involvement of the patient and carer in the decision. They found that 'the decision to 'commit' patients to long-term nutritional support via PEG is often difficult and the implications of such a commitment may have major implications for patients and their families.' They conclude that the information needs of patients and carers are currently not met, and that this warrants review.

There is a small body of research on the views of professionals who are involved in the decision process. Watts, Cassel, and Hickam (1986) studied attitudes of health professionals towards ANH ('life-sustaining treatment') in nursing homes in Oregon. Using hypothetical scenarios, respondents were asked whether they would 'favour tube-feeding to correct malnutrition in each scenario.' Nurses showed higher preferences for tube-feeding than did physicians, with both professional groups stating that patient happiness was the strongest and most significant influence upon preferences for tube-feeding. Interestingly, both professions showed a significant tendency to give younger patients tube-feeding in more cases than for older patients.

More recently, Todd, Rosendaal, Duregon and Verhoef (2005) studied the perspectives of nurses on (i) the process of decision-making regarding the placement of feeding gastrostomies, (ii) their role in the process, (iii) the impact this participation has on them personally and (iv) gastrostomy placement in general.

Using in-depth semi-structured interviews and a self-administered questionnaire the authors established views of nurses experienced in percutaneous endoscopic gastrostomy decision-making. They found that the majority of nurses 'would not want to have a gastrostomy for themselves if they were unable to maintain some quality of life', although this definition was not explored. They concluded that the process of decision making was found to be poor in terms of coordination and access to information, and stated that nurses were perceived to play an important, although underused, role in decisions 'to commit patients to long-term feeding'.
The issue of information giving and informed consent was the subject of research by Brett and Rosenberg (2001). They undertook a retrospective review of medical notes to assess the quality of informed consent in hospitalized patients undergoing placement of gastrostomy tubes. They found that medical records documented a procedure-specific discussion of the benefits and burdens related to tube feeding in only 1 of 154 patients. Only 12 out of 33 'definitely or probably competent patients' signed the hospital consent form; in the remaining 21, a surrogate decision-maker signed the form. They concluded that the quality of informed consent for placement of gastrostomy tubes was inadequate in a large community-teaching hospital.
Riley, Mahoney, Fry, and Field (1999) conducted a systematic review to 'synthesize empirical data about patient/surrogate decision making related to withholding or withdrawing nutritional sustenance toward the end of life, and the contextual factors that influence their decision making.'
The authors conclude that 'End-of-life decisions that focus on withholding or withdrawing nutrition and/or hydration present difficult choices at particularly vulnerable times for patients and families' highlighting the need for further research to clarify current practice in this field.

3.7. Summary

This chapter provides an overview of the clinical context in which the study is situated. Over recent years, there has been an increased awareness about the implications of dysphagia and aspiration after stroke. Despite this, the evidence regarding the type and timing of nutritional interventions is sparse. It is acknowledged that ANH decision making has both clinical and ethical implications, hence the approach and outcomes vary in practice. On reviewing the evidence, it is seen that there is limited previous research on ANH decision making. Some studies

have addressed the ethical aspects involved when considering use of ANH for progressive clinical conditions such as dementia. Others have explored decision making through the retrospective accounts of those involved. There has been one major recent trial (the FOOD trial), looking at the timing and nature of nutritional interventions, and the impact on clinical outcomes. To date, there has been no prospective analysis on how nutrition decisions are made after stroke. This study aims to provide this.

4. Bioethical Context

The clinical area under study is multifaceted, drawing on a number of academic and professional disciplines. One major aspect relevant to this research is the bioethical context and background.

This chapter will outline the key theoretical and philosophical factors that are relevant to the clinical decision under investigation. The chapter will start with the broad sociological context, and will then focus on the specific healthcare issues that apply.

4.1. Sociological Context

The sociological factors relevant to this research are far reaching and complex. In the broad context, the views of a society on the treatment of fellow humans, is central to many of the issues in this clinical decision process. In order to understand the healthcare decision, it is necessary to identify the sociological factors that influence 'moral' reasoning. It is, therefore, necessary to consider the evolution of ideas within UK society, and the impact of various disciplines on philosophical thinking. Religious, moral and ethical thinking are distinct fields but are inherently interconnected. Each of these aspects will now be discussed.

4.2. Religious Perspectives

Religious philosophy has had a major effect on healthcare in the UK, and in the past has 'lead the way' in providing doctrine or guidance over clinical practice.

The last population census for England and Wales (NSO 2001) revealed that out of 76.8% of people who responded to register their faith group, 71.6% of these were Christian. Although there were identified flaws with this census (for example, an internet campaign to encourage respondents to respond with 'Jedi Knight'), the national statistics office report this to be representative of religious identity across England and Wales at the time. It is, therefore, not surprising that the Christian faith, and in particular the Roman Catholic church, has provided the greatest voice for religious healthcare views in the UK. Organisations such as the Guild of Catholic Doctors and the Christian Medical Fellowship group offer religious perspectives to support medical professionals in their clinical decision making.

'Doctrines' originating as Roman Catholic guidance have become accepted as bioethical and legal determinants. The views of the Pope and the Vatican have given explicit guidance on the 'rights and wrongs' of clinical practice.
In this context, the impact of religious guidance is significant at both a societal and an individual level with healthcare decision making.
With reference to the specific clinical area under study, there have been contributions from a number of faith groups, each providing valid, but differing interpretations. The provision of Artificial Nutrition and Hydration (ANH) remains controversial in terms of whether it constitutes basic sustenance (food) or medical treatment. This issue generates differing interpretations over the instigation, withholding or withdrawal of ANH.
The Roman Catholic and Anglican denominations have produced a number of guidance documents that have been instrumental in generating healthcare principles. In addition, these are used for reference by both clergy and medical clinicians when faced with practical dilemmas. One of the key documents relevant to this research is the Declaration on Euthanasia (1980) produced by the Vatican ecumenical council. With regard to life sustaining treatment, the guidance states

> *'When inevitable death is imminent in spite of the means used, it is permitted in conscience to take the decision to refuse forms of treatment that would only secure a precarious and burdensome prolongation of life'*

This guidance has attracted attention in the context of ANH and interpretations of this have been widely debated within religious and clinical forums. In 2003, The Catholic Bishops Association gave their interpretation on withholding or withdrawal of ANH in patients who are not imminently dying:

> *'although the shortening of the patient's life is one foreseeable result of an omission, the real purpose of the omission was to relieve the patient of a particular procedure that was of limited usefulness to the patient or unreasonably burdensome for the patient and the patient's family or caregivers.' (Catholic Bishops Association (2003)).*

However, in March 2004 at a Vatican conference, this viewpoint was negated in a statement by Pope John Paul II who stated that

> *"The administration of food and water, even when provided by artificial means, represents a natural means of preserving life, not a medical act,"*

He further stated that '

> *'withdrawing such "basic care" is "euthanasia by omission," (VEC (2004))*

This influential viewpoint created a ripple of confusion over practical implementation in a clinical setting. The interpretation by some hospitals in the USA was that some hospitals were "morally obliged" to continue artificial feeding and hydration for people in a persistent vegetative state. This is in contrast to the evangelical Lutheran viewpoint that ANH should be considered as medical treatment, hence allowing withdrawal or withholding if the treatment is burdensome.

Other faith groups have also provided specific views on ANH decisions.

The Jewish perspective on ANH is largely based on the principle of sanctity of life. Schostak (1994) highlighted the difference in interpretation between withholding and withdrawal of ANH stating that

> *'while there is some debate about whether elderly patients may refuse the initiation of 'tube-feeding', there is a consensus that once initiated, it may not be withdrawn'*

This view is supported in an account of Jewish ethics in healthcare by Rosin and Sonnenblick (1998). They further comment on the interpretation of whether ANH is a treatment or a basic care with their view that

> *'we uphold the principle that as long as feeding by naso-gastric (N-G) or percutaneous endoscopic gastrostomy (PEG) does not constitute undue danger or arouse serious opposition it should be given, without causing suffering to the patient. This is part of basic care, and the doctor has no mandate to withdraw this.'*

More recently, Dorff (2004) studied Jewish bioethics in relation to PVS. He stated the view that

> *'Jewish law allows removal of life-support systems that are impeding the natural process of dying in a terminally ill patient, but it forbids hastening that process.....'*

After describing the clinical tests for establishing brain stem death versus PVS, he concludes with some ambiguity

> *'Since PVS patients fulfill none of these criteria (for brain stem death) most rabbis consider them alive, but some would permit withholding or withdrawing artificial nutrition and hydration.'*

The Hindu perspective on withholding or withdrawing life-sustaining treatment is also ambiguous

> *'Although life should be preserved and prolonged, the condition of life should also be factored into the decision. . . .' (Sharma 2003).*

There is little specific guidance to date on the interpretation for ANH within the Hindu tradition.

The varying and diverse views across these and other faith groups create a context of uncertainty for healthcare decisions. This is amplified in individual clinical situations where patients, family members and professional clinicians may hold differing religious beliefs to inform their decisions.

4.3. Morality

Morality is a social construct that interlinks and overlaps with both religion and ethics.

Rachels (1995) defines moral philosophy as

> *'the attempt to achieve a systematic understanding of the nature of morality and what it requires of us – in Socrates' words – of 'how we ought to live' and why'*

When moral philosophy is applied to a situation, Beauchamp and Childress (1994) define morality as distinct from ethics.

> *'the term morality refers to social conventions about right and wrong human conduct that are so widely shared that they form a stable (although usually incomplete) communal consensus, where as ethics is a general term referring to both morality and ethical theory'*

As reflected in the differing perspectives of religious beliefs, there exists a moral 'plurality' within today's society about the 'right and wrong' conduct of human beings. The account of moral pluralism is clear in writings by Berlin (1997) amongst others, who stated

> *' it seems to me that the belief that some single formula can in principle be found whereby all the diverse ends of men can be harmoniously realized is demonstrably false'*

Holloway (1999) considers morality as a 'maxim' that is separate from religious perspectives within a pluralist society. He argues that

> *'Morality is as much an art as it is a science and it calls for a certain versatility from us, the ability to improvise and respond to actual circumstances and particular situations. The difficulty that faces us today is that we have moved into a state where no single moral system has universal or even widespread appeal.'*

Holloway's account of euthanasia highlights the competing beliefs of religious faiths when attempting to resolve this issue, hence his call to reject religious fragmentation in favour of a more humanitarian (and he argues, more 'morally consistent') perspective.

Recognition of the fact that morality exists in the absence of religion, was central to the notion of a 'medical morality' outlined by Tuten (1951). The evolution of medical morality with technological advances and within a pluralist society was described further by Pellegrino (1987) as being threefold.

> *'the fact of illness, the act of profession and the act of medicine. The first puts the patient in a vulnerable and dependent position; it results in an unequal relationship. The second implies a promise to help; The third involves those actions that will lead to a medically competent healing decision'*

These issues have direct relevance to the clinical decision under study, in that the clinical decision necessitates a moral position by virtue of taking a professional role. This may or may not be congruent with religious or other moral perspectives.

Warnock (2003) makes a further distinction in her view of the foundations of morality, when she described differences between public morality (or morally based public policy) and personal/private morality. The first relates to shared values in context, the second being a moral 'sensibility' or conscience.

Keown (2002) describes the interplay of all aspects of moral thinking when determining a view on the 'value' of human life and subsequent clinical decisions.

It is clear therefore, that a moral perspective has a significant and individual contribution to the decision process under study.

4.4. Ethical Theory

Beauchamp and Childress (1994, op cit) define ethics as

> *'a generic term for several ways of examining moral life. Some approaches to ethics are normative, others descriptive.'*

Normative ethics is a consistent and systematic approach to determining 'right' or 'wrong' acts. Descriptive ethics conversely, studies not what people 'ought to do', but instead looks at how they reason and act.

Ethical theories provide frameworks and principles in which a person is able to make morally appropriate decisions and determine morally appropriate actions. Ethical

theories are diverse and have their origins in a number of academic disciplines. Historically, two types of ethical theory have dominated the field of academic debate. These are the *deontological* perspective and *teleological* theory (including consequentialist viewpoints).

Deontological theory is based on the premise that some acts are fundamentally considered to be 'right' or 'wrong' owing to what Kant (1734-1804) called the 'categorical imperative' (in Beauchamp and Childress, 1994, op cit). For example, Kant argues that 'rules' exist to define ethical and moral behaviour – 'do not lie', 'do not kill', 'keep promises'. Inherent in this belief is that individuals have rights, duties and obligations that determine their moral acts within a society, and are often non-negotiable. The deontological perspective therefore does not focus on the outcome or consequences of an act, but states that an act is good or bad 'in itself'.

Teleological theory conversely, studies the purpose or consequences of an act in order to establish the moral worth. One major subclass of teleological theory is consequentialism, where actions are judged to be either 'good' or 'bad' according to the consequences they generate. This approach rejects the idea that intrinsic moral values (such as truthfulness or fidelity) are sufficient to support an action. One of the most prominent consequentialist theories is that of utilitarianism (Hume, 1711-1776 and Bentham 1748-1832, in Beauchamp and Childress, 1994, op cit) whereby the outcome of the 'greatest good for the greatest number' within a society justifies the action. The key principle within utilitarian theory is utility, the net effect of 'maximising happiness' and 'minimising suffering'.

These approaches to ethical philosophy are 'act-centred' and focus on the moral virtue of the act itself or the consequences of the act. Another approach to ethical theory can be taken, whereby the moral value is 'agent-centred', resting in the 'virtues' of the person committing the act. These have been called 'ethics of conduct' and 'ethics of character' in order to illustrate the different perspectives taken.

Despite having its roots in Aristotle's (350BC) theories, the ethics of 'character' or '*virtue ethics*' has received increased prominence and attention over recent years (Hursthouse 1999). In virtue ethics, the fundamental principle is based in the belief that an action is 'right' if it is virtuous to the circumstances, and carried out by a person with a virtuous nature. The latter is defined by exhibiting traits such as compassion, trustworthiness and a desire to do good.

The impact of ethical theories will now be discussed in terms of applied ethics within healthcare.

4.5. Evolution of Bioethics

It is thought that ethical theory has been applied to healthcare since the origins of the medical profession itself. The Hippocratic oath was written in the 4th Century BC and this highlights the integral force of ethical thinking in medicine.

As technological advances have seen exponential growth within the field of medicine, ethical thinking has been developed and refined to guide clinicians in decision making. Indeed, scientific and technological growth is so rapid within medicine that often, ethical thinking has to be developed and applied after the dilemma has presented, as for example, in high profile cases of 'designer babies' or separation of conjoined twins.

Bioethics is the term given to the 'branch of applied ethics that explores man's obligations to act correctly within the medical field' (VanRensselaer 1971).

In recognition of the need for specialist ethical thinking within medicine, philosophers and academics have developed guidelines to facilitate systematic approaches to medical decision making. Beauchamp and Childress (1994 op cit) outlined four principle components of biomedical ethics which are universally cited as the key framework for determining healthcare delivery. This has been adopted widely within the UK and internationally. Being influenced by both the consequentialist and deontological perspectives, Beauchamp and Childress aimed to draw up a 'process or reasoning that is consistent with both a rule-utilitarian and a rule-deontological theory' in order to facilitate applied ethics in healthcare. The four principles which they offer are those of Autonomy, Non-Maleficence, Beneficence and Justice. In recognition of the virtue ethics perspective, Beauchamp and Childress also acknowledge that the focal virtues for any decision maker should include compassion, discernment, integrity, and trustworthiness. Each of the four key principles will now be discussed.

4.5.1. Autonomy

This encompasses a set of diverse notions including self-governance, self determination, and an individual's right to liberty, privacy and choice. Supporting Kant's original views, this principle states that a person has unconditional worth, and should be supported in their choice to determine their own destiny. This approach is evident in many aspects of public and private values within society. The Human Rights Act (1998) draws from the principles of obligations and rights, with European

and UK directives adopting these principles in public policy. In the NHS, the rights to self-determination have been central to the policies on patient choice and consent to treatment. The Human Rights Act will be further discussed in chapter 5.

4.5.2. Non-Maleficence

Non-Maleficence or not inflicting harm has been associated with the maxim *'Primum non nocere'* – 'Above all (or first) do no harm'. The principle of non-maleficence (and indeed beneficence) is represented in the Hippocratic Oath as 'I will use treatment to help the sick according to my ability and judgment, but I will never use it to injure or wrong them'. The definition of harm is ambiguous, but can apply to individual harm to a patient, or 'wider' harm to carers or society. In the latter interpretation, the principles of utilitarianism are evident.

4.5.3. Beneficence

This refers to the principle whereby society has a duty to not only prevent harm to an individual (non-maleficence) but also to take positive steps to contribute to a person's welfare. In healthcare, this principle is largely assumed with the belief that the goal of the NHS is to encourage health, welfare and well-being and that an individual has rights to expect this minimal level of attention. The recent developments in health promotion in the NHS highlight the increasing influence of beneficence in UK policy.

4.5.4. Justice

Justice considers society as a 'system' where social burdens, benefits and positions require allocation. Rawls (1971) described justice in terms of 'fairness' and this definition is evident in healthcare delivery in the UK with attempts to approach resource allocation in a consistent and fair way. Bodies such as the National Institute for Health and Clinical Excellence (NICE) have been established in order to avoid the 'postcode lottery' criticisms of healthcare resource allocation in the early 1990's. This aims for an equitable distribution of health care for all UK residents.

4.5.5. The application of ethics

The four principles outlined have been adopted by clinicians, researchers, policy makers and lawyers for situations when there is uncertainty in health or social care

decisions. Each of the principles in isolation can be viewed as 'good' or virtuous aspects of any clinical decision. However, the interpretation and application of the principles reveals the diverse nature of their use, and the subjectivity that is inherent when applying them. Presenting the four principles as above suggests that each principle has equal weight and value in every clinical decision. In practice, this is rarely the case and the 'four principle' framework can be criticised as being overly simplistic.

The evolution of healthcare ethics has seen 'phases' where some principles dominate over others. These views are informed and developed by wider sociological issues such as economics, law and population characteristics. The period of time after the second world war generated the welfare state, a redistribution approach that encouraged 'maximum utility, social inclusion and justice' (Esping-Anderson 2002). In this way, consequentialist beliefs may be seen to have been dominant. Healthcare in the 1980's in the UK, saw a shift towards giving the needs of each individual greatest priority, hence patient *autonomy* could be argued to have greater influence than distributive justice. Garnett (2004) described the contribution of Thatcher's government to healthcare as creating a 'hollowed-out Hobbesian philosophy'. This reflected the views of philosopher Thomas Hobbes (1588-1679) whereby self-interest motivates individuals.

At the current time, the ethical principles and philosophy that underpin NHS provision is fraught with contradictions and conflict for clinicians. The current NHS plan (DOH 2000) places a priority on 'patient autonomy, choice and rights' as well as 'reducing inequality, improving access for all'. Whilst reflecting the values of each of the bioethical principles, practical applicability and equal influence is rarely possible within a resource-limited service.

4.6. Ethics and End-of-Life Decisions

This research study addresses clinical decisions that are made for patients who may be described as being in an 'end-of-life' position. Although prognosis is often uncertain after stroke, the ethical dilemma relating to nutrition largely pivots around the issue of whether the patient is going to live or die. It is, therefore, necessary to move from the broad ethical principles as discussed, to consider the specific ethical thinking relating to 'end-of-life' decisions. These will now be discussed

4.6.1. The Doctrine of Double Effect

This principle has its roots in Roman Catholic doctrine, where it was originally a papal decree for the religious position on abortion. Within healthcare, this concept is prominent when obligations and values conflict and in some cases, where principles of non-maleficence and beneficence appear mutually exclusive. The most commonly cited example of 'double effect' relates to side-effects of medication whereby, the 'end justifies the means'. In palliative care, this was most evident when decisions were made to relieve suffering, but having the potential to contribute to a person's death. For example, increasing morphine dose to a lethal level in order to eliminate pain was one of the most widely cited examples of double effect. The doctrine is explicit in that it is the *intent* of the action that makes the action justifiable. If the intent is to alleviate pain, the action is considered justifiable and ethically 'right'. Within the context of ANH decisions, the principle of double effect offers some defence and justification if withholding provision of ANH has the intent of alleviating suffering (or burdens) believed to be associated with it.

4.6.2. Ordinary & Extraordinary Means

The distinction between ordinary and extraordinary means has again evolved from Roman Catholic doctrine, and has been applied within clinical and legal decision making. *Ordinary means* refers to those interventions that are obligatory or imperative, whereas *extraordinary means* refers to those acts that are optional or elective.

In the President's Commission (1983) (cited in Beauchamp & Childress, 1994 op cit), the clearly stated position is that ANH constitutes an *extraordinary* treatment, hence there is no obligation to provide it. They state that

> *'no medical intervention, including a feeding procedure, is required if it merely delays the moment of death'.*

Further, the commission states that in cases of permanently unconscious patients, ANH has the sole conceivable benefit of 'sustaining' the body, 'which is viewed as no real benefit at all'. The Commission concluded that where ANH was simply life-sustaining, the costs could be burdensome to the family and society, and in some cases, could be seen to violate the patient's autonomy.

However, as previously discussed in section 4.2, Pope John Paul II gave a more recent view that ANH should be considered to be *ordinary* means.

As stated previously, the issue of whether ANH is considered to be life-*sustaining* or life *prolonging* is unclear, which further complicates the debate.

With reference to refusal of treatment, the American Medical Association (AMA) House of Delegates (1973) supports that this is acceptable in some cases when the patient is dying. They state that patients or carers could decide about the

> *'cessation of extraordinary means to prolong the life of a body where there is irrefutable evidence that biological death is imminent' (Larue 1989).*

The Roman Catholic position is such that traditionally, a patient's refusal of ordinary means of intervention was considered suicide and should therefore be discouraged, where as refusal of extraordinary means of intervention would not be considered suicide.

As the issue of ANH is the subject of divided opinion in terms of whether it constitutes ordinary or extraordinary means, the focus of the debate has sharpened in clinical cases where withholding or withdrawing ANH is under scrutiny. In these cases, the issue relates to the intent behind the cessation of feeding, and makes reference to the literature and perspectives on euthanasia.

In 1980, the Congregation for the Doctrine of the Faith issued the Declaration of Euthanasia (op cit). This declaration holds that the principle of ordinary and extraordinary means is useful, but often lacks clarity in the context of medical technological advances. The Congregation suggest that the terms "proportionate" and "disproportionate" may facilitate the debate in that a medical clinician may legitimately wish

> *'to avoid the application of a medical procedure disproportionate to the results that can be expected. . . .'*

The Congregation further state that

> *'when inevitable death is imminent in spite of the means used, it is permitted in conscience to take the decision to refuse forms of treatment that would only secure a precarious and burdensome prolongation of life, so long as the normal care due to the sick person in similar cases is not interrupted.'*

There are often differing interpretations of 'treatment' and 'normal or basic care' as outlined by Graham (1999) and this will be further discussed with reference to the legal context in Chapter 5.

4.6.3. The value of Human Life

Keown (2002, op cit) argues that many end-of-life decisions are directly influenced by the perceived value of human life held by decision makers.

Keown presents three 'competing' views on the values of human life that underpin ethical thinking. These are i) vitalism ii) sancity or inviolability of life and iii) Quality of life. He argues that it is imperative to reflect on the different approaches to ascertaining the value of human life if engaging in a debate about end-of-life issues.

Vitalism is the view that human life holds absolute moral worth. Vitalists therefore believe that human life should be preserved at all costs and life-prolonging treatments should always be given.

Sanctity/Inviolability of Life refers to a moral and legal principle outlining a 'right to life'. This perspective holds that a person has a right not to be intentionally killed, but that life need not be preserved at all costs. The focus on 'intention' echoes the principle of 'double-effect' and this is further defined by what might be 'foreseeable' in each case. In cases where ANH has been withdrawn (as in Bland, 1993 – see section 5.6), the principle of double-effect has been adopted in that even though death could be 'foreseen' as a result of treatment withdrawal, the intention was not to shorten life. Whether the act is wrong, lies in the justification given for the act.

The principle of *Quality of Life* using Keown's definition relates to 'assessing not only the worthwhileness of the treatment, but also the worthwhileness of a person's life'. He contrasts this with a more generic use of 'quality of life' where an assessment is made of a patient's condition as a precursor to establishing the worthwhileness of any treatment. Keown further states that his definition of Quality of Life allows judgment on the rights/wrongs of interventions. He states that 'this valuation of human life grounds the principle that, because certain lives are not worth living, it is right intentionally to end them, whether by act or by deliberate omission'

Keown argues that an understanding of the issues within the euthanasia debate, or any clinical discussion about ANH initiation, withholding or withdrawal must acknowledge the value principle placed on human life.

4.6.4. Euthanasia - Killing or Letting Die

It is imperative within healthcare and particularly for care at the end-of-life, to have a moral and legal framework that distinguishes acts of killing and those of letting die. *Killing* can be defined as an intentional act to cause death, and in the majority of circumstances is morally unacceptable and illegal.

Letting die results in the same eventual outcome for the person, but the intent or motivation would be different. For example, 'letting die' in healthcare might be acceptable to relieve patient suffering, if it was felt that an intervention would prolong death rather than maintain or sustain life.

Rachels' work on active and passive euthanasia (1979) and (1986), explored the issue of killing and letting die in terms of the intent and the morality of the distinction. He argued that a passive *omission* to intervene in an attempt to prevent death was morally no better that an *act* of killing. A widely cited scenario given by Rachels is the hypothetical position of Smith and Jones. Both Smith and Jones wanted their six year old cousins dead so that they could benefit from inheritance. Smith drowned his cousin while he was taking a bath; Jones, on the other hand, watched while his cousin slipped and hit his head whilst in the bath, and he then stood by, doing nothing while the boy drowned. Rachels posits that although Smith acts to kill and Jones is passive in letting die, the morality of both is comparable and questionable. Whilst the examples given by Rachels are compelling to support his argument that killing and letting die are morally the same, it does not follow that they are morally equivalent in all situations. For example, within healthcare, an active intervention such as giving a lethal injection and an omission to intervene, such as withholding antibiotics in a dying patient are widely accepted to have a different moral intent. At present in the UK, the former is illegal in all contexts, owing to the weight of opinion that this is morally wrong. An example of this is the case of Diane Pretty, to be discussed further in chapter 5. In contrast, withholding of treatments (such as antibiotics) is seen to be accepted practice in some patient situations. For example, many authors including van der Steen, van der Wal, Mehr, Ooms and Ribbe (2005), state that when patients are dying, antibiotics should be withheld in order to avoid 'prolongation of suffering'.

In some countries, this issue has been integrated into legal guidance so that a person can request help in ending their life if they are physically unable to do so. In these cases, it must be clear that the patient is requesting this voluntarily and with

unquestionable mental capacity and competence. In Europe (Holland, Belgium and Switzerland) and in the American state of Oregon, Voluntary Active Euthanasia (VAE) or Physician Assisted Suicide (PAS) is permitted for such patients. In the UK, the Assisted Dying Bill is currently subject to debate before Parliament in a bid to follow these examples in the UK legal system (2003-current).

Consensus remains that Non-Voluntary Active Euthanasia (NVAE), where a patient is not aware of the act and does not autonomously request it, is currently classed as both immoral and illegal '*killing*.'

Passive Euthanasia (PE) relates to 'letting die' which is the omission to treat in the example above. This is considered by some to be morally and legally acceptable in certain scenarios such as some aspects of terminal or palliative care. However, opponents fear that this approach is susceptible to the 'slippery slope' argument, whereby relaxing a view on passive euthanasia would lead to NVAE, in some cases for people who are not dying. This concern is raised by advocates for vulnerable groups, such as people with dementia or adults with learning disabilities, where it is feared that a judgment might be made by a clinician that the patient is suffering, hence intervention is not worthwhile, or indeed that living with disability equates to a life that is 'not worth living'.

For ANH, the 'Acts and Omissions' outlined and their implications for killing or letting die, have most relevance in the context of withholding or withdrawing ANH. This has received attention in the literature and in professional guidance such as the BMA and the GMC in their guidance on 'Withholding and Withdrawing Life Prolonging Medical Treatments' (2001 and 2002 op cit).

For ANH, a key issue lies in whether the withdrawal of artificial feeding constitutes an act, compared to withholding feeding which may be viewed as an omission. If these distinctions are valid, medical clinicians might perceive withdrawal as an active intention to cause death (killing) as opposed to withholding which would aim to prevent suffering (letting die). This being the case, clinicians might support the latter as being morally acceptable, with the former being unacceptable.

4.6.5. Burdens and Benefits

The clinical terms of 'harms and benefits' are often broadened within ethical debate to see 'harms' as non-clinical 'burdens'.

Burdens and Benefits are reflected in the terminology previously outlined in terms of 'proportionate' and 'disproportionate means' where there is a need to consider the 'balance' between the effects of the intervention and the effects of the outcome. This concept is widely used in healthcare decisions where a medical clinician is charged with acting in a patient's 'Best Interests'. The principle of Best Interests will be covered in section 5.3, but relates here to the assessment of an intervention in terms of the burdens for the patient *and* their family/society alongside the benefits for society. From a bioethical perspective, this highlights the broad interpretations of beneficence and non-maleficence that can be taken in end-of-life decision making. For ANH decisions, this is particularly relevant but has inherent difficulties. For example, it is often unclear from whose perspective the burden/benefit measure should be considered.

Authors have reflected on burden/benefits judgments in other clinical decisions and have revealed that the judgment is not limited to the patient's situation, but often considers the impact on others. These include the carers, (Coetzee, Leask and Jones 2003), the physician and clinical team (Andrews 2004) and society 'at large' (Perkins, Bauer, Hazuda and Schoolfield 1990).

4.7. Ethical Guidelines for ANH decisions

Having outlined the broad ethical principles and the specific principles in end-of-life decisions, it is now necessary to consider the ethical 'guidance' relating to ANH decisions.

Provision of ANH is one such area where the 'hindsight' position has alerted clinicians to ethical dilemmas that could not have been foreseen. When PEG's were first carried out in the early 1980's, the original intended use was to provide feeding for infants and children who could not swallow. Through broadening the use of PEG's to older patients who have dysphagia or low consciousness states, the implications as a 'life-prolonging' medical treatment have become evident. Following the highly publicised Schiavo case (2005) (see section 5.6 for more detail), Jeff Ponsky, one of the original team who developed the PEG feeding technique in 1979,

said that the team never imagined their procedure would lead to such 'massive ethical dilemma's' as it does today. He further stated that

> *'too often the tubes are used in patients with no potential for recovery. Once they are in, it's so emotionally difficult to take them out and let someone die' (The Associated Press (2005))*

Views on the use of ANH remain divided and diverse within the UK and across the world. As such, there are currently no national or international guidelines for outlining the definitive use of ANH. Attempts have been made to provide guidance for issues to consider in ANH decisions, and these will now be discussed.

The British Association of Parenteral and Enteral Nutrition (BAPEN) published a document which outlines the issues for ANH in terms of ethical and legal considerations (BAPEN 2000). This document was mainly promoted to dietitians and gastroenterologists and has not yet been revised in light of changes since 1998. Lennard-Jones (2000), one of the original authors has also been involved in a more recent working party report for the Royal College of Physicians (RCP 2002). This report gives guidance for doctors over their responsibilities for nutrition, ranging from oral to non-oral provision. To date, it can be seen that guidance documents have been fragmented, offering unidisciplinary rather than mulitidisciplinary perspectives.

A number of authors have produced decision making 'maxims' for ANH decisions. Rabeneck, McCullough and Wray (1997) published guidelines for PEG placement with prescriptive guidance on which patients should or should not be offered ANH. Doyal and Wilsher (1994) provided similar ethical maxims to defend withholding or withdrawal of ANH in elderly patients.

Mcfie (2001) op cit gives a perspective on ANH in terms of the outcome rather than the decision process. He states that from a surgeon's view

> *'failure to provide nutritional support in one form or another for patients who have, or who are expected to have 7 days or more of inadequate oral intake should now be considered unethical'.*

At the current time, however, there are no national guidelines for facilitating practical interpretation and application of bioethical principles in ANH decision making. In response, many local NHS Trusts are attempting to synthesize information from a variety of sources, with national 'equity' inevitably under question.

4.8. Summary

This chapter has considered the sociological, religious, moral and ethical influences on the clinical decision process under study. Although stroke is not a progressive condition, there are situations when decisions consider 'end-of-life' or ethical issues, particularly in the context of whether ANH should be withheld or withdrawn from patients. Previous influential cases have centred mainly on PVS or terminal conditions where the prognosis or outcome is clear. In conditions such as stroke where the clinical outcome is less certain however, there is little guidance to support the clinicians in ethical practice. This study therefore aims to explore the current practice in stroke care.

5. Legal Context

In the UK, legal review of healthcare decisions and medico-legal policy development has increased over recent years. Decisions that were once under the auspices of clinicians are now exposed for public debate. Many of the clinical cases requiring legal review have centred on end-of-life decisions, where clinicians are uncertain regarding the legal context of their actions. Once complete, these individual instances of 'case law' provide guidance and precedents for future clinical decision making. In some cases, individual case law leads to changes in professional guidance and may even influence statute.

There are some key aspects of law internationally and in the UK that relate to the research area under study. These will be outlined in order to contextualise the impact of the law on nutrition decisions after stroke. This chapter will move from statutory influence to case law, and will conclude with the current interpretation in professional guidance.

5.1. The Human Rights Act

One key influence on healthcare decisions within the last decade has been the statutory requirements of the Human Rights Act.

In 1948, the General Assembly of the United Nations adopted and proclaimed the Universal Declaration of Human Rights. This was developed into the European Convention on Human Rights and Fundamental Freedoms, with the UK government being the first to ratify this convention in 1951. The Human Rights Act (1998) became statute in the UK, giving a legal premise and clear definition to the universally agreed fundamental human rights for UK citizens.

The United Nations defines Human Rights as 'those rights which are inherent in our nature and without which, we cannot live as human beings' (1998). This encompasses 'any basic right or freedom to which all human beings are entitled and in whose exercise a government may not interfere'.

The implications of the Human Rights Act for healthcare decisions are widespread throughout each of the 18 Articles. The key articles that are directly pertinent to the issue of ANH decision making and end-of-life care are:

- Article 2, The Right to Life
- Article 3, The Right not to have degrading treatment

- Article 5, The Right to security of the person
- Article 8, The Right to Privacy
- Article 9, The Right to freedom of conscience
- Article 14, The Right to not be discriminated against

By its nature, the Human Rights Act promotes the bioethical principles previously discussed from the perspective of the individual within society. The impact of the primacy on individual rights has been apparent within the NHS, and has provided the 'platform' for many legal cases or challenges.

Two highly publicised cases that have used the Human Rights Act as a basis for legal judgment are those of Diane Pretty vs Director of Public Prosecutions (2001) and Leslie Burke vs the GMC (2004). These cases will now be discussed to illustrate their impact on healthcare decisions.

The case of Diane Pretty highlighted the lack of choice for some patients in the UK in terms of exercising their right to die. Diane Pretty, a woman with Motor Neurone Disease who had become progressively disabled and was aware of her imminent death, wished to end her life at the time and manner of her choosing. She requested 'assisted suicide', and sought a court judgment to seek assurance that her husband would not be prosecuted if he assisted her suicide. She argued, using the Human Rights Act that her rights as outlined in articles 2, 3, 8, 9 and 14 would be infringed if she was denied her husbands assistance. The ultimate judgment was clear that this could not be allowed as assisted suicide is illegal within UK law. Further, it was stated that allowing assisted suicide potentially infringes the rights of other people (in this case her husband) to have the option to refuse. In conclusion, the judgment made reference to the added complexity created through the Human Rights Act when making decisions in these cases. In summing up, the judgment stated that 'before the convention became part of English law, there is no doubt that her claim would have failed immediately.'

The second high profile case to employ the Human Rights Act is one that is relevant for ANH and nutritional decisions. In Leslie Burke vs the GMC (2004), the case centred on Mr Burke's challenge to the GMC guidance on withholding and withdrawing life-prolonging treatments (2002). Burke argued that this guidance was unlawful, and was incompatible with The Human Rights Act, particularly articles 2, 3, 6, 8 and 14. Leslie Burke had a diagnosis of progressive cerebellar ataxia, a degenerative condition from which he was likely to experience progressively worsening dysphagia or inability to eat and drink orally. His wish is

that he should receive ANH up to the time of his death, and that the clinicians should neither withdraw nor withhold feeding if they feel it is not in his 'Best Interests' (as determined by a clinician). Burke's desire to ensure that he would continue to receive ANH beyond the point when he loses capacity to request it, is an example of an advanced '*demand*' for care or treatment, something that has not previously been supported in UK law. In recognition of the 'special' nature of ANH compared to other forms of treatment, the initial court judgment ruled that Burke should be able to demand that ANH should be maintained in advance. Lord Justice Munby further advised that in future cases, there should be a 'legal test of Intolerability' based on whether 'the life that this treatment would prolong would be so cruel as to be intolerable' (Burke vs GMC (2004)op cit). Whilst allowing recognition of the inherent difficulties with determining best interests, 'intolerability' is similarly subjective and currently lacks clear definition.

In response to this judgment, the GMC appealed in order to 'seek clarity' on the issue of advanced demands for treatments. This appeal was upheld on 28th July 2005, with the result that there is currently no legal precedent for any patient to *demand* treatments in advance.

As highlighted in the case of Diane Pretty, the issue of whose rights take precedence is complex in end-of-life decisions. The rights of 'carers' (either family or paid carers) is an issue within ANH decision making if the patient is physically disabled after a stroke and is unable to physically carry out their choices. Respecting rights is further complicated if a patient after stroke is unable to state their wishes, hence views of carers and professionals might overshadow the 'silent' rights of the patient.

In terms of rights, there have been some attempts to outline ethical positions on patients who are unable to state their own wishes and some literature refers to this in terms of 'personhood' for the individual. These issues have been used to form the basis of some legal cases. Jurisprudence, the study of legal philosophy employs terms such as 'personhood' when determining ownership and rights for individuals in criminal law and healthcare law. Personhood depends on self-awareness and its implications are highlighted by Harris (1985) who states that 'without self-awareness a patient cannot be regarded a person with the associated rights, including a right to life-saving treatment'. This concept may be illustrated through the legal case of Re B (A minor) (1990) which considered the rights of a disabled child to treatment and concluded that the child's life was 'demonstrably awful' and therefore treatment

should be withheld. This concept was adopted by Doyal and Wilsher (1994) who gave their view on ANH decisions for older people. They stated that non-treatment is advised when 'the person that used to exist no longer does and no other person can evolve instead'. The authors further suggest that ANH should be withheld or withdrawn in cases where the intervention leads to a 'demonstrably awful life'. Further examples of the definitions and properties of being 'human', hence being entitled to certain human rights such as access to healthcare, have been provided by other legal phrases such as a 'life not worth living' and 'worthwhileness' of a life. These issues are paralleled in clinical settings as clinicians attempt to determine Best Interests and 'Quality of Life' for individuals.

5.2. Mental Capacity

As stated, many healthcare decisions in the UK currently place emphasis on respecting the individual's rights, and in particular, the bioethical principle of autonomy. Patient participation and involvement is seen as the expression of this philosophy in current NHS policy. As part of this shift from paternalism, assessment of a patient's ability to understand and make his/her own decisions about healthcare options has been developed and given increasing priority.

Within the specialist field of Mental Health, the issues relating to providing treatment for patients who are not seen to be 'competent' to participate in their treatment choices are not new. They are, however, extremely challenging, with the legal position under constant review.

In 1989, the Law Commission commenced an investigation into UK Mental Health law in order to review the Mental Health Act (1959). This was prompted by some examples of case law whereby greater clarity was required over perceived levels of competence for participation in healthcare decisions. There was a need to extend and define the use of 'competence' for patients for whom the Mental Health Act was not appropriate. These difficulties in interpretation exist today, as highlighted in the cases of Re C (1993) and more recently the 'Bournewood' case (2004).

The Law commission issued a report 'Mental Incapacity' (1995) and the subsequent consultation period resulted in the revised and renamed Mental Capacity Bill in 2005. It is envisaged that this Bill will be enacted in 2007 to create the statutory framework for *all* patients, irrespective of their mental health status.

The terms 'Capacity' & 'Incapacity' have replaced the terms competence and incompetence, but relate to the same general principles of establishing a patient's ability to engage and participate in their treatment choices.

The legal definition of Mental Capacity as given by the Law Commission is 'the ability to understand the effect of a general transaction or document'.

Within the Bill, Incapacity is defined as follows

> *'a person lacks capacity in relation to a matter if he is unable to make a decision for himself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain'*

Mental Capacity within healthcare has previously been referred to in terms of the patients 'capability'. If a patient cannot contribute to their own care decisions, either through physical or cognitive disability, they were previously viewed as being' incapable' of being included in decision making.

The draft Mental Capacity Bill is an attempt to move away from subjective determination of 'capability' to a clear framework for assessing a patient's capacity. The assessment of Capacity has four distinct components i) to understand the information relevant to the decision, ii) to retain that information, iii) to use or weigh that information as part of the process of making a decision iv) to communicate the decision to others. For a patient to be deemed to 'have capacity' they will need to satisfy all of the above requirements in the assessment, and then automatically assume rights to self-determination. Conversely, a person who is unable to demonstrate the above could be deemed to 'lack capacity' and their rights are then open for discussion.

The Mental Capacity Bill states clearly that in all cases, there should be a presumption towards a patient *having* capacity unless this is demonstrated to be otherwise through the above assessment criteria.

The relevance and impact of the Mental Capacity Bill in general medicine is in its infancy at the current time. However, issues relating to assessment of capacity will become increasingly fundamental to end-of-life decisions after stroke.

5.3. Best Interests

The BMA guidance on withholding and withdrawing life-prolonging medical treatments (2001, op cit) gives the following legal context for the phrase 'best interests'.

> *'At present in England, Wales and Northern Ireland, no other individual has the power to give or withhold consent for the treatment of an adult who lacks decision making capacity, but treatment may be provided, without consent, if it is considered by the clinician in charge of the patient's care to be necessary and in the best interests of the patient'*

The term 'best interests' was first introduced in statutory declarations on the rights of children. (Geneva declaration of the rights of the child (1924) and the UN universal declaration of the rights of the child (1959)).

The use of the term has broadened over the years, and is now standard in legal and clinical contexts to apply to situations involving children or adults who lack capacity. As outlined in the BMA statement above, where a patient is deemed to 'lack capacity' based on the steps outlined in section 5.2, the clinician should make decisions based on what would be in their 'Best Interests'.

In recognition of the potential for subjective interpretation of 'best interests', a definition of 'Best Interests' is detailed in the Mental Capacity Act (2005). The Act is scheduled for implementation in April 2007.

Within the Act, the broad context for the 'Best Interests principle' is given as

> *'an act done, or a decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests' (2005)*

The principle is further qualified with the statement that the 'consideration of a person's best interests is only relevant once it has been shown that the person lacks capacity to make the decision in question'.

The Act further outlines a 'checklist of common factors that must *always* be taken into account' when determining a patient's best interests. These include

- Whether the person in question is likely to regain capacity, and if so, when this is likely to be;
- The person must be given full encouragement and opportunity to participate in the decision wherever possible;
- The person's past and present wishes and feelings, and their values and beliefs must be taken into consideration;

- The views of other people, including carers or a lasting power of attorney with duties delegated by the court must be taken into consideration;
- There must be a 'reasonable belief' that the decision taken is in the best interests of the person.

It is stated that the checklist given in summary above, 'is not a definition of best interests, nor an exhaustive list of factors to be taken into account when determining best interests. Rather, they are factors that must always be considered in determining what is in a person's best interests'

The Act acknowledges that there are inherent 'problems' associated with determining best interests, citing 'competing and conflicting concerns' and 'confidentiality' as key difficulties.

In conclusion, the guidance suggests that the aim of determining best interests is to achieve 'consensus' through 'balancing the pros and cons of all of the relevant factors'.

Despite the definition focussing on 'best interests' of the *patient*, it is clear from the literature that in reality, the best interests determination often takes a broader view. Perkins et al (1990, op cit), looked at life-support decisions (including ANH) for stroke patients, and found that 'external' factors such as physician legal liability and family wishes about patient care had a major impact on the ultimate decision.

DeGrazia (1995) acknowledges the gap between theory and practice and is critical of the suggestion of 'neutrality' when determining best interests. He states that the influence of *values* on the decision is neglected, and advocates that the best interests standard should incorporate value theory more explicitly.

It is clear, therefore, that the determination of best interests is fundamental to the process of clinical decision making when a patient lacks capacity. However, the process and issues underpinning this judgment are variable. Despite originating as a legal term (hence its inclusion in this chapter), it is acknowledged that many of the issues in determining best interests involve clinical, legal and ethical factors in order to arrive at the ultimate judgment.

5.4. Legal context for Withholding and Withdrawal of Treatment

The majority of clinical decisions in healthcare remain under the auspices of the clinical team and legal jurisdiction is rarely sought. Case law, where it exists, is largely in connection with decisions to withhold or withdraw treatment for patients. In order to examine issues relating to ANH decisions, it is necessary to set this in context of the current legal position on withholding and withdrawing other medical treatments.

There have been many legal cases in the UK where court judgment has been sought to approve *withholding of treatment* based on the 'best interests' of the individual, hence legal precedent is established. Recent notable cases include those of Charlotte Wyatt (2004) and Luke Winston-Jones (2004) where legal 'permission' to withhold further attempts at artificial ventilation were sought. In both cases, the courts granted clinicians the permission to withhold ventilation based on the view that resuscitation would not be in the children's best interests. Interestingly, this was subsequently reviewed in the case of Charlotte Wyatt as her medical prognosis improved.

With respect to *withdrawal of treatment*, there have been many legal cases regarding withdrawal of ventilation. Most of these cases relate to situations of Permanent Vegetative State (PVS), but this is not exclusively the case, as shown in the examples below.

The legal case of Karen Quinlan (1976), was one of the first in the USA where 'life maintaining' treatment was withdrawn from a patient who was not dying.

Quinlan, a 21 year old patient, had a clinical diagnosis of PVS following a road traffic accident. Her family requested withdrawal of artificial ventilation, and this was referred for legal judgment. Whilst not imminently dying, Quinlan's clinical condition was assessed to be that of a severely reduced consciousness state, with little hope for recovery. Withdrawal of artificial ventilation was sought and approved on the basis that this was a medical treatment that was no longer in her 'best interests'. Ventilator support was withdrawn, although Quinlan was subsequently able to breathe independently, and survived a further ten years.

In the UK, Ms B (2002), also sought ventilation withdrawal, but in this case, she was not in PVS, and sought withdrawal of treatment on her own behalf. Following a spinal cord haemorrhage, Ms B was quadriplegic and required artificial ventilation.

Ms B had capacity, was aware of the implications of her condition for her future life, and requested that her artificial ventilation should be withdrawn. The medical team were reluctant to support her wishes, as this would result in her inevitable death. Ms B therefore sought legal approval of her wishes and won her case. As capacity was evident, the court ruled that Ms B's rights to self determination should take priority, hence her refusal of treatment should be respected. Artificial ventilation was withdrawn and Ms B subsequently died.

These accounts consider withdrawal of medical treatments in cases where there is complexity and in some cases, disagreement over 'best interests'.

It is uncertain how many cases of withholding or withdrawal of treatment do *not* get referred for legal consideration and are instead, resolved in the clinical setting.

As can be seen however, there are clear legal precedents that medical treatments can legally be withheld or withdrawn, subject to the best interest's standard.

In terms of professional guidance, the GMC guidance (2002, op cit) clearly advises clinicians that 'withholding or withdrawing treatment is regarded in law as an 'omission' not an 'act''. The implication of this lies in the interpretation of the current UK situation whereby there is generally no legal liability for a 'mere omission to act'. This contrasts with the position where 'acting' (or providing an intervention) that is deemed to be harmful, can be open to a claim for medical negligence. If the legal position is such that both withholding and withdrawing treatments are 'omissions' to act, the GMC is suggesting that *both* of these 'decisions' are comparable in terms of potential legal outcomes.

5.5. Withholding & Withdrawal of 'Basic Care'

Given the context of this research study, it is necessary to make clear the distinction between provision of oral and non-oral diet, and the legal position regarding withholding and withdrawal of any nutritional intervention.

There is a very clear legal position about a patient's rights to the provision of 'basic care' including oral nutrition and hydration.

The BMA guidance document (2001, op cit), defines basic care as

> *'those procedures essential to keep an individual comfortable'. This includes 'warmth, shelter, pain relief, management of distressing symptoms (such as breathlessness or vomiting), hygiene measures (such as management of incontinence) and the offer of oral nutrition and hydration'.*

Further, the BMA states that

> *'whilst treatment may, in some cases, be withheld or withdrawn, appropriate basic care should always be provided unless actively resisted by the patient' It is clear therefore, that oral nutrition and hydration should always be provided for patients, unless the patient 'actively resists'.*

Professional and legal investigations have highlighted the reality of some clinical practice where this is open to challenge. For example, a coroner's inquest in March 2005 reviewed the clinical practice in Kingsway hospital, Derby, where there was routine withholding or withdrawal of oral nutrition and hydration from patients with dementia. The outcome of the inquest was such that food and drink had been deliberately withdrawn from 11 patients, but this fact could not have been said to contribute to their deaths. Other high profile cases in the UK include the suspension of Dr Ken Taylor in 1999. Dr Taylor, a GP, agreed with the family of a stroke patient that it was not in her best interests to be given oral intake. However, nursing home staff disagreed, and the GMC ordered Dr Taylor's suspension after investigation.
As shown therefore, the legal and professional territory is clearly defined in terms of withholding and withdrawing *oral* nutritional intake as this is deemed within legal and Humans Rights terms to be 'basic care'.

5.6. Withholding & Withdrawal of ANH

The issue of a patient's 'rights' to nutritional intake when provided in the form of ANH is considerably more complex and challenging.
There has been little legal precedent to date regarding withholding of ANH. It is possible that this can be explained in a number of ways. For example the timescale for court review places impractical constraints on withholding ANH until court decisions are known. Additionally, it is possible that in reality, difficulties resolve as one or other party compromises their position or changes their view.
Much of the legal review to date has centred on withdrawal of ANH in patients who are in PVS.
In (1990) in USA, Nancy Cruzan suffered a Road Traffic Accident that left her in a condition of PVS. In 1990, her parents sought legal approval to have her PEG feeding tube removed. 'Evidence' was gained to ascertain what her previously expressed wishes would have been. On the basis of this, the court ruled that withdrawal of feeding would have been in accordance with her personal views, and

would be in her 'Best Interests'. Nancy Cruzan's case was one of the first in the USA to support a previous expression of a refusal of treatment.

Advanced healthcare directives ('Living wills') have subsequently received increasing weight to support a patient's previously expressed *refusal* of treatment. In 1993 in the UK, the widely publicized case of Airedale Trust vs Bland (1993) allowed withdrawal of a Nasogastric feeding tube from Tony Bland who remained in a PVS state following the Hillsborough football stadium disaster. Tony Bland was 19 years old in 1989, when he suffered anoxic brain damage as a result of crush injuries in Hillsborough. The diagnosis of PVS was given, and potential for any recovery was considered improbable. Both the doctors treating him and Bland's parents were in agreement that the NG tube feeding should stop. However, court opinion was sought as Bland was not imminently dying. The outcome of this case was that the feeding tube was deemed to be a 'medical treatment', hence subject to the same legal principles relating to withdrawal as any other clinical intervention. This, therefore, set a legal precedent for ANH withholding or withdrawal in the UK in relation to PVS. Advice is such that where there is clinical agreement over the probable poor prognosis and diagnosis of PVS or similar reduced consciousness states, court opinion should be sought in all cases where withholding or withdrawal of treatment or ANH is considered.

Where this case provided clarity over legal precedent for PVS, the case of Tony Bland has left profound legal uncertainty in the UK for ANH in any other clinical conditions. As stated in the BMA guidance (op cit)

> *'the courts have not specified that declarations should be sought before withholding or withdrawing ANH for patients who are not in PVS. Although a body of medical opinion has developed that such action would be appropriate in some cases (such as some patients who have suffered a serious stroke or have severe dementia) UK courts have not yet considered such a case. This arguably leaves doctors in an area of legal uncertainty, and therefore open to challenge, particularly following implementation of the Human Rights Act'*

In essence, many clinicians working with stroke or dementia are determining clinical and legal 'best interests' in a vacuum of legal precedence.

The Tony Bland judgment has divided opinion in legal, ethical and clinical areas and has proved contentious rather than aiding understanding. The issue of the treatment being 'worthwhile' has been the subject of debate in literature. Keown (2002, op cit)

provides criticism of the judgment from many legal aspects and challenges the semantic interpretation and use of 'worthwhile' in relation to the Bland case. His view is that as Tony Bland was not dying, the ANH was in fact worthwhile to keep him alive, but that the judgment was based in the perceived 'worth' of his life or more specifically his Quality of Life.

'Quality of Life' and determination of a patients 'Best Interests' are widely used concepts within healthcare decision making, although the conceptual basis is far from clear and remains difficult in terms of practical application

A more recent high profile case in USA was that of Terri Schiavo, a woman who had been in PVS for 15 years (2005). Schiavo died in March 2005 after her PEG feeding tube was deemed to be treatment and was legally withdrawn.

There are divided views within legal, clinical and ethical camps regarding the outcome of these two cases. The cases of Tony Bland and Terri Schiavo have arguably created a situation reflecting John Campbell Argyll's (1678-1743) view that 'Hard cases, it is said, make bad law'.

Grubb, Walsh, Lambe, Murrells and Robinson (1996) conducted a survey to look at the attitudes of British physicians to the management of PVS. They reported that 'there is a broad consensus among doctors that treatment-limiting decisions are sometimes appropriate for patients in PVS'. With regard to ANH withholding or withdrawal, they conclude that 'It is not clear why some doctors thought a decision not to treat could be appropriate while a decision to withdraw ANH would not be.' This highlights the potential for perceived differences between withholding and withdrawal of ANH, and these will be further discussed in the context of the findings and discussion within the current research study.

5.7. Legal influence on Professional Guidance.

As seen, the context of ANH decision making is currently uncertain in terms of legal, clinical and ethical aspects. It is often the case that legal cases provide further clarity on some aspects of uncertainty, and as such, legal precedents generate professional guidance review.

Following the Tony Bland case in 1993, the British Medical Association (BMA) and the General Medical Council (GMC) both produced guidelines to help clinicians with decision making for 'Life Prolonging Medical treatments' (BMA 2001; GMC 2002). The guidelines firmly place ANH within the category of a 'life-prolonging' treatment.

Whilst these are professional guidelines rather than legal documents, the basis of the guidance is the legal test cases to date and the clinical interpretation of the legal context.

The guidelines give clarity to the legal position in the management of PVS, and highlight areas of uncertainty within law, hence within clinical practice.

The outcome of the Bland and the Schiavo cases define ANH as 'medical treatment' rather than 'basic care'. As such, ANH is subject to the same legal principles that apply to any other forms of medical treatment.

In recognition of the 'special nature' of ANH however, the BMA & GMC have issued 'additional procedural safeguards' for ANH decisions that may not be relevant for other clinical decisions. These include issues such as routinely seeking a senior review (or second opinion), ensuring legal advice is sought in all cases before withdrawing ANH, and ensuring that all cases are available for clinical review if requested from the Secretary of State. As well as protecting the patient, these safeguards are designed to protect the clinician by supporting the principles of the 'Bolam Test'. As defined by the Ethox centre, this is such that the doctor

> *'will not be found negligent if the court is satisfied that there is a responsible body of medical opinion that would consider that the doctor had acted properly.'(2006).*

The BMA recognises that there is a perceived distinction between withholding and withdrawal of ANH in clinical practice. With reference to withholding or withdrawal of ANH, the guidelines state that

> *'there are no legal, or necessarily morally relevant, differences between the two actions.'*

However, there is an acknowledgment of the differences in 'emotional impact' between withdrawal and withholding of ANH, withdrawal being perceived to be a more *overt action* in some cases. In response to this, the BMA outline the professional perspective on these positions:

> *'treatment should never be withheld.....simply because withholding is considered to be easier than withdrawing treatment'*

The practical suggestion given by the BMA and the GMC is that clinicians should instigate a *trial* of ANH with a review of the benefits and burdens of the intervention once the effects of the 'treatment' are known.

To date, there is limited information regarding the implementation of these clinical guidelines in practice.

5.8. Summary

This chapter has outlined the legal context that supports the current research study. There have been a number of influences from both statutory and case law that create uncertainties when making ANH decisions. Issues of 'autonomy' and 'best interests' have dominated clinical care due to the development of the Human Rights and the Mental Capacity Acts. Unfortunately, there is currently limited guidance or definition of the terms to enable implementation in clinical practice. The position of ANH in legal terms generates further uncertainties. The outcome of the Tony Bland case classified ANH as 'treatment' as opposed to 'food'. This shift legally permits withholding or withdrawing of ANH in cases of PVS. To date, there has been no legal guidance or precedent in the UK to support the management of ANH in stroke care. This study aims to explore whether legal issues have an impact upon current clinical practice.

6. Health Care Decision Making

6.1. Introduction

Having outlined the contributing influences upon the clinical decision under study, this chapter aims to discuss the key features within health care decision making. It will start by outlining decision theory, and will progress to consider decision making in healthcare. It will then conclude with a review of the previous literature relating to ANH decision making, and will provide a synthesis of the previous chapters.

The study of decision theory is vast and as such, cannot be justifiably addressed within this thesis. However, a brief insight will be given in order to contextualise the basis for health care decision making.

Chia (1994) defines a decision as

> *'a point (or incision) contained within a stream of events that seeks to affect the later flow of events in some way'*

Implicit within this definition, is the notion that a 'decision' represents a 'moment' in a series of events, hence the preceding and subsequent events are essential to our understanding of the decision.

Investigation into an individual's approaches to decision making has a long tradition, particularly within the discipline of cognitive psychology. Broadly speaking, perspectives to date include decision theory or analysis, which looks at the *process* of decision making (Kahneman, Slovic and Tversky 1982) or cognitive information processing techniques, which seek to explore the analytical or cognitive *components* within decision making (Newell and Simon 1961).

These two approaches will now be briefly discussed.

6.2. Decision Theory

Kleindorfer, Kunreuther and Schoemaker (1993) suggest that there are three broad types of decision theory. These are cited by Bekker, Thornton, Airey, Connelly, Hewison, Robinson, Lilleyman, MacIntosh, Maule, Michie, and Pearman (1999) as normative theory, descriptive theory and prescriptive theory.

6.2.1. Normative theory

Normative theory describes a rational and logical approach to decision making, based on 'mathematical and statistical proofs' (Bekker et al, 1999 op cit). These approaches assume that decision makers are fully informed about the available options that they might have, and apply consistent probabilistic methods to the options available. The logical choice is therefore determined by the option that maximises 'expected utility'. This approach is most successful where there is a comprehensive evidence base from which to compare and contrast options, hence general heuristics can be developed.

There are a number of criticisms regarding this approach for healthcare decisions, the major one being that individuality in naturalistic settings is discounted. This objective approach creates 'redundancy of information in the real-world' and takes no account of the impact of contexts on healthcare decisions (Bearman 2004).

6.2.2. Descriptive theory

Descriptive Theory acknowledges the reality that normative theory often omits. In recognition of the fact that people rarely make decisions in a logical, normative context, descriptive theories attempt to describe *how* people approach decision making in reality. Early work in this area was carried out by Simon (1955) who revealed the limitations of decision making by nature of humans having 'bounded rationality.' By this, he was acknowledging that human beings are only 'partially rational', with objective thinking bounded by emotions and irrational thinking. Descriptive decision theory aims to describe 'what people do' when faced with situations, rather than offering a structured approach to decision making. Advocates of this approach argue that understanding the process gives an idea of typologies or similarities in approach across groups of decision makers. Simon (1960), suggested a three stage decision process with phases of Intelligence, Design and Choice relating to awareness of information, evaluation and choosing between possible options.

Critics of descriptive theory include Kahneman and Tversky (1979) who highlighted the limitations of application. They state that whilst accurate descriptive models were possible, they were only useful in 'isolated types of decisions with limited choices'. Otherwise, they argue, the possibilities would be too many and varied so as to preclude meaningful interpretation.

6.2.3. Prescriptive Theory

Prescriptive theories, as with descriptive theories, recognise the human limitations in decision making arising through the inability of the human mind to compute objectively. Supporters of prescriptive theory suggest that simplistic maxims such as guidelines or decision aids are required in order to 'prescribe' next steps in decision processes.

Given the healthcare setting, it is recognised that prescriptive approaches to decision making are often attractive in order to standardise clinical care.

Decision aids for example, have been heralded as a way to

> *'improve knowledge, decrease decisional conflict, and increase participation in the decision making process for people who must make healthcare decisions.' (O'Connor, Rostom, Fiset, Tetroe, Entwistle, Llewellyn-Thomas, Holmes-Rovner, Barry and Jones 1999).*

However, there are concerns for some that prescriptive approaches oversimplify the decision, and may be inaccurate. For example, most decision aids in healthcare attempt to standardise approaches for care where there is inherent risk and uncertainty. Given this, critics such as Kahneman et al (1982, op cit), raise concerns about the 'calibration' or weighting placed on the information. Placing too great an emphasis on the probability of the identified 'risk' outcome, might preclude consideration of the potential benefits. This can lead to an outcome based on caution rather than true probabilistic weighting. Another example relates to the 'framing' of the decision choices, where the potential gains are emphasised over the potential losses. This affects the risk taking propensity of humans where the safe option is often taken in preference to the riskier option (Tversky and Kahneman 1981).

Therefore, decision theory adds knowledge to the field of clinical decision making in terms of the processes underpinning the decision, and methods to attempt standardisation of processes.

The impact of the cognitive *components* of decision making will now be discussed.

6.3. Cognitive Information Processing Techniques

The second broad perspective on decision making, lies in analysis of the 'cognitive' components (such as memory, motivation, sequencing skills etc) contributing to the decision itself. Essentially, this approach examines the 'internal' cognitive problem solving skills that individuals use to approach and evaluate options. Supporters of cognitive analysis suggest that in every decision process, there are factors that are unique to each individual as a result of the way they *think*. This being the case, the purpose of cognitive analysis is to identify which internal processes carry the most influence on the decision task.

Examples of cognitive analysis in decision making are evident in the literature. Stout, Busemeyer, Lin, Grant and Bonson (2004) for example, investigated cognitive components in decision making tasks with a study sample of cocaine users. They focussed on various parameters of problem solving tasks, and concluded that motivation and choice had a stronger effect on decision making than memory or learning factors. This study highlights the potential benefits to increasing our understanding of the influence of which aspects of cognitive analysis are most influential on decision making.

Through use of cognitive modelling techniques, Kushniruk and Patel (1998) extended the work on cognitive processing to develop information technology for medical decision making. Their approach was based on 'think aloud' trials, where clinicians were encouraged to verbalise their cognitive reasoning whilst gathering information and making decisions. Through this method, they posit that computer based decision aids can be used in healthcare for a variety of healthcare decisions (Kushniruk 2001). Given the acknowledged individuality of cognitive processes, however, it is questionable as to whether these aids will inevitably follow simple heuristics rather than true modelling of cognitive processes.

These are isolated examples of a field that is rapidly expanding and diversifying. Of relevance to this study, however, is the need to identify the nature of the decision making under investigation.

As the aim of this research is to consider how decisions are made for nutrition after stroke, the focus is on the *process* and *underpinning factors*. The cognitive processes involved are, therefore, not investigated.

6.4. Healthcare Decisions

Making decisions within health care is an increasingly complex process, and one that is receiving attention from a variety of academic disciplines.

Hunink and Glasziou (2001) attribute this complexity to the 'web of diagnostic and therapeutic uncertainties, patient preferences and values, and costs' in the current healthcare setting.

There are numerous perspectives on the potential influences on decision making in healthcare.

Thompson and Dowding (2001) identify cultural changes driven by policy and professional initiatives within the NHS as having an impact on healthcare decision making. Since the launch of the NHS plan (2000, op cit), they state that

> *'driving this culture is a societal concern for greater transparency in the decisions taken on its behalf by policy makers and the professionals charged with interpreting and delivering the policies of central governments.'*

Benner and Tanner (1987) suggest that there are profession 'specific' influences and they particularly describe the importance of intuition within the nursing profession, as a legitimate component of decision making approaches. The impact of intuition on decision processes and outcomes has also extended into social science and humanities research. For example, Ubel and Loewenstein (1997) amongst others challenged the healthcare professionals to identify 'those situations that call for intuitive decision making to be recognised against those calling for more systematic approaches'.

The influence of wider policy, such as changes in law and statute are also seen to be influential. Loughrey (2001) highlights that healthcare decision making has become increasingly complex following the introduction of the European convention of Human Rights into UK law in 1998. Loughrey argues that this creates additional challenges for health care clinicians when determining basic 'rights' for individuals.

In response to growing interest, models of health care decision making have seen rapid growth in the literature over recent years. Approaches vary on a continuum from use of descriptive theories such as informal sociological perspectives attempting to describe how something is approached, to the development and use of normative and prescriptive approaches, as evidenced in formal scientific algorithms or decision aids. Bekker, Hewison and Thornton (2003) define decision aids as 'interventions that help individuals focus on a deliberative choice between

two or more treatment options'. They further state that a 'decision aid has a minimum of two components (a) a visual representation of the risks, benefits and consequences of all decision options relevant to the individual's health, and (b) an explicit discussion of the individual's values or attitudes about the decision options and consequences.' Bekker et al (2003 op cit) evaluation of the efficacy of decision aids generated some valuable insights into their use. Interestingly, their findings highlighted the issue that giving patients more information and choice, led to more negative emotions throughout the process, but ultimately generated an outcome that was considered positive. They concluded that 'It is likely that both patients and professionals will find the consultations less rewarding than routine practice, despite resulting in more effective patient decision making'. The models for healthcare decision making are therefore varied in both philosophy and application. There is an acknowledgement that the culture of healthcare generates unique issues that may influence application of any model adopted, and that models need to vary between contexts and settings (Galotti 2002).

6.4.1. Value-based approaches

Seedhouse (2000) highlights that the values held by decision makers are largely underrepresented by many decision 'tools'. Seedhouse describes values in terms of both 'tangible' and 'intangible' dimensions. There are *physical* and *aesthetic* values relating to tangible belongings, and there are those values that are difficult to articulate, such as *principles* and *ideologies*. All of the values held by participants in a decision process need to be acknowledged and respected if the decision outcome is to be valued itself.

Fulford, Dickenson and Murray (2002) suggest that 'Values Based Practice' (VBP) is unique to health and social care as determined by the nature of the context and decisions being made. They define values as 'the unique preferences, perceptions, expectations, points of view, wishes, desires, etc' of all participants in a decision process, and acknowledge the limitations of approaches that attempt to 'standardise' decision making, such as clinical guidelines, as they exclude reference to values.

Seedhouse (2000 op cit), on the other hand recognises the need for value based decision making, but also acknowledges that a structured framework for decision

making helps to standardise the *approaches* to the decision rather than the values themselves. He states that

> *'a deliberation which examines only the consequences of actions, or only the law, or only duties, might happen to produce good results, but it will not have been carried through with integrity' (Seedhouse, 2000 op cit).*

The challenge therefore, is to generate approaches to decision making that preserve individuality within a 'transparent' or standard framework. This reflects the current position in healthcare decision theory, where clinicians attempt to preserve an individual patient focus in a context of standard clinical guidelines or pathways (Jones 2005).

6.4.2. Decision making in teams

Another aspect within healthcare decision making that requires consideration lies in the changing nature of healthcare delivery and organisation. The shift towards working in multidisciplinary, interdisciplinary and inter-agency teams has created the need for new approaches to decision making as explored by Cook, Gerrish and Clarke (2001). This is supported by others in the literature with Myers and Lamm (1975), for example, describing the influence of group dynamics such as 'polarisation', where the views of individuals become more extreme in a group. Conversely, Janis (1982) observed 'groupthink', where individuals suppress their opinions in the interest of the group. Mohammed and Ringseis (2001) considered the impact of human behaviour dynamics in group decisions when they studied the degree of 'cognitive consensus' within a group. Cognitive consensus involved identifying 'shared assumptions' across group members in order to understand differing viewpoints and opinions. In groups where cognitive consensus was observed, expectations over both the decision process and ultimate action were more consistent and positively received.

These aspects highlight some of the issues contributing to the complexities of group decision making. Given the context of this research study, the nature of the group decision, and hence the impact of group processes requires consideration.

6.4.3. Dealing with uncertainty in healthcare

Hammond (1996) suggests that clinicians have always lived and will continue to live in situations of irreducible uncertainty in diagnosis, prognosis, therapy, and indeed in all aspects of the health care process.

Hippocrates also highlighted that the 'art of medicine' lay in understanding the limits of certainty. Van Crevel (2002) loosely translates Hippocrates words as 'you will never see and treat enough cases to avoid every error in your practice.'

The evolution of healthcare technology has generated further scope for uncertainty in modern healthcare. It is uncertain about what *can* be done for patients, but, increasingly, there is uncertainty over what *ought* to be done.

The Royal College of Physicians (RCP) recently raised the impact of environment and the arts on health and well-being in a national conference (RCP 2005). Central to this theme, was the current position of medicine as a science of 'truth'. Drawing from the work of Sanders and Bardhan (2004), the RCP highlighted that there are increasing challenges facing clinicians in terms of dealing with the inherent uncertainties in healthcare against the backdrop of a society that expects certainty. This 'climate' creates 'spurious certainties' defined by Watkins (2005) as the mechanisms developed to create a 'sense of certainty' despite little evidence base. For example, the evolution of numerous clinical guidelines (based on evidence as defined by Sackett, 1996 op cit) has created a degree of confidence that may be misguided. Further examples of 'spurious certainties' include the increasing reliance on expert witness testimonials, as lawyers attempt to fill the 'uncertainty gap.'

The tension over reality and societal expectation was recognised in the Kennedy Report (2001, op cit) following the Bristol inquiry. In its final report, it called for a change in clinicians' abilities to communicate and live with uncertainty

> *'an attitude of public service also calls for the ability to convey uncertainty without fearing that it will appear weak'*

This view is taken up by Watkins (2005, op cit) who encourages clinicians

> *'to take responsibility not only for handling difficult situations but, in particular, for managing the uncertainties which feature in so many clinical encounters'*

This will now be discussed with reference to the changing role for clinicians over recent years.

6.4.4. Clinical Roles

Criticisms of the 'medical model' and the role of 'paternalistic' doctors were at a peak in the 1970's, as authors from social sciences such as Illich (1975) challenged the power of the clinical professionals. One of the key issues for Illich and others was their belief that doctors acted as 'agents of social control'. In this way, there were concerns expressed over the potential for abuse of power if doctors perpetuated 'social order' through their perceptions of themselves and the value of their patients.

This viewpoint, largely borne out of a pro-autonomy perspective has, in part, influenced the move towards patient choice and involvement in healthcare today, as previously discussed.

Of key relevance to this study, is the issue of roles and responsibilities for doctors when making end-of-life decisions.

In order to act in a patients 'best interests', clinicians of today are expected to make decisions based on clinical *and* social/ethical factors. This is in contrast to the expectations and role historically, as highlighted by the BMA.

> *'In the past, best interests were seen solely in terms of best medical interests and the prolongation of life at almost any cost was often regarded as being in the patient's interests. Modern technology and the ability to sustain some essential functions far beyond the irrevocable loss of awareness and ability to interact with others increasingly demonstrate this to be unsustainable' (BMA, 2001, op cit)*

In this way, current expectations for clinicians to make decisions that are not paternalistic but are motivated by best interests has been acknowledged by many authors to increase clinician's uncertainty over their role. A clear account of this is given by Wong, Poon and Hui (2005) who give a clinical scenario challenging the role of the doctor in a situation where a patient's mother gives him anti-psychotic medication covertly in his soup. In the current climate, the question is raised as to what the doctor's role and responsibility would be in this case. The authors comment that the best interests of the patient can sometimes be difficult for the clinicians to define or ascertain in practice.

The changes in clinical roles can influence responsibilities in decision making. This is particularly evident when making decisions in teams, as is the case in this study.

6.5. Decision theory and ANH decisions

To date, current processes for ANH decisions are neither standardised nor linear. This has been acknowledged by Doyal and Wilsher (1994) amongst others in their quest to develop clinical guidelines.

In attempts to elucidate and understand the process, perspectives on ANH decision making have drawn from normative, descriptive and prescriptive theories. Some examples will now be discussed.

Normative and prescriptive theories formed the basis of the algorithm developed by Rabeneck, et al. (1997) for decisions about PEG tube placement. Although probabilistic weightings were not possible, their critical pathway analysis generated a flowchart for decision making. This approach pinpointed the logical choice out of possible options, based on both diagnosis and prognosis. For example, they suggest that clinicians should 'offer but recommend against PEG feeding for patients with permanent vegetative states', and that 'deficits' in quality of life should lead to a non-directive counselling approach. However, it could be argued that this approach is too rigid for clinical practice, based on the fact that the algorithm is lacking in flexibility for some clinical diagnoses, and too broad and subjective in other conditions. This algorithm has not been adopted into standard clinical practice in the UK, hence the applicability is limited. Doyal and Wilsher's (1994) views focussed on decision guidelines for withdrawal or withholding of life-prolonging treatment in the elderly client group. This issue highlighted many of the complexities relating to ANH decisions. This controversial paper addressed less practical issues, but more philosophical perspectives on 'personhood.' They stated that 'to exercise their rights, patients must have some potential ability to formulate aims and beliefs, and to choose to act accordingly. Without such potential, patients cannot be regarded as 'persons' with any associated rights, including the right to lifesaving treatment'. In their view, ANH could be withheld or withdrawn in these patients, without ethical contention. In reality, these philosophically based decision guidelines have proved controversial and once more, have not been adopted in clinical practice.

Alongside some attempts to use normative and prescriptive approaches as outlined above, descriptive approaches have been used to look at the issue of ANH from a

sociological perspective. Slomka (1992), a social scientist, observed decision making 'in action' and described the observed process as a 'cascade of negotiations' around the meanings of technology and prognosis and not the controlled decision-making the physician would perhaps, like to believe is taking place. She suggests that there is 'an illusion of choice in medical decision making, as offered by the physician' and that this 'begins a negotiation of meanings that allows a sharing of moral responsibility for medical failure and its eventual acceptance by patient, family and physician alike.' Slomka recognises a moral responsibility in ANH decision making that is inherently subjective, hence requires an individualistic approach. In this way, she negates the possibility of useful decision aids or prescriptive approaches.

In recognition of the need for individuality in complex healthcare decisions, recent approaches to decision aids have moved from a rigid prescriptive focus towards systems that help the patients and/or carers to engage more directly in the process. Attempts to develop decision aids of this nature have been applied to the process of ANH decision making. Mitchell, Tetroe, and O'Connor (2001) published a decision aid for long-term tube feeding in cognitively impaired older people. The aid encourages decision makers to consider all eventual possibilities or outcomes associated with their potential choices. This is an attempt to avoid the subjective interpretations as outlined by Slomka (1992, op cit). The authors conclude that they have developed a decision aid that 'improves the decision-making process for long-term tube feeding in cognitively impaired older patients by decreasing decisional conflict and by promoting decisions that are informed and consistent with personal values.' Whilst there are attempts to include personal values in this decision aid, the approach can be criticized as it places constraints upon the diverse range of values that may be present within the team.

As can be seen, the theoretical basis underlying the ANH decision process is, therefore, poorly developed to date. As a consequence, awareness of the key issues is sparse.

6.6. Summary

This chapter has outlined some of the key issues in decision theory and implications for healthcare. On reviewing the literature, it can be seen that there are a number of potential influences affecting the process of decision making, and that there are a range of possibilities to facilitate decisions. For ANH decisions, there have been attempts to apply prescriptive approaches, although the limitations of these have been identified in clinical practice. To date, there have been limited attempts to explore values based or descriptive approaches to ANH decisions. This study aims to identify some of these issues.

The first section of the thesis has explored the gaps in current knowledge about nutritional decision making after stroke and the various contextual influences upon this. This study aims to investigate current practice in nutritional decision making in a clinical setting and analyse the relative influences of the healthcare, clinical, ethical and legal contexts upon this.

Section Two : Design and Methodology

7. Theoretical Perspectives and Methodology

7.1. Personal Background

The purpose of this research was to examine the current decision making processes for oral and artificial nutrition and hydration after a stroke.

I am a Speech and Language Therapist, with 17 years of clinical experience in the NHS in England. I have been involved in numerous clinical cases where decisions for oral or enteral feeding have been made. My own personal and clinical experiences generated the research question under study arising from my interest in the evident variability of approaches and outcomes between patients. There are currently no standard guidelines or decision aids that have been universally adopted within this field of clinical decision making. As a result, the key issues that underpin the decision process in reality are difficult to identify.

The preceding chapters have outlined the possible variety of influences on decision making for artificial nutrition and hydration. To date, the literature on this aspect in the clinical field of stroke has been sparse. Similarly, there has been little previous research to investigate the decision process *prospectively*.

Given the exploratory nature of the research, a hypothesis could not be given in advance. A methodology was required that would encourage an *inductive* process, allowing 'theory to emerge from the data' (Strauss and Corbin 1998).

I was intrigued by the nature and content of the clinical decision process, hence I required a research methodology that would 'offer insight, enhance understanding and provide a meaningful guide to action' (Strauss & Corbin, 1998 op cit). A study design using the principles of grounded theory was therefore developed.

7.2. A Methodological Choice

Given the context outlined above, I was aware in the early stages of the research design that I required a methodological approach that would capture the complexity and diverse nature of the decision process in action.

At this stage, I also needed to consider the theoretical basis of the methodological choice to ensure that it was consistent with my personal 'worldview'. A worldview is

defined by Creswell (1998) as 'a basic set of beliefs or assumptions' that guides the inquiry of qualitative researchers.

At the beginning of my research, I recorded my personal beliefs in my research diary about how I felt ANH decisions were made.

> *'I strongly feel that the patient/carer is not given enough time or information on which to base their decisions. In many cases, my view is that the consultants make the decisions and do not do this with all appropriate information available to them. Increasingly, I feel that there is a wealth of inaccurate information and 'myth telling' - within ALL professional groups. There appears to be an increasing focus on the legal aspects of the decision. Anecdotally, there are many cases where the family view is considered to be the most influential - particularly when the view of the patient themselves is unclear. I suppose in summary, I feel that the approach is random and 'ad hoc' with all of us acting on our past experiences and personal beliefs about what is right or wrong'*

Although I was not expressing this as a philosophical paradigm, it is evident that my worldview expressed a view of 'multiple realities', where individuals have differing beliefs as a consequence of past interactions and experiences. This supported my subsequent choice of grounded theory methodology, as will now be discussed.

7.3. Methodology

The decision to use grounded theory methodology was made at an early point in the research design. The use and application of grounded theory, however, required further consideration. Grounded theory methodology lends itself to methods for both data collection and analysis that are not prescriptive, but vary according to the specific philosophical stance taken.

As with many qualitative research methodologies, the development of grounded theory since its inception in 1967 has been considerable. For this reason, the use and application of grounded theory methodology and methods needs explanation in terms of the philosophical foundation and current application. This section will outline the development of grounded theory over time. This will set the context for the rationale on the use of grounded theory methodology and the methods used in this research study.

7.3.1. A rationale for qualitative design

Clarke (2001) states that 'a distinction is usually made between two approaches to data collection and analysis: the qualitative and the quantitative.' He further states that 'it is common to find these two approaches presented as representing divergent and opposing research traditions in the social sciences.' This dichotomy has now been largely rejected. Cresswell (1998, op cit) outlines the approaches are not mutually exclusive, but that the choice of approach within research should be based on the nature of the research question.

In general, research aims to do one of two things, either to generate theory (induction) or to 'test' theory (deduction). Traditionally, the hypothetico-deductive approach to testing theory has its roots in quantitative and positivist research. In contrast, inductive approaches, where researchers move from observations of naturally occurring phenomena to the development of explanatory theory have been at the heart of sociological and qualitative traditions. In reality, Gilbert (2001) makes clear that the processes are not distinct, and that often both are adopted within the course of research as the investigator aims to predict and explain social phenomena.

The current research study aims to investigate a process of clinical decision making for which there is little past research or developed theory. It is therefore not possible to deduce or 'test' a hypothesis about how decisions are made in this context. The complexity of the clinical area required an approach that was both sensitive to 'new' observations, yet rigorous enough to identify patterns in the data. In recognition of the empirical nature of the research, an inductive approach was required, hence a qualitative methodology and methods were deemed most appropriate.

Grbich (1999) believes that there are two main approaches to qualitative research, these being 'methods based' and 'paradigmatic' perspectives. 'Methods based' approaches align themselves to a more positivist perspective in their use of rigorous and consistent techniques for capturing the 'reality' of the world 'out there'. 'Paradigmatic' approaches on the other hand, require the researcher to acknowledge a particular 'worldview' which has both theoretical and methodological implications.

The methodological choice of grounded theory is a paradigmatic approach, hence it is situated within a specific theoretical tradition. The approach does not seek a single 'truth' but instead, looks for a multiplicity of views. Paradigmatic influences will now be discussed in order to contextualise the methodological position.

7.3.2. Paradigmatic Influences

In order to contextualise this study in terms of data collection and analysis, it is of benefit to consider the paradigmatic influences on qualitative research.
Denzin and Lincoln (2000) take a paradigmatic approach to research in which they identify seven 'moments'. These 'moments' reflect historical influences on the philosophy of how humans derive and develop knowledge. Although reflecting chronological eras, the 'moments' are not immortalised in a linear pathway, but are seen to represent views on a spectrum of beliefs. The resulting paradigms reflect the philosophical beliefs of the researcher, and largely determine the methods used for data collection and analysis. The paradigms they offer are outlined as the 'phases' below:

The traditional era or positivism; Denzin and Lincoln (1994) describe this as the 'first moment' and attach its predominance to the first five decades of this century (1900-1950).This is generally associated with quantitative research, where there is a view that the scientific 'facts' about the world are constant. Positivists aim to uncover the 'objective truth' about the observed world, with their hypothetico-deductive approaches 'proving' or 'disproving' their original thesis. In this view, there is one truth, with reality being 'external' to the researcher.

Modernism or postpositivism; This paradigm is identified as the second 'moment' according to Denzin & Lincoln (1994 op cit) and they place this phase as a twenty year period from 1950's to 1970's. The modernist era introduced the idea of 'subjectivity' and the role of the researcher or 'interpreter' in the research process. The idea of an objective reality was challenged by the view that hypothetico-deduction was not an objective science, but was based in some subjectivity of interpretation. Hence, to address these concerns, modernist qualitative researchers pursued methodological rigour through the development of systematic data procedures. It was in this period that Glaser and Strauss (1967) first developed and published their approach in 'The Discovery of Grounded Theory.'

Blurred Genres; The period from 1970 to 1986 identifies the third era as described by Denzin and Lincoln (1994 op cit). Geertz (1973) generated the term 'blurred genres' in recognition of the fact that the boundaries that were previously evident between social sciences and humanities were becoming blurred as models in each of the disciplines were 'poached' and cross-fertilised. The acceptance of subjectivity within research informed the perspective that there are 'multiple realities' for individuals as opposed to objective facts. This further informed the development of a 'constructionist' view such that knowledge acquisition was believed to be 'constructed' by individuals within society as a result of their experiences.

Crisis of Representation; The fourth moment (1986 -1990) highlights the 'consequences' of blurred genres and the lack of confidence that this generated in qualitative research credibility. Denzin and Lincoln (2000 op cit) describe a crisis period resulting from the erosion of previously accepted classic approaches within disciplines. Despite the 'crisis', this stage was instrumental in allowing the development of processes within qualitative research that are now accepted as procedures for ensuring methodological rigour. Credibility, transferability and auditability within qualitative research replaced the positivist and modernist terms of reliability and validity.

Postmodernist era; In the last decade of the twentieth century, Denzin and Lincoln (2000, op cit) view a fifth moment, or post modern stage in qualitative research. This era identified further 'struggles' for qualitative researchers who were attempting to represent the experiences of 'others', but acknowledging the role of the researcher in 'constructing' the representation. In this stage, the 'aloof observer' was rejected in preference for a more directly participatory role.

Postexperimental era; Lincoln and Denzin (2000 op cit) identify their 'sixth moment' as being characterised by complete rejection of the positivist scientific traditions. In this stage, issues relating to the ethics of naturalistic inquiry are raised, in particular, the issue of 'ownership' of information and consent to inclusion in research. These issues are not the exclusive domain of a qualitative tradition, but reflect the societal shift towards human rights and expectations within all research.

'The future'; Denzin and Lincoln's (2000, op cit) 'seventh moment' is an attempt to predict the landscape of qualitative research in the future as a 'civic sociology.' They recognise that qualitative research is 'an interdisciplinary, transdisciplinary and sometimes counterdisciplinary field' being 'multiparadigmatic' in its focus. As society

evolves, they anticipate a move towards a civic sociology where fieldwork will 'embrace all of the disciplines.'

Multiparadigmatic and multimethod approaches are increasingly acceptable within healthcare research as discussed by Johnson, Long and White (2001). However, critics of the pluralist approach lead to what Baker, Wuest and Stern (1992) call method 'slurring' where flexibility of approaches compromise the rigour and academic credibility of qualitative research.

Denzin and Lincoln (2000, op cit) also recognise this potential threat to the quality of qualitative research and state that in order to maintain credibility, all qualitative research must include and define generic activities. In this, they include theory, method, analysis, ontology, epistemology and methodology. They state further that

> *'Behind these terms stands the personal biography of the researcher, who speaks from a particular class, gender, racial, cultural, and ethnic community perspective. The gendered, multiculturally situated researcher approaches the world with a set of ideas, a framework (theory, ontology) that specifies a set of questions (epistemology) that he or she then examines in specific ways (methodology, analysis).'*

This historical and philosophical account has been necessary to 'place' the current research study in context in order to ensure transparency and therefore credibility for the methodology and methods used. This will now be further explained through examining the evolution of grounded theory and the perspectives that underpin this research study.

7.3.3. The discovery and development of grounded theory

Grounded theory was developed during the second of the paradigmatic 'moments', (the postpositivist or Modernist era) as described in section 7.3.2.

In the early 1960's, two sociologists, Barney Glaser and Anselm Strauss, conducted a study to investigate the phenomenon of dying in a nursing home or healthcare institution. Following the work of Fulton (1964), it was reported that 53% of all deaths in the USA at that time occurred in hospitals or nursing homes. Glaser and Strauss were intrigued by the management of dying, and based their research over a six year period in healthcare institutions within the USA and across Europe. The field work was intensive, involving a combination of interviews and observations.

The study culminated in an account of the technical aspects of managing dying processes ('Awareness of Dying' (Glaser and Strauss 1965)) and insights into the temporal aspects of approaching death ('Time for Dying' (Glaser and Strauss 1968)). These were of particular clinical interest to health care professionals in gaining an insight into the patterns and implications of individuals' experiences.
Of major significance for the social scientist audience however, was their account of the theoretical basis and methods used. This was recorded in detail in 'The Discovery of Grounded Theory' (Glaser and Strauss 1967), where Glaser and Strauss published their procedures for 'discovering theory from data systematically obtained from social research.' This work had an impact on the research community for two reasons. First, Glaser and Strauss came from different philosophical and research traditions, but jointly developed a method for approaching data collection and analysis that remained true to both foundations. Second, they were amongst the first sociologists to expose their methods in a way that allowed open scrutiny.
Strauss received his education in the 'Chicago' school of sociology, having philosophers such as Blumer (1969) and Mead (1934) at its roots. These sociologists shared a theoretical belief that individuals act on the basis of meaning, and that meaning is defined and redefined through interaction. ('Symbolic Interactionism', Blumer 1969, op cit). This approach required the researcher to get 'into the field' in order to understand the background and context of the phenomena under study.
Glaser, on the other hand, came from the 'Columbian' tradition of sociology. This approach brought the methodical and systematic approach to making comparisons between data, in order to identify, develop and relate concepts under study.
The collaboration therefore generated the perspective that subjectivity and methodological rigour could be achieved without compromising either principle. This was characteristic of the postpositivist era as previously described.
In the years that followed, Glaser and Strauss continued to develop their ideas, but their traditions took them in different directions. Strauss collaborated with Juliet Corbin in 1990, and together, they published 'Basics of Qualitative Research' (Strauss and Corbin 1990) a set of procedures for data collection and analysis, based on the principles of grounded theory.
Glaser (1992) rejected this development of the original methodology, with the criticism that the 'cookbook' provided in 1990 was a 'regression to a positivist stance'. Interestingly, however, it has been argued by some (Annells 1996), that

Glaser's own development of grounded theory (Glaser 1998), took a more positivist stance through his belief that there was a 'single reality' to be uncovered, and that objectivity was required. Variability in theory was attributed to the differences in researcher's interpretations, not that there were 'multiple realities'.

Strauss and Corbin (1990, op cit), held the view that there are 'multiple realities' for participants, and that the researchers role is to 'give a voice' to their participants. In keeping with Strauss' foundations of symbolic interactionism, the procedures published in 1990 (op cit) introduced strategic and intervening conditions, which addressed the impact of actions and interactions on participant's beliefs and experiences. This had its basis in relativism, in that reality was seen to be relative to the individual's perspective. Their stance was still broadly positivist, with their methods aiming toward 'unbiased data collection, proposing a set of technical procedures, and espousing verification' (Strauss and Corbin 1990, op cit)

Charmaz (1995) provided a critique of grounded theory methodology when she applied the method to her research study on chronic illness. She argued that the development of grounded theory by both Glaser (1998, op cit) and Strauss and Corbin (1990, op cit) provided an objectivity that she could not support. Her view was that in order to be applicable to healthcare research at the time, a constructivist position was required. By this, she meant that the underpinning paradigm required 'a middle ground between postmodernism and positivism' reflecting the role of both the participants, and the interpretations or 'constructs' as perceived by the researcher. Her view that 'constructivism assumes the relativism of multiple social realities' recognises the 'mutual creation of knowledge by the viewer and the viewed, and aims toward interpretive understanding of subject's meanings' (Charmaz 2000).

In this way, Charmaz recognises the role of the researcher as having a more explicit and fundamental impact on the research findings, than is suggested by Strauss & Corbin (1990, op cit).

Thus, Charmaz (2000, op cit) believes that the methods offered by Strauss and Corbin (1990, op cit) 'offer rich description and make conditional statements, but they remain outside of the experience.' She states that her paradigmatic stance of constructivism within grounded theory methods means 'listening to their stories with openness to feeling and experience.'

7.3.4. Theory building

Grounded theory refers to theory that has been generated inductively through detailed analysis of the data. This is in contrast to a deductive approach, where a preconceived 'hypothesis' is 'tested' for verification or rejection. This illustrates one of the key issues developed by Strauss and Corbin (1990, op cit) when they designed a process for verification as well as generation of theory within their method.

A key aim in grounded theory methodology is to generate theory from the data that explains the phenomenon under study.

Strauss and Corbin (1990, op cit) define theory as

> *'A set of well-developed concepts related through statements of relationship, which together constitute an integrated framework that can be used to explain or predict phenomena'*

The development of theory is a complex and iterative process, involving processes such as conceptualising ideas, placing concepts into a structured schema, determining relationships between concepts and understanding implications of the ultimate theory.

Grounded theory methodology identifies different levels of theoretical development based on the scope or application of the resulting theory. The terms used for the levels of theory are 'formal' and 'substantive' theories and these will now be defined.

'Formal' theories are derived from the study of a phenomenon in a variety of contexts or settings. As formal theories are less specific to certain contexts, they are applicable to a wide ranging set of disciplines and problems. These theories transcend the detail of the data, to provide an over-arching 'context' for the research. In the case of this research study for example, models of decision making, such as the work by Simon (1955), would be viewed as a formal theory in which to 'anchor' the findings generated.

'Substantive' theories, are generally located *within* a formal theory, and are specific to phenomena associated within a certain area or context. As such, these represent tangible accounts of a 'local' issue, with a narrow application of findings. Although theories generated at a substantive level can be 'transferable' to other settings, this is neither the aim nor the claim of substantive theory development. With reference to the current research study, the findings will generate *substantive* level theory about the process of decision making for nutrition for patients admitted to hospital in the

acute stages of stroke. The findings can have no direct implications for these same decision processes in other contexts or clinical diagnoses and do not attempt to generate *formal* level theory. Although the findings allow some transferability of issues to other clinical areas, they cannot directly attempt to explain ANH decision making for example, for patients in nursing home settings, or for patients with dementia.

7.3.5. Rationale for the use of grounded theory 'methods'

Glaser and Strauss' (1967, op cit) original 'discovery' of grounded theory utilised methods of observation and interviewing. Their study of dying was conducted in healthcare institutions where they investigated the actions and views of a variety of disciplines and professionals. This was successful in determining both the structural and the semantic processes occurring in a 'medicalised' social phenomenon. This work has many similarities to the current study.

I was drawn to the methods used by Glaser and Strauss (1967 op cit) as I believed that observational and interview data could provide information on the participants understanding of the process, plus a naturalistic account of the decisions 'in action.' Given the context of the data, it was clear that another rich source of data lay in the participants 'narratives' of events, the clinical case notes.

When designing the study, I was keen to capture data from the variety of perspectives available. I therefore decided to triangulate methods, involving observations, case note documents and in-depth interviews. These will be described in chapter 8.

Comparing the approaches outlined by Strauss and Corbin (1990, op cit), Glaser (1998, op cit) and Charmaz (2000, op cit) for grounded theory methodology, I concluded that the approach offered by Charmaz (2000) based on Strauss and Corbin's (1990) methods was most appropriate for the current research study. My own belief, as revealed in my early research diary entry is that humans develop knowledge based on their experiences, and that, as a result, there is no central or universal truth for social experience. This corresponds with Strauss and Corbin's philosophical stance. In addition, my own personal and clinical experience of the research area precluded any possibility that I could become a neutral or objective observer to events. In support of Charmaz' view, I felt strongly that my past

experience would enrich data collection and interpretation and that this would be advantageous to the research rather than invalidating it. Glaser's pursuit for objectivity did not concur with my own beliefs about a single reality, hence this was rejected.

I therefore chose the analytical procedures of Strauss and Corbin (1990) to inform the methods used for this study, whilst adopting a philosophical position as stated by Charmaz (2000).

My aim for the research supports Charmaz' view as follows

> *'To seek respondents' meanings, we must go further than surface meanings or presumed meanings. We must look for views and values as well as for acts and facts. We need to look for beliefs and ideologies as well as situations ad structures. By studying tacit meanings, we clarify, rather than challenge, respondents' views about reality' (Charmaz 2000)*

In summary, this research study adopts a *relativist ontology*, such that it recognises 'multiple realities' for human experience. The *epistemological stance is subjectivist* where the researcher and participants jointly influence the ultimate interpretive account given. Theory is developed though inductive and iterative techniques using principles of grounded theory methods as developed by Strauss and Corbin (1998). The underpinning paradigm is *constructivist*, recognising the interpretivist nature of the theory generated.

7.4. Theoretical basis for 'methods'

As stated, I used a multi-method triangulation approach for data collection in this study. In order to understand the rationale and purpose of the methods used, it is necessary to see each method in a historical and theoretical context.

7.4.1. Observational data

One of the key reasons for my use of observational methods was to explore the clinical decision making process 'in action'. Literature relating to this clinical area is predominantly based on retrospective accounts of decision making, or interview data, where participants state their views on how decisions are made. To date, there has been limited published work, taking a prospective and naturalistic view of how decisions are made for nutritional interventions after stroke.

Observational methods developed research credibility through their use in anthropology and ethnographic approaches. Adler and Adler (1998) cite a broad definition of 'observation' by Morris (1973) as

> *'the act of noting a phenomenon, often with instruments, and recording it for scientific or other purposes'.*

They further define observation by the fact that it is traditionally non-interventionist. Angrosino and Perez (2000) cite Gold's classic typology (1958) of observational roles in naturalistic inquiry. These typologies outline one of the first considerations required when undertaking observational research. Gold identifies four types of observational role, the complete participant (a highly subjective stance), the participant-as-observer, the observer-as-participant, and the complete observer.

My first decision when using observational methods was to identify and describe my role as researcher. I was clear that I did not want to adopt an extremely subjective stance (as complete participant) due to my inexperience with the method. I feared that I would lapse into my 'established' role as a clinician in these settings, and did not feel confident that I could delineate the role for either myself or others. The complete observer role is a 'purist' stance whereby the researcher has no interaction with the participants. I rejected this role for two reasons. First, I knew that this would be personally challenging due my inexperience and my personal nature. Second, in the context of maintaining an ethical and unambiguous role as will be discussed in section 7.5, I felt that the complete observer role was not appropriate. I opted for the role that Gold (1958, op cit) described as 'observer-as-participant'. Adler and Adler (1998, op cit) state that this allows the researcher to interact 'casually and non-directively' with the participants, but without crossing a line into 'friendship.'

One criticism of using observational data that has been a direct challenge for my research study on a number of occasions is the issue of the 'Hawthorne Effect' (Franke and Kaul 1978). This refers to the impact of 'being observed', where a participant may change behaviour such that the data is no longer naturalistic or representative of the 'unobserved' occurrence. This criticism has been made of ethnographic work since its inception, and its legitimacy depends on the philosophical stance of the researcher. If the researcher claims complete objectivity and adopts a role as 'participant-as-observer' for example, the contradictions are evident. My position of a constructivist perspective allows the subjectivity supported by the 'observer-as-participant' role, hence the impact of being observed was acknowledged rather than avoided.

As will be discussed in chapter 8, the effect of my presence on the clinical setting was variable. At times, my presence was directly acknowledged as the participants referred to me and my need for data. On one occasion for example, a consultant physician repeated what a patient said to him 'for the benefit of the tape-recorder'. On other occasions, and over the course of the longitudinal involvement, it was clear that participants relaxed to an extent that they talked between themselves about personal or sensitive issues, with the tape-recorder on full view.

In this study, observational methods were particularly useful for capturing the intervening events during the decision process due to the flexibility for viewing professionals in a number of settings. For example, observing a consultant physician going from a ward round to a multidisciplinary team meeting, and then into a meeting with a patient's relatives, allowed a view of the 'evolving' nature of the decision. In particular, the style adopted by the clinician in each setting was pertinent to investigating information exchange and the relative influence of both the key clinician, and other individuals on the process. Goffman (1969) highlights the issues of 'structures' in social encounters that influence the interactions and outcome. In his account of the 'presentation of self', he raises themes relating to the setting (the 'stage') the individuals (the 'performance') and the team dynamics ('team performers') that are relevant to information exchange and interactions. The decision process under study is subject to all of these factors, hence observational methods allowed insight into the relative influences of these issues.

Another rationale for the use of observational data alongside interview data was to establish the congruence or otherwise between 'thought and deed'.

Decision making within a legal context has received considerable attention from social scientists. There is increasing recognition of the fact that complex decisions in law apply a logical and consistent information base, but that 'discretion' has a major role in the decision process and eventual outcome. Galligan (1986) for example, outlines the challenges for socio-legal studies in that 'action may not necessarily be predictable from scrutiny of the legal rules themselves'. Hawkins (2001) describes the inevitable need for discretion when translating 'rules' into 'actions' by highlighting the level of interpretation and choice that must be made when the rules are applied in context. Discretionary behaviour is compelled by the reality of a situation, the 'vagaries of language' and the 'diversity of circumstances' (Galligan 1986) cited by Hawkins (2001, op cit).

The use of and evidence of discretion is transferable to clinical decision making within a healthcare setting. Clinicians make decisions with a background of some research 'evidence' or frameworks, but are generally required to interpret these in the individual context of the patient presentation. In order to understand the decision process under study therefore, the use of interviews aimed to elucidate the structure and framework for the decision process, with the observations providing the insight into 'discretionary' behaviours.

Having established a need to use observational methods, there were further issues relating to the ethical and procedural approaches that were required. These will be described in chapter 8.

7.4.2. Documentary data

Lincoln and Guba (1985) distinguish between two types of written text collected as data: records and documents. For records, they include text having a formal basis, such as marriage certificates and driving licences. For documents, they refer to the text having 'personal use', such as diaries or letters. They make this distinction on the basis of a differing purpose, hence a different style and context. Hodder (2001) recognises the practical utility of this distinction, but outlines the problems that this 'dichotomy' brings for qualitative analysts. He argues that the distinction is in danger of creating a mechanistic approach to differing sources of text. Hodder acknowledges that all text should be treated 'equally' and that the approach should define the context and outline 'patterned similarities and differences'.

For the current study, a variety of text sources were used. For the patient participants recruited, consent was sought for access to a variety of relevant clinical records. These included medical case notes, nursing notes, speech and language therapy notes, and dietetic notes. In addition, my field diary notes and research diary provided personal reflective accounts of the process under study.

Clinical case notes have long been used as a data source for healthcare and social research. Traditionally, this has taken the form of systematic audits, content analysis or thematic analysis and has contributed to epidemiological studies or subsequent research design.

For qualitative analysis of documents, Macdonald (2001) refers to Scott (1990) as having identified four issues that require consideration

Authenticity; This relates to whether the data sample is genuine and consistent. Where documents are used as data, this cannot be selective, but must be comprehensive and remain true to the original source. In order to preserve authenticity, it was important that the case notes used were 'copied' accurately and comprehensively. This created some practical issues for the current study (as will be discussed in chapter 8), but was achieved through photocopying complete sets of notes from all professional disciplines for all participants recruited.

Credibility; This refers to the degree of accuracy between the 'event' and the account of the event. Gilbert (2001) raises the issue of selective recording of events, either through time lapse between the event and the record being made, or for manipulative reasons. This is relevant for the textual data collected, in that although professional guidelines given by the Department of Health in 1990 state a requirement to write notes 'within the same working day', this may not be achieved in reality. In addition, the use and purpose of clinical notes is not explicit, as will be discussed at a later point.

Representativeness; The text collected must be representative of the documents used within the area under study. For example, omitting text, or selecting text sources that are in the 'minority' for the context would be open to fair criticism of poor methods and questionable relevance.

Meaning; Gilbert (2001, op cit) suggests that establishing the 'meaning' in documentary analysis occurs at two levels, the literal (surface) meaning, and the interpretative level. He believes that the two approaches are necessary to see the holistic view, but acknowledges that the interpretation is most difficult to achieve. Garfinkel (1967) (as cited by Gilbert (2001, op cit)) analysed the content of medical records for psychiatric patients and raised the issue of interpretation and clinical use. Garfinkel found that there were 'good' organisational reasons for 'bad' clinical records, and that the rationale for patient treatment was 'shrouded' in ambiguities. He concluded that clinical records may be kept to serve the clinicians interests more than contributing to the patients care.

These issues were relevant to the current study, and were considered throughout the interpretative process.

The use of patient notes as research data in this study was important for the following reasons.

The research question aims to understand and investigate the process of decision making in a complex environment. Acute ward settings are dynamic, with variability

in terms of patients, staff, events and processes. Medical notes maintain a form of continuity that is consistent to all wards and settings. Whilst the content and style of records may differ, there is accepted Department of Health policy and widespread agreement (within the acute hospital service culture) that medical records should be kept for every patient. The Health Service Circular 'For the Record' (DOH 1999) gives an account of the purpose of medical records, including to support patient care, to support evidence based care, to support administrative and medical decision making, and to support the research needs for health care. There is guidance regarding the storage and handling and 'structure' of notes, but little guidance regarding the content of notes. Given the nature of the research question, it was evident that medical notes would provide further information about the patients 'journey' and the multidisciplinary communication and information processes.

The degree to which the medical notes facilitate medical decision making receives little attention in the literature, although some advocates of computerised records claim that standardised approaches improve clinical care (Stead and Hammond 1983). There is also little attention given to the extent to which the 'account' recorded is representative of the actual event. Where research has been conducted, there is consensus that accuracy of records is questionable (Fox, Reuland, Hawkes, Hebel, Hudson, Zimmerman, Kenzora and Magaziner 1998; Ehrenberg and Ehnfors 2001). In view of Lincoln and Guba's (1985, op cit) distinction of the types of text, and Garfinkel's work on the purpose of medical notes, it was impossible to establish whether the use of medical notes in this clinical area is formal or 'personal' in terms of style and content.

Given this context and the fact that medical notes are considered an essential component of healthcare, it was clear that this source of data was essential to include in order to fully investigate the research question.

7.4.3. Interview data

Conducting interviews to elicit data has a long tradition within qualitative research and social sciences. The particular strength of interview techniques is that the method seeks to understand the respondent's own interpretative meanings of the phenomenon under study. Using interview methods can be open to criticism as highlighted by Ball (2001) in that 'they tend to generate retrospective accounts of

events and idealised presentations of self.' However, when used in combination with other methods, interview data provides insights into the perspectives and 'constructs' held by participants.

Fontana and Frey (2001) raise further potential criticisms with respect to interview methods in that they are not neutral tools, but involve a negotiated interaction between the researcher and the participant. However, they recognise the inevitability of this if researchers are to access information on how people make sense of their actions, as well as viewing the actual events themselves.

Fielding and Thomas (2001) identify three main approaches associated with qualitative research interviews. At one 'extreme' is the *structured* interview, where the interviewer has a tight schedule and asks the same question of each respondent in exactly the same way. This allows a degree of standardisation, and is the approach advocated for market research as described by Macfarlane-Smith (1972).

The *unstructured* interview is at the other extreme, where interviewers have a general list of things to discuss but prefer the conversation to be guided by the participant. This 'guided conversation' as described by (Lofland and Lofland 1994) generates rich and diverse data, and is most appropriately adopted when the researcher is completely naïve to the context.

The *semi-structured* interview is a mid-point between the two extremes. Fielding and Thomas (2001 op cit) describe the position of the researcher as being able to ask the major questions in the same way each time, but is 'free to alter the sequence and to probe for more information.' For these interviews, the researcher has a 'topic guide' as a prompt for the areas to be discussed.

The current research study used a semi-structured approach to in-depth interviewing, with the inclusion of vignettes as described below. This was for the following main reasons. First, my background as a speech and language therapist raised some difficult challenges in terms of asking open questions and without facilitating responses. Often, my clinical work is conducted with patients who are aphasic, hence have an acquired language disorder. For patients with aphasia, the clinical approach is often to ask closed questions, or to facilitate their responses within a structured setting. My first anticipated challenge in qualitative interviewing therefore was to adopt a more 'flexible' approach. I was clear that structured interviews would provide too many constraints, but unstructured interviews would be too challenging for me given my relative inexperience.

Second, the interview stage in my study followed a period of intensive observation in the ward. I anticipated the development of focused questions arising from this period of observation.

Irrespective of the format, qualitative interview questions share a common approach in that the researcher asks questions allowing the participant to respond individually, with no constraints on the type or length of response offered.

Also common to all styles of interview are techniques such as probing or prompting for responses (Kvale 1996). Prompting refers to techniques used to encourage a response from a participant who is quiet or not forthcoming. This may mean simply repeating a question, or re-phrasing a question slightly. Probing relates to follow-up questioning with an aim of eliciting a fuller response. Probes may be non-verbal, such as a silence or an expectant pause, or verbal, such as a direct question 'can you tell me more about that?' In recognition of the potential for 'over direction' by interviewers, Burgess (1982) developed a scale to evaluate the part played by the researcher in shaping the ultimate outcome of the interview.

7.4.3.1. Vignettes

Vignettes are mostly described in the literature relating to household survey development as outlined by Morrison, Stettler and Anderson (2002). Gerber, Wellens and Keeley (1996) define vignettes as 'brief descriptions of hypothetical situations designed to create a reality for participants'. Their purpose is to move respondents from thinking in abstract terms into providing a more concrete context. Vignettes have been traditionally used in medical education as a means of standardising clinical information given to students under test conditions (Wood 2003). When attempting to understand how a student has reached their conclusions, Wood et al (2003, op cit) state that vignettes are invaluable for 'anchoring' information within a specific context.

In designing the current study, the early exploratory stages identified that the variability of patient scenarios would benefit from the 'anchoring' described. It was clear that giving a hypothetical scenario could generate further insights into the underlying thought processes used by clinicians when making decisions. Authors such as Hughes and Huby (2002) and Galante, Araha, Beraldo, and Pela (2003) advocate the use of vignettes in exactly those cases where the decision process or outcomes for clinical interventions are variable. Watson (1994) explored decision making in a clinical context where nurses were perceived to make 'irrational' or

inconsistent decisions. Watson recognized that structured approaches such as simulations or decision frames had been used to examine decision making in the past, but that these had not been matched with 'actual' clinical behaviour. Watson's study observed nurses in practice, compared this with hypothetical simulation techniques and followed this with interviews in which the decisions were further explored. Their study was successful in exploring a variety of perspectives of the phenomenon under study. On this basis, the use of hypothetical simulation techniques was considered useful for the current study. It was acknowledged that observational techniques would generate data on actual behaviour, interviews would generate a rationale for behaviour, but neither of these sources would identify whether clinicians adopted universal approaches to decision making. This was the rationale for the use of vignettes in the current study.

Traditionally, vignettes are used in surveys or questionnaires, where there is a tight design to control variables in scenarios given (Denk, Benson, Fletcher and Reigel 1997; Escher, Perneger and Chevrolet 2004). The purpose for the vignette in this study was not to gather statistical or factorial data, but to provide a view of the overlapping and divergent issues considered when given the same hypothetical clinical scenario.

The vignette design and use is discussed further in chapter 8.

7.5. Absence of the patient's voice

Having outlined the theoretical underpinnings for the methodology and methods used, a final point should be made with reference to the participant involvement. Adopting a relativist stance assumes acknowledgment and involvement of all the key individuals in the process under study. Research that excludes particular voices has been subject to criticism regarding the overall credibility (Rier 2000).

This study has a specific focus on patients in the acute stages of stroke, for whom ANH decisions are frequently being made by clinicians. A comprehensive account of all perspectives would usually be expected in order to understand the range of experience. However, early in the research design, I made the decision not to actively seek the views of the patients or their families in the interview process for the following reasons.

By nature of their illness, and stage in recovery, the patients are often unable to contribute to the process of decision making in reality. Establishing their views at

this stage would have been difficult due to their levels of consciousness, but also may have 'interfered' with the clinical pathway. This same rationale applies to the decision to not interview families during the process. The early stage after stroke can be overwhelming for all concerned, hence the research design required methods that were as unobtrusive as possible.

Whilst acknowledging the absence of the patient's voice as a potential conflict to the theoretical underpinnings, this was justified by a need to ensure that the patients, families and the process itself were not affected by the research process.

8. Research Design and Method

8.1. Research Aim

The research aim was to investigate the key factors in decision making for nutritional intake for patients who have had an acute stroke.

8.2. Research Objectives

In order to achieve this aim, a number of key objectives were identified:

- To explore the views of the clinical team about the decision process for nutritional intake after stroke.
- To observe current practice regarding the decision process for nutritional intake after stroke through prospective data collection
- To identify the key individuals who are involved in the decision making process.
- To explore views about the options for enteral feeding (for example NasoGastric tube or Percutaneous Endoscopic Gastrostomy) and their implications.
- In particular, to examine the factors which influence the clinical team when making decisions about whether to commence, withhold or withdraw enteral feeding, and at what point these actions are given consideration.

8.3. Research Design

The research question has received limited focus of attention in the literature to date. A hypothesis was therefore not possible. Given the exploratory nature of the study, and the need to address the complexity of the decision process, a qualitative research design allowing for theory generation was indicated. This was felt to be particularly important given the possible implications for policy or procedural development within the context of healthcare decision making within the NHS.
The principles of Grounded Theory methodology have been described in detail in Chapter 7, and this outlines the theoretical basis and methods for achieving theory generation. As described previously, this study adopts the principles of grounded theory in both the research design and the analytical procedures used. The study

used a variety of data collection methods, combining techniques to gather both naturally occurring data and participant accounts of the research area. The clinical decision process in question is complex and multifactorial. Each decision appears clinically individualistic, with no clear consensus about how, when and where the 'decision' for feeding after stroke occurs. This is reflected in the literature, as it is largely reported as descriptive and anecdotal accounts. When considering the research design therefore, multiple methods of data collection were necessary in order to reflect the complexity of the process. The main methods used were semi-structured interviews with professionals in order to gain participants personal accounts of the decision making process, as well as observational and documentary data about specific patients. These combined methods enabled the development of a prospective, longitudinal view of decision making 'in action'. The detail of data collection methods is further described in section 8.6.

8.4. An Ethical Approach

The research study focuses on patients who had an acute onset of stroke and were admitted to hospital for inpatient care. As a result, the study group were potentially 'vulnerable' in terms of their ability to engage in both their healthcare decisions and inclusion in research studies. It was essential to ensure that this research study adopted the philosophy of research ethics at every level of its design and execution. This was consistently reviewed throughout the research process, with adherence to key frameworks and processes.

The study followed the Research Governance framework first issued by the Department of Health for England in 2001 and revised in 2005 (DOH 2001/2005). This document sets out the standards and protocols required for any research undertaken within the health or social care settings. Research Governance is a mechanism within the NHS for ensuring organisational accountability and setting standards for good practice for research. The process of ethical 'approval' for research undertaken in the NHS includes mandatory review by an Ethics Committee. This allows for independent and objective views on the design and methods proposed. As the study sites were located in a small geographical area, an application was made to the Local Research Ethics (LREC) Committee covering the study site location. LREC approval was given before the study commenced.

As well as the procedural aspects of ensuring an ethical approach, the research design encouraged a transparent process through overt methods of data collection, information dissemination and consent from all involved.

8.5. The role of the researcher

As previously stated, my previous clinical role informed and generated the research question under study. It was essential in the early stages of the design to explicitly acknowledge my role as a researcher and to consider the implications of my clinical 'past' on the research design. This was important for both myself and my clinical colleagues in order to adjust to my new role.

Throughout the period of the study, I maintained a part-time clinical remit. This decision was made at the beginning of the study for a number of reasons. The funding for my research was secured through a personal fellowship award given by the NHS Executive, North West R&D department. The terms of this award are such that the NHS employer should allow a period of secondment in order to ultimately retain the clinical and research skills in the NHS. I commenced my study in January 2002, the year in which my NHS employer, a Community Trust, was 'reconfigured' to Primary Care Trust (PCT) status. At this time, the major organisational changes in the NHS, plus a national shortage of Speech and Language Therapists created concerns over covering my absence from the PCT. After negotiation, it was agreed that I should work for four days a week on the research study, and one day a week in my clinical role. This created further pragmatic and practical issues for my research. I needed to ensure that my clinical work did not compromise my researcher role throughout the study. In order to avoid ambiguity of roles for both myself and the study participants, I ensured that my clinical role was conducted in a different hospital to the sites under study.

My clinical background raised some issues in terms of access and confidentiality. I had previously held a clinical role in one of the study sites, although there was a sufficient gap so that the clinicians did not ask me for clinical advice. Being a Speech and Language Therapist, there was an assumption on the part of some staff that I could have access to all patient notes. It was therefore essential that I sought permission more explicitly at every step. This raised some awareness early in the study about the culture of wards and access to information and highlighted the need for protocols on confidentiality and consent. This is discussed further in section

8.6.3. In a similar vein, I ensured that participants were aware of my role as a researcher rather than as clinician. This approach could be viewed by some as an attempt to 'hide' my role as a clinician (Behar 1993). Denzin and Lincoln (1998) also raise concerns with attempts to 'ask for revelations from others, but we reveal little or nothing of ourselves; we make others vulnerable, but we ourselves remain invulnerable'. They raise the potential for power imbalance between the researcher and the 'researched' and encourage an open 'equal' approach. This view is further supported by Schwandt (1994) who advocates that researchers should publicly declare their history, values and assumptions. My compromise to this was to introduce myself as a researcher, but with open discussion about my clinical role if participants requested more information.

When considering the impact of my clinical background on the research, it was clear that this affected different data sources in different ways.

When considering interview data, Richards and Emslie (2000) give an interesting perspective on the impact of the interviewer's professional background on the type of information divulged by the interviewee. They compared the data gained using the same interview protocols, but introducing one interviewer as a medical General Practitioner (GP) and the other as a Sociologist from a university. They found that the GP was perceived to have a higher status, hence was described by interviewees in professional terms. The Sociologist was perceived and described according to her personal characteristics as a 'young woman' ('the girl from the university'). In their conclusion, they highlight that the respondent's view of the researcher influences the interview interactions, and suggest that this requires consideration in research design. Acknowledging all of these perspectives, I required an approach that was consistent and credible, but one that was sufficiently neutral to avoid others potential preconceptions of my role. My decision to refer to my role as predominantly researcher was a pragmatic and practical solution. I hoped that my approach allowed for both honesty and transparency, whilst maintaining an unambiguous and explicit purpose for my role. In reality, this was difficult for the following reasons.

When carrying out interviews, I was aware that being a 'researcher' in the context of my clinical experience, was not immediately comfortable for me or for others. In some cases, I was interviewing participants who knew of my clinical background, and this posed challenges. For me, there was the issue of how to ask questions with sufficient naivety to facilitate the research, but in a way that the participant didn't feel I was asking an 'obvious' question. This required a balance of style to gain

neutrality, but without appearing patronizing. For the participants, there was the issue of wanting to give their viewpoint, but feeling potentially vulnerable about divulging their thoughts to a fellow clinician. On one occasion, a Speech and Language Therapist participant stated

> *'I know you know some of this, so it's difficult to work out how much detail to give you....I know I should assume you know nothing about it....but it's hard when I keep wondering if you would agree with what I'm saying....and if it seems right from your point of view!.....'*

This raises another issue relating to my role in interviewing, that being the potential for a power differential by nature of an interview structure. Oakley (1981) offered a feminist perspective on interviews with women, and reflected that a 'question and answer' structure could convey 'covert' signals that the more powerful woman asks the questions and the less powerful woman gives the answers. As I was interviewing participants who I would generally regard as peers in a clinical setting, this potential for power imbalance created some anxiety, at least on my part.

With regard to observational data, the 'shift' of roles from clinician to researcher created a situation with a potential conflict of interests. Despite my assertion that I would be adopting a role as a researcher, I quickly realised that I did not easily become a naïve observer in a ward setting. Regular supervision was essential to heighten my critical awareness in the field. For example, at times, I was unable to see the 'everyday and mundane' issues as being rich data. The naïve perspective of my supervisors enabled appreciation of these issues. The potential problems linked to observations in familiar settings are acknowledged by Chew-Graham, May and Perry (2002). Far from seeing these as limitations, however, the authors see the combination of views from both the naïve and familiar observers to produce comprehensive perspectives.

During observations, there were occasions that I found particularly challenging when there were perceptions of my dual role. For example, where participants were aware of my clinical background, I found at times, that I inadvertently had an impact on the clinical interaction. In some cases, my 'silent' presence arguably gave the impression of 'colluding' or 'endorsing' (by omission) the clinical practice observed. For example, at an early stage in the study, I observed a ward round where a medical clinician carried out a swallowing assessment that would ordinarily be conducted by a Speech and Language Therapist. At the end of the assessment he explained his reasons for doing the assessment to the junior staff present as follows:

' I mean.....I think....a lot of people don't get given fluids.... because people are scared to at least try to see if they swallow.....provided you give a tiny amount.....and you watch them.....which we did.....and we had a speech therapist there.....we knew if we did anything wrong ...you'd have soon told us.....(looking at me)'

Whilst this particular incident generated no cause for concern in terms of the ultimate judgment made by the clinician, it raised questions for me regarding observation of practice that might place me unwittingly in a dual role, and observation of decisions that might challenge my personal beliefs. I needed to develop a personal 'code of ethics' to ensure that I could be prepared for the inevitable tensions of being a researcher, but having fundamental responsibilities as a clinician. This required considerable and constant personal reflection to preserve integrity for both the research and my personal clinical ethics. This process of r*eflexivity* is a principle that requires consideration in qualitative research process to ensure that the perspective taken supports the theoretical underpinnings of the methodology used.

Grounded Theory adopts the social constructionist perspective that human beliefs are products of interactions or social influences. By doing so, there is explicit acknowledgement that the past experiences and beliefs of the researcher cannot be ignored, and moreover, that they should be highlighted within the research process. Social constructionists encourage researchers to adopt a sense of self awareness to their role in both the research and the wider social context. This means being alert to the nature of social constructions underpinning ones own beliefs, and considering the impact on the research interactions. Gilbert (2001, op cit) states

'an adequate conceptualisation of the social world has to include the activity of researching it; the researcher is not simply observing from a position of detachment'

My own experience of the research process *as a researcher* was at times challenging and uncomfortable. I did not consistently enjoy the role of observer as participant and often felt uncomfortable about observing the exchanges between the patients and the staff. This was predominantly due to the 'one-way' nature of non-participant observation. In my clinical role, I am familiar with a didactic process where there is an exchange of views, and I ultimately feel I 'give' something to the other person. In my non-participant role, I was 'taking', but contributing nothing to the other person or the situation. This was a clear challenge to my own personal

constructs of needing to be 'helpful' and perhaps at times, a need to be in control of situations.

Although my observational role was overt and non-participatory, I did not actively avoid interaction with the participants. For example, I did not intrude on the situations or events unless I felt a 'human' contact was needed. On one occasion, a patient who was extremely upset, asked for my opinion about what she should do. My response was neutral and I deferred the question to a member of staff. Although I did not ignore or dismiss her question, my personal upset and anxiety over these situations was high. The fact that I could not 'help' to address the concerns of participants remained a challenge to me throughout the period of data collection. My role in this study was therefore explicitly stated as researcher, but reflexivity over prior experience & potential expectations was acknowledged and remained integral to the process of both data collection and analysis.

8.6. Data Collection

Data were collected in two NHS hospital sites in the UK over a time period lasting 2 years and 4 months.

8.6.1. Study Sites

The sample group was identified as patients who had been admitted to hospital following acute signs of stroke. The study sites therefore were identified to be acute hospitals that admitted patients either directly via General Practitioner referral, or through Accident and Emergency (A and E) admission. As discussed in chapter 3, current stroke care in the UK is delivered in a variety of settings and service models. In acute care, there are two typical models of service provision currently seen as mainstream. These are stroke units or general medical wards. The study sites were two hospital sites that were formerly separate NHS hospital Trusts. Following a hospital merger, the two sites were run independently, but under the 'umbrella' of the same NHS Trust. The hospital sites were both general hospitals, located in the North West region of England.

- **Site a** – was a large general hospital serving a population of 191,210 according to the population census in 2001(NSO 2001). This hospital had 655 beds in total, with 2687 staff recorded at the time of the study. This equates to a 4:1 staff:patient ratio. This site had a dedicated and

comprehensive stroke unit model of care for patients admitted in the acute stages of stroke. All newly admitted patients were initially seen in the acute admissions unit (AAU), and from there were transferred to the acute stroke ward if they had a confirmed diagnosis of stroke. This transfer time was variable, ranging from a few hours to a few days. After a period of time in the acute stroke ward, some patients were transferred for further rehabilitative care to the rehabilitation stroke ward. This transfer time ranged from a few days, to a few weeks depending on medical stability. Both the acute and the rehabilitation stroke wards had 24 beds, giving a total of 48 beds in the hospital dedicated to stroke care. There were three named medical consultants who had responsibility for patients on the stroke wards, although these consultants had general physician responsibilities on other wards in the hospital. Each of these consultants had their clinical expertise based in Care of the Elderly (CofE). There was a stroke care coordinator working across site **a**, who had responsibility for overseeing the immediate clinical 'pathway' for stroke, and liaising to encourage transfer of patients within the hospital to the stroke care wards. A local care pathway for stroke was available for clinicians use on this site.

- **Site b** – was a relatively small general hospital serving a population of 118,218 according to the population census in 2001(NSO 2001). This hospital had 231 beds in total, with 987 staff recorded at the time of the study. This equates to a 4:1 staff:patient ratio. This site had a general ward model of care for patients admitted in the acute stages of stroke. All newly admitted patients were initially seen in the admissions ward and from there were transferred to the first appropriate and available bed within general medicine in the hospital. Allocation of patients to the consultant staff depended on either clinical speciality and the patient's primary clinical need, or bed availability. In the initial stages, the patients were placed under the care of one of the six general physicians. This was for a time period ranging from a few days to a few weeks. There were no specified beds for stroke patients, with patients being treated in wards with varying speciality focus. For example, patients with acute stroke were treated on the respiratory ward, or the cardiology ward, depending on bed and consultant availability. After the acute stages, some patients were transferred to another consultant or ward depending on their clinical need. There were two consultants in the

hospital who take primary responsibility for rehabilitation of patients with stroke or general rehabilitation needs. Each of these consultants had their clinical expertise based in Care of the Elderly (CofE). There was a rehabilitation ward with 24 beds and some patients with stroke were transferred to this ward for on-going rehabilitation needs. A local care pathway for stroke was available for clinicians use on this site.

Given the historical background to the 'merger' of the hospitals, there were some differences in the sites' service provision in relation to issues such as PEG insertion, stroke care and care pathways. This reflects the reality of differing services across hospital care in the NHS however, so was not considered to be detrimental to the study design.

8.6.2. Access to study sites

The NHS hospital Trust was approached before embarking on the research proposal to ensure agreement and access before proceeding. The approach was initially made to the medical director, nursing director and the Trust's Research and Development (R&D) department's who all indicated their willingness to be involved. This allowed proposal development and LREC application.

After gaining consent at these levels, and following LREC approval, each of the key potential participating clinicians was contacted to seek consent for their teams and their patients to be approached for study inclusion. Clinicians and departmental managers were contacted from each of the disciplines, medical, nursing, speech and language therapy, dietetics, psychology, occupational therapy, physiotherapy, and the stroke association. All were sent information sheets and were requested to sign consent forms. This was completed quickly, with no refusals or significant delays encountered.

Access and copying of medical notes required another level of approval via the 'Caldicott guardian' for the Trust. Caldicott guardians were introduced into the NHS following the 'Caldicott Report' 1997 (DOH 1997). Caldicott guardians have responsibility for safeguarding the confidentiality of patient information, hence accessing and copying medical notes for research purposes required additional scrutiny.

8.6.3. Data Collection Methods

As previously stated, the research question aimed to investigate a complex clinical and social process where there is potential for variable views, perspectives and issues. The context of decision making required a multi-method approach to data collection.

This study used a triangulation of methods, with data collected from three main sources: observational, documentary and interview sources. The practical considerations related to these methods will now be discussed.

8.6.3.1. Sampling

There was a rigorous approach to sampling for participants and data. This was refined throughout the exploratory stage and the pilot stage of the study.

The sampling process for patient participants is included as appendix 1. The inclusion criteria were that they should have had an acute stroke and would have been placed Nil by Mouth (NBM) as a result of reduced consciousness or concerns about swallowing 'safety'.

Grounded Theory methodology adopts an approach to sampling that Glaser and Strauss (1967) called *theoretical sampling*. They defined this as

> *'the process of data collection for generating theory where the analyst jointly collects, codes and analyses his data, and decides what data to collect next and where to find them, in order to develop his theory as it emerges'.*

In order to do this, they suggest that the initial sample is designed within a partial framework 'designating a few principal or gross features of the structure and processes in the situations that he will study'. My initial approach could not adopt a loose framework to this extent, due to the requirements for a transparent design as determined by the NHS research ethics guidelines. It was felt that a theoretical sampling approach was neither possible nor practical within the necessary policy and time constraints for the study. The initial sample was therefore a *purposive sample*, that is to say a non-probabilistic and non-randomised approach.

Arber (2001) describes purposive sampling as 'focused' sampling and purports that it is the most appropriate method when the researcher aims to 'generate theory and a wider understanding of social processes and social actions.' Given my research question and qualitative methods, purposive sampling was a necessary starting

point from which to develop sampling. My initial sample was selected based on tight criteria, and from this, further sampling was directed by emergent categories in analysis.

Sampling for patient participants met a practical constraint that raised a methodological challenge, namely the presence of nurses as 'gatekeepers'.

It was clear that the nurses were gatekeepers on two levels, first for alerting me to a potential recruit, and second, for allowing initial access to medical notes. In a busy hospital ward, I found that I had to access information in a way that suited the setting and the staff involved as well as avoiding a system that would be unduly time-consuming for staff. My approach was to take the lead from each individual staff member in terms of how much information they gave me. On occasions, nurses gave me the medical notes to search for relevant details. As a clinician adopting an ethical approach to patient confidentially for research, I did not reject this method, but always sought the approval of the nurses before I approached patients and their families. This was particularly necessary given the potentially sensitive and distressing circumstances that can be experienced for patients and next–of-kin after a stroke.

Seymour (2001) acknowledges the methodological constraints with this approach in that this could be seen as filtering out patients who might be eligible. In terms of patient inclusion, this could introduce 'bias' relating to who determines that a patient is 'fit' to be included? Seymour acknowledges however, that in order to achieve 'sustained engagement' for the research process, the participants (in this case, the nurses) must not be unduly distracted or disturbed from their day-to day business. This was particularly important for me given the longitudinal nature of my involvement.

The potential constraint on patient access was therefore acknowledged, but was accepted as a position of necessary compromise to the study design.

8.6.3.2. The challenges of consent

As previously discussed, the study adopted an ethical approach to participant involvement and inclusion. Central to this philosophy, was the need to ensure that participants received information and gave consent to involvement and that this was a system of 'process consent' (Usher and Arthur 1998) where the 'contract' could be reviewed at regular intervals. This posed a number of challenges in the context of this research design.

8.6.3.3. Informed Consent

Norris (1993) states that adherence to the principle of informed consent to research involvement is based on two main factors. First, that the participant is aware of, and has understood the purpose of the research. Second, that from a position of knowledge, they freely give their consent to be involved. Norris (1993, op cit) outlines the challenges that this creates within research as the explanations constructed 'are always conditional on the audience which one is addressing.' This highlights the potential for inconsistency and assumptions on the part of the researcher, when deciding what constitutes sufficient information. Further, within ethnographic research, Norris states that explanations are difficult when 'one only has a vague sense of what one is looking for.'

For this research study, there were particular challenges relating to informed consent from both the patient and the next-of-kin as participants.

The first difficulty related to the degree of information given about the purpose of research. It was decided that all participants would be recruited to the study based on inclusion criteria of being Nil By Mouth. Given that the research question focuses on nutritional intake, there were some concerns that raising issues of nutrition might highlight awareness and anxieties for participants about the *lack* of nutrition at this stage. For example, if my research information raised issues about decision making for enteral feeding when this had not previously been raised by the clinical team, it was felt that this would be counterproductive for both the participants involved, and the research integrity. As a result, the information sheets for the research gave enough information to indicate the broad area of research, but did not specifically raise issues of enteral feeding (See appendices 2a and 2b). It is acknowledged that this may raise criticisms about the degree of informed consent gained, as information was non-specific. Norris (1993, op cit) justifies this approach in his own ethnographic research as follows

> *'Such accounts are not untrue, but they are veiled. They construct the research role so as to make it understandable and acceptable to the researcher.'*

As my intention was to avoid raising anxiety and the potential for interfering with the clinical process, I felt similarly justified in my approach.

Another difficulty that I encountered with this research study, and personally the most challenging, related to gaining informed consent from participants who may be

unable to consent on their own behalf. There were a number of patients who could not be approached directly due to poor levels of consciousness, or severe aphasia (a language disorder) following their stroke.

The Department of Health's research governance guidelines (2001/2005), state that 'informed consent is at the heart of ethical research' and that

> *'when a study involves participants under the care of a doctor....professionals are informed that their patients or users are being invited to participate and agree to retain overall responsibility for their care'.*

There are no specific guidelines issued by the Department of Heath for gaining consent to research involvement when patients lack capacity, and in particular, there is little guidance over who has responsibility to offer proxy consent. This is covered in detail in section 8.6.3.5.

8.6.3.4. Consent : Professionals as participants

Following 'access' approval, as previously outlined, I sought individual consent for involvement in the study from the key clinicians and professional groups that I anticipated would be involved. This was to ensure that all staff would be informed of the study and my role within the hospital.

Further individual consent was needed from the professionals who were interviewed for the main study. This was relatively straightforward, with the professional staff member signing a consent form having read information sheets about the study.

A more difficult challenge however, was raised in relation to gaining consent from professionals for observation in an in-patient acute setting. Patients transferred between a variety of different locations in the early stages of their hospital admission. This resulted in a huge variation of staff involved, some of whom were transitory and had 'fleeting' involvement. It was clear that I could not 'halt' proceedings in order to alert staff members to my role and purpose every time a new member of staff was observed. This would have been too intrusive for the clinical setting, but also would have affected the design for a non-participatory observation style. Through the exploratory stage of the study, I developed an informal protocol whereby I would approach any 'new' member of staff after the observation, if I felt their involvement or role would be directly referred to within the study data. Where the staff member provided 'contextual' data, it was considered unnecessary to seek written consent, but verbal information was always given.

Staff observation was carried out in a weekly Multidisciplinary Team (MDT) meeting at site **a**. All regular attendees to this meeting were approached for consent in advance of the study, and all provided written consent forms. During these meetings, I wrote field notes and took audio-tape recordings of all proceedings. There were practical challenges associated with gaining consent from 'new' staff who had inconsistent attendance for the meeting, and this was addressed in a similar fashion as described above for other ward observations. However, there was a more challenging issue relating to confidentiality of using audio-recording for an entire meeting where some of the patients discussed had not consented to study involvement. I drafted an initial plan in which I would only tape record discussion about patients for whom consent had been given. This proved immediately problematic as I realised I was more intrusive in the meetings due to turning the tape recorder on and off, but also the context of the MDT meeting was potentially lost due to my 'editing'. Instead, I developed a system where I recorded all of the discussion, transcribed the information and contextual data for those who had consented, and then deleted the 'non-consented' information from the tape. My eventual approach was successful in preserving integrity in both the consent processes and in data representation.

8.6.3.5. Consent : Patients as participants

As stated previously, the practical and philosophical issues of gaining consent with this client group was inherently challenging in some cases. This related to their general vulnerability, and whether or not they had 'capacity' to consent to research involvement.

8.6.3.5.1. Patients with capacity

In cases where the patient could directly consent to involvement, they were approached with information and I returned the following day to ascertain their views on involvement. Those who agreed to be involved, were asked to sign the consent form. Those who declined, were not approached again.

In cases where there might be conflict between the views of the patient (who had capacity) and others (for example to Next-of-Kin or the professionals), I planned in advance that I would be predominantly led by the views of the patient. I established this position in order to preserve patient autonomy and choice. The potential caveats to this included the degree of anxiety that might be caused by my involvement if conflict persisted. This did not occur at any point within the research study.

8.6.3.5.2. Patients who lacked capacity

The study aimed to recruit patients in the acute stages of stroke, some of whom may have been unconscious, and some of whom may be experiencing a language disorder (aphasia) related to the stroke. This raised the issue of dealing with participants who 'lack capacity', using the definition as described in section 5.2. My initial planning of the research design involved lengthy discussion about the relative merits of approaching or excluding participants who lacked capacity to consent. There is debate within the sociological literature, particularly relating to 'marginalised' and vulnerable groups over the extent to which excluding people who lack capacity to consent to involvement further marginalises their inclusion and access within society (Baxter, Thorne and Mitchell 2001).

After considerable debate with my supervisors and others, it was acknowledged that often, it is this group of patients that pose the most difficult challenges and dilemmas for the clinical decision under scrutiny. It was agreed that the research question would not be successfully answered by excluding this group of participants. The study findings are obliged to represent the broad reality of the issues, hence it was decided that the benefits gained from including participants who lacked capacity to consent were sufficiently great to justify involvement.

The Department of Health issued guidelines (2001), relating to gaining consent for individuals with a learning disability for treatment and inclusion in research. This includes a statement of the position of both the Medical Research Council (MRC) and the Royal College of Physicians (RCP) with respect to research.

> *'it can be lawful to carry out research on incapacitated adults which will not benefit the individual, as long as this is not against the interests of the individual.....such research should never be considered in incapacitated people if it is possible to carry it out instead on people with capacity' (DOH 2001).*

Sugarman, Cain, Wallace and Welsh-Bohmer (2001) outlined the need for research on some patients who lack capacity, in order to improve future care of the client group. When conducting research into dementia, he stated that

> *'because there is tangible need to do research on such devastating and prevalent diseases while concomitantly ensuring that these vulnerable persons are protected, alternative means of doing the ethical work of informed consent have been used. Typically, permission or proxy consent is obtained from family members'*

For this study, the decision was therefore made to include participants who could not give consent on their own behalf in order to understand the clinical decision process as it applied to them. In keeping with good practice approaches, proxy consent would be obtained in all cases from both the medical clinician and the Next-of-Kin. The issue of proxy consent is controversial within both clinical care and healthcare research, with differing views and laws in different countries.

Proxy consent can legally be given by appointed substitute decision makers in some states of USA, as outlined by Mitchell and Kiely (2001). In Scotland, the Incapacity Act (SE 2000) gives legislative 'powers' to 'proxies' to act on behalf of an individual who lacks capacity. In England and Wales, however, there is currently no such legal or procedural clarity.

In the absence of guidance for research, I adopted a good practice approach by referring to guidance on approaching consent for clinical examination or treatment within a clinical setting. In 2001, the Department of Health issued advice on gaining consent from patients who lack capacity due to a learning disability (2001 op cit). The guidelines state that:

> *'no-one, (not even the persons parents or those close to them), can give consent on behalf of adults who are not capable of giving consent for themselves. However, those close to the incapacitated person should always be involved in decision-making, unless the person makes clear that they don't want particular individuals to be involved. Although legally, the health professional responsible for the person's care is responsible for deciding whether or not a particular treatment is in the person's best interests, ideally, decisions will reflect an agreement between professional carers (doctors, nurses, dentists etc) and the individuals family and friends' (Department of Health, 2001)*

To maintain good practice therefore, it was agreed that in cases where a participant lacked capacity, I would seek the assent for patient involvement from both the Next-of-Kin and the 'responsible' clinician. It is acknowledged that this type of 'proxy' consent has no legal status in England and Wales (Dimond 1990) and that it potentially negates the ethos of patient choice (Barnbaum 1999). However, my decision to seek proxy consent was in part to ensure procedural transparency of approach so as to cover my accountability. This was evident in cases where a 'proxy' denied patient access. I adhered to their wishes at all times in order to respect their own views, but also to protect my own need for being 'safely'

accountable for my actions. I felt strongly that this approach would also serve to remind me of the potential power imbalance, and reduce any complacency that I might hold due to my previous inherent 'access rights' to information as a clinician. There were other issues relating to proxy consent that became evident over the course of the research. These related to the potential 'burdens' created when asking Next-of-Kin to give consent on behalf of the patient. Sugarman (2001, op cit) highlighted the issue of emotional burden for proxy consent-givers when consenting for research involvement on behalf of a relative with dementia. He stated that

> *'the degree of burden related to making a decision to participate in research seems influenced by a number of intersecting factors, most importantly, the risk and nature of the study, the extent to which participants were able to participate in the decision, and the duration and severity of dementia'*

In my study, this was particularly highlighted when I pursued the need for a signature from a relative of an unconscious patient, in order to seek her assent to her husband's involvement. The relative consented verbally, but omitted to sign the form on a number of occasions. When I contacted her again for a signature, she stated that she was very happy to be involved, and happy for me to observe her husband's care, but that signing a form would make her feel anxious. She stated

> *'I am happy for you to come in and see anything that happens to (patient's name).....but please don't ask me to sign a form...I make a point of never signing anything without (patients name) agreeing in case I'm signing something that will cost me money later....'*

In this case, I did not persist, and the patient was not recruited to the study. However, it raised issues for me relating to the nature of informed consent, and the extent to which I could demonstrate this without 'badgering' the Next-of-Kin.
The relative merits of seeking a signed consent form have been studied with reference to surgical intervention (Byrne, Napier and Cuschieri 1988; Kissam, Gifford, Patry and Bratzler 2004). The problem of ensuring that patients are informed before proceeding for surgery has received some attention in the literature, with an acknowledgement that a signature does not guarantee information, nor does it give legal support for actions.
The introduction of signed consent forms for research is a relatively recent 'code of ethics' within England and Wales, (DOH 2001). Whilst the intention is to ensure information has been given, I found that relatives were often relaxed about my involvement until I requested a signature. In addition, the practical problems of

gaining a signed consent form proved problematic within this study. At times, this created delays in data collection due to contacting 'distant' relatives, where the next-of-kin did not visit or lived at a distance from the hospital. On occasions, I spoke to relatives over the telephone and sent the consent forms by post. This inevitably created a delay in recruitment of the patient, where some observational data could not be collected. In some cases, this resulted in delays that were so lengthy as to preclude patient recruitment.

I established a flow-chart for gaining consent (see Appendix 3), and this was successful in ensuring consistency of approach for patients and proxy consent-givers. However, the practical and philosophical issues relating to ensuring informed consent remained a challenge throughout participant recruitment.

8.6.3.5.3. Patients with variable Capacity

The clinical nature of stroke is such that variability in consciousness and capacity is common. Although I adopted a 'process consent' position, it was clear that I could not reiterate requests for consent at every point when the patient's situation changed. My position of gaining consent from patients (where possible), proxy consent (where necessary) and consent from the Next-of-Kin for their involvement, gave confidence that information was given at every level. Where a patient's condition varied, I was aware that my continued presence served to remind all participants of my continued involvement. This gave every opportunity for all participants to withdraw from the study at any point if they felt this necessary. There were no instances of consent withdrawal.

8.6.3.6. Consent : 'Next of kin' as participants

The Next-of-kin were required to give their own consent to inclusion, as well as proxy consent in some cases for the patient. Next-of-kin consent was required to allow audio-tape recording at ward rounds or meetings where they may have been present with clinicians.

8.6.3.7. Consent : Document Access

The exploratory stage of the study included a trial of case note analysis to ensure that the documents were accessible for analysis. This necessitated a request for medical case notes for patients with stroke, who had previously undergone PEG placement. These patients had not given consent to access their notes and as all of

the patients were deceased, it was necessary to seek the consent of the medical records manager on both sites. This is in keeping with the guidance in the 'Access to Health Records Act' (DOH 1990) which requires the record holder to make a judgment over the public interest justification of disclosure in the case of deceased patients.

All case notes were anonymised during data collection.

8.6.4. The Stages of Research

The study was carried out in three main stages, each with methodological rationale and purpose. These were:

- An exploratory stage collecting observational and documentary data. This had the aim of identifying and 'mapping' the data sources
- A pilot stage to determine the efficacy of the design and the practicalities of implementation
- A main study for data collection and analysis

Each of these stages will now be discussed.

8.6.4.1. Exploratory Stage

The need for an exploratory stage within the study became quickly evident, as the research design was initially fraught with practical problems. Due to the empirical nature of the research, there was limited information from which to create the initial research design.

Therefore, the rationale for the exploratory stage was to identify the data sources and 'map' the practical issues relating to observational and documentary data collection. The two site design created complexity in terms of the number of forums that would be observed and the variety of clinicians who would be involved. This stage was instrumental to outlining the practical issues and constraints for the subsequent research design.

The medical notes of six 'discharged' patients, three from each site were studied in order to draw 'timelines' for the clinical decision points. This stage allowed retrospective data analysis to determine the extent to which there was a defined clinical pathway for gastrostomy placement in both hospitals. If it was found that there were key decision points or influential decision forums, this would need to be considered in the sampling framework. As it became clear that decision points were

not consistent, this stage was illuminating and informed the design of the first data collection protocol. My original intention to adopt standard 'time sampling' as a method was disregarded after this stage as it became evident that essential information would not be captured.

In order to develop the sampling method for observational data, preliminary prospective observations were conducted with six 'current' patients, three from each of the hospital sites. Participants were recruited to the study on admission to the hospitals following a clinical diagnosis of stroke. The participants were given information and each gave consent to their inclusion in the exploratory period of the study. Observations were carried out in the ward environment, in the multidisciplinary team meetings and on ward rounds. These observations were recorded on audio tapes on some occasions. This stage allowed the practical aspects of patient recruitment, consent and data collection tools to be developed. From this information, it was decided that data collection should run concurrently from each hospital site, rather than in sequential blocks. This was predominantly influenced by the limitations of time and having a single person to collect data. In addition, the sampling method and recruitment criteria were finalised (appendices 1 and 4).

In addition to observations, the case notes (Medical, Speech & Language Therapy, Nursing, Dietetic and Stroke Association) were studied for those participants recruited to this stage of the research. Protocols for data access, recording and analysis were developed.

The information gained from this stage was beneficial in 'mapping' the process and potential participants for the pilot and main study. The exploratory stage was conducted over a period of three months, from August 2002 to November 2002.

8.6.4.2. Pilot Stage

The purpose of the pilot stage was to trial both the proposed data collection methods and the initial analysis techniques to ensure quality and relevance of data for exploring the research question. This differed to the exploratory stage in that the exploratory stage *informed* the study design and the research methods, where as the pilot stage looked at the efficacy of the design for addressing the research question.

8.6.4.2.1. Pilot stage sample

Four patient participants, two from each site, were recruited to the pilot stage of the study. They were included with adherence to the recruitment and consent procedures developed in the exploratory stage. As this stage involved more intensive observations, further refinements were made to the protocols in terms of identifying key ward rounds and decision forums. Whilst this did not alter the data collection methods, this stage gave further practical information for planning my time between the two sites.

The process for recruiting patient participants for both sites is included as appendix 4.

8.6.4.2.2. Observational Data

My role was observer as participant, with all participants being informed about the research study and the reason for my presence.

Throughout the period of the pilot stage study, I moved between the two hospital sites based on the patient participants recruited and the ward rounds or meetings that were taking place. This inevitably led to a compromise situation where I could not be omnipresent to all potential sources of relevant information in the decision making processes. However, I established a 'timetable' that incorporated both the 'everyday' observations on wards, and the key forums for multidisciplinary team meetings. It was clear to me that my decision for breadth of data across a number of participants required a pragmatic compromise over the volume and depth of data possible for each individual. In terms of the research question, my priority was to gather sufficient depth of data across a range of patients in order to investigate patterns across and within groups. The decision was therefore to gather data concurrently from both sites, and a timetable of key data collection samples was designed.

The key settings for observations included general ward routines, ward rounds, meetings between professionals and patients/next-of-kin, and on site **a**, a weekly multidisciplinary team meeting.

General Ward routines – due to the spontaneous nature of day to day events, this observational data could not be audio taped. The approach to data collection in these settings adopted some of the principles supporting ethnographic data collection in that my own recording of data was arguably *my* account and interpretation of events. This differed to some extent from those settings that were

tape recorded, as these generated verbatim transcripts of the exact language used by participants.

I maintained a research diary, where I recorded all contextual data about the people involved, the setting, the language used, the precursors to events, the observed consequences of interactions and my 'feelings' or immediate interpretations of events (Elliott 1997). An example of a field diary entry is included in chapter 9, section 9.1.4.

Ward Rounds - the variable nature and structure of these forums were such that a pre-determined and rigid protocol for observations was not possible. The ward rounds varied in terms of the people who attended (for example, whether they were led by consultants, or whether they were led by Senior House Officers) and this determined the nature and purpose of the ward round. Consultant ward rounds were often held on a once weekly basis on both sites, although occasionally, these were twice weekly. Senior House Officer ward rounds were often more frequent, sometimes daily. The role and purpose of the ward rounds will be discussed in later sections considering the analysis of data. The structure of the ward rounds was also variable, posing some practical challenges for data collection. Most commonly, the ward round is organised by bed occupancy, where the order of patients reviewed is determined by their bed placement. The notes trolley is moved between ward bays and beds, and this progresses through the ward until all patients who are under the consultants care have been reviewed. This created a difficult scenario in terms of observation, because there was often little scope to 'drop-in' to the ward round for only for those patients who were recruited to the study. Joining the ward round only for those patients who had consented had the potential to affect the team's dynamics, where as joining the ward round for all patients, raised issues of patient privacy and confidentiality when they were not consenting to my presence. Once again, a pragmatic decision was made based on an individual judgment of the level of privacy intrusion. It was decided that I should join ward rounds in their entirety, but only 'record' the sections relating to those patients who had given consent. Where it was clear that a clinical assessment required respect for privacy, I removed myself discretely from the ward round until the team moved to the next patient. Whilst recognising that this introduced subjectivity in terms of the observation process, I did not feel that this affected the quality of the data collected, and more importantly, it was in-keeping with the ethical approach and respect for confidentiality that was paramount within the design. These pragmatic choices in

qualitative research are recognised as legitimate necessities in naturalistic settings (Holloway 2005).

Where possible, all ward round observations were recorded overtly, but discretely, on a tape recorder. Contextual notes were made throughout in the field diary.

Multidisciplinary Team Meetings (Site a only) – These meetings took place for a two hour period on a once weekly basis, and focussed on the 48 inpatients on the two stroke wards. The purpose and function of the meetings will de discussed further in chapter 14. As previously described, the issues of consent for observing this meeting were the first consideration. Given the 'fluid' nature of the meeting, participants moved in and out of the meeting throughout the two hour period. Attendance at the meeting varied. The meetings were tape recorded overtly, but discretely and the entire discussion was recorded in order to capture data in context. In addition, field notes were made when discussion took place about patients who had consented to inclusion in the study.

Meetings between professionals and patients/next-of-kin – These were less consistent in terms of a regular pattern or structure. Generally, meetings were requested by either the clinical team or the patient/next-of-kin, hence they were pre-planned, with a loose 'agenda' for discussion. Where this was the case, I contacted all parties before the meeting to ensure that they would be happy for me to attend. Occasionally, meetings were spontaneously arranged and my attendance at these was dependent on my being 'in the right place at the right time'. All meetings attended were audio recorded, with additional field notes taken.

8.6.4.2.3. Documentary Data

The documents used in the study included a breadth of any written information that related to the patient participants. For each participant therefore, the available documents included some or all of the medical notes, nursing notes, speech and language therapy notes, dietetic notes, and stroke association notes.

Initially, I typed all written information in the notes verbatim into a laptop computer. However, it became quickly evident that this was not going to be practical if I was to gather sufficient depth of data in the time available. Through discussion with the Caldicott guardian, the medical records managers, the SLT managers and the dietetics managers for both sites, it was agreed that I could access the notes for information throughout the study, but that I could additionally photocopy all notes on completion of the observational data collection. This was required to follow a strict protocol for ensuring that any photocopied notes taken off site were completely

anonymised. This process was agreed in the pilot stage, but was carried out at a later stage in the study when the observational phase was complete.
The purpose, use and role of the written documents will be discussed further in chapter 14.
The pilot stage identified that the data collection method was successful in that it was both practically possible for me to achieve, and generated data that was sufficiently detailed and rich for analysis. Further changes to the study design were, therefore, not required, and it was agreed with the project team that four participants were sufficient to consider that the methods were appropriate. As a consequence, the pilot stage was relatively short, lasting a period of 6 weeks between December 2002 and early February 2003. As the data collection methods did not change, the four patients recruited to this stage could justifiably be included in the 'core' sample of patient participants for the main study. These four participants continued to be 'tracked' through their hospital admission during the main study stage and their data was included within the whole sample analysis.

8.6.4.3. The Main Study

The main study period commenced in February 2003, with data collection continuing through to November 2004.
There were three phases to the study :

- Phase 1 – Patient Participants (prospective data collection using observations and documents)
- Phase 2 – Professional Participants (Semi-structured depth interviews)
- Phase 3 – Contextual data (Semi-structured interviews with professionals in comparable fields of medicine)

8.6.4.3.1. Phase 1 – Patient participants

This phase focussed on gathering prospective data on decision making in individual patient cases. The data as previously described, was both in the form of observational information and written documents. Sixteen patients were recruited to this stage, which in addition to the four pilot stage participants, gave a total of twenty patient participants for analysis. The patient sample demographics are summarised in table 1 below.

Table 1 – Patient Participant Demographics

Patient ID	Hospital site	Sex	Age
p1a	a	F	76
p2a	a	M	66
7a	a	F	71
12a	a	F	84
16a	a	F	75
22a	a	F	90
34a	a	F	84
58a	a	F	86
65a	a	M	81
68a	a	M	71
82a	a	M	62
p1b	b	F	88
p2b	b	F	66
3b	b	F	74
4b	b	M	63
6b	b	F	60
7b	b	F	76
9b	b	M	90
11b	b	M	82
23b	b	F	78
N = 20	Site a – 11 Site b - 9	13 F 7M	Mean - 76.1 Range 60-90

Following the previously described sampling method (Appendix 1) and methods outlined above for data collection, the participants were involved from the moment of recruitment through to either their death or their discharge from hospital. All data collected via audio-recording were transcribed verbatim in readiness for analysis. The data collected for each participant is summarised in Appendix 5.

8.6.4.3.2. Phase 2 – Professional Participants

This stage of the study used semi-structured depth interviews in order to gather 'accounts' of decision making as described by the professionals who are routinely involved in the process.

The semi-structured interviews were not included in the pilot stage of methods, hence the first interview conducted within this stage served as a pilot for the interview schedule employed.

- **Sampling** for this stage of the study was largely purposive as I aimed to approach a spread of professionals from a range of clinical backgrounds and having different levels of experience and responsibilities in the decision process. As previously described however, emerging information from each of the interviews led to some theoretical sampling based on the information given. For example, inclusion of auxiliary nursing staff was the result of one of the interviewees having raised that they felt this would be a key role to explore. There were no strict inclusion criteria for these participants, as an open structure was needed in keeping with the principles of Grounded Theory methodology. The only constraint on inclusion therefore was that all participants should feel sufficiently informed and should give consent to the process. Any professional who declined involvement was not approached further.
- **Professional participants**; Twenty four health care professionals working in the two hospital sites were recruited. The demographics relating to their professional group are included as table 2 below.

Table 2 – Interviews with Professional Participants

Site	Medical	Nursing	Dietitians	Speech and Language Therapists	Total per site
a	5	3	1	2	11
b	5	4	2	2	13
Total per professional group	10	7	3	4	N = 24

- **Interview data**

The twenty four participants were engaged in semi-structured interviews ranging from 60 to 120 minutes in length. The duration of the interview was determined by the participant themselves. All interviews were audio-taped with participants consent.

A 'topic guide' was developed before the first interview, based on the observational and documentary data in phase 1 of the main study. The purpose of the topic guide (Lofland and Lofland 1994) was to ensure broad areas were covered within the interview, but was not used to structure the interview process. The interviewees did not see the topic guide, as this was for my use only as a guide for some of my questions. All interviews followed a different structure, with participants being encouraged to talk about a range of issues that they felt were relevant, and important.

A vignette was developed (Appendix 6) based on observational data collected in the exploratory stage and these were given to the participants in written form towards the end of the interview. Each participant was then asked to talk through the issues that they felt were relevant relating to both general patient care, and enteral feeding in particular. Given the purpose of the vignette for this study, it did not require a rigorous approach to controlling variables or 'weighting' of information given as previously described. It served instead to encourage participants to demonstrate their hypothetical thinking processes within a more tangible set of clinical and social issues. This allowed for 'cross group' comparison within the analysis of the data.

One final component of the interview information was to seek definitions of terms that were observed to be widely and regularly used in the clinical settings, but ones that lacked clinical definition. For example, 'TLC' ('Tender Loving Care') and 'Keep comfortable' were often used verbally and within written documents, although the precise interpretation or intent was unclear. The rationale for looking at the terms used was two-fold. First, to ensure my interpretation of the data during analysis needed to reflect the participants own descriptions of the terms used. Second, to investigate the degree of consensus over the terms themselves, and the message intended was important for analysis of the communication processes within decision making.

The content of all interviews were transcribed verbatim in readiness for analysis.

8.6.4.3.3. Phase 3 - Contextual Comparative data

This phase of the main study reflected the stage of selective coding and discriminate sampling as described by Strauss and Corbin 1998 (op cit). They define discriminate sampling as situations when a researcher

> *'chooses the sites, persons and documents that will maximise opportunities for comparative analysis. This might mean returning to old sites, documents, and persons or going to new ones to gather the data necessary to saturate categories and complete a study'*

Throughout the process of analysis, questions were generated that were pursued through subsequent stages of data collection. Within this study, there were questions that could not be answered directly from the study environment. For example, one key issue related to the philosophy of care and culture of stroke care services. In order to investigate whether some of the phenomena observed were isolated to the stroke care context, or whether they were typical of general health care services, it was considered important to seek the views of healthcare professionals in comparable clinical fields. For this stage, information was sought to look at clinical decision making for withholding and withdrawing clinical treatments in other settings. Intensive Therapy Units (ITU's) may admit patients following stroke, and it was important to consider whether the approach in this setting was similar to that observed in Stroke wards or general medical wards. In addition, it was evident from interviews in phase 2, that clinicians described withdrawal of ventilation in different terms to those used when referring to ANH. It was therefore important to establish in what ways these clinical interventions differed or were similar.
Similarly, patients who have a clinical condition such as Subarachnoid Haemorrhage (SAH) may present with signs of stroke, but may be admitted to neurology wards where they are considered for surgical intervention. Given the initial presentation may be similar to stroke, it was necessary to investigate the decision processes that occur with this group of patients, and how that compared to a stroke care approach.
Another issue that was raised in the study related to responsibilities within a hospital organisation for nutrition and food provision. This led to the need to investigate the views and role of the catering staff on both hospital sites.
The semi-structured interviews conducted for this stage of the study were audio-taped with consent. The issues raised through these comparative interviews will be further discussed in section 3 of the thesis.

8.6.4.4. Data presentation

On a presentation note, the data will be presented as verbatim text, using italics. The identification code for locating the source of the data is given before the text and highlights

- the data source (I=interviews, O=Observations, D = Documents)
- the professional group involved (M = Medical staff, N = Nursing staff, S = Speech and Language Therapist, D = Dietitian)
- The personal identification number (M1 = first medic recruited, S4 = 4th Speech and Language Therapist recruited etc)
- the hospital site (**a** or **b**)

For example, **ON2a** would identify data taken from an **O**bservation such as a ward round, using the words of a **N**urse being the **2**nd nurse recruited on study site **a**.

Where patient participants are directly included in the text, the key indicates

- the hospital site (**a** or **b**)
- the personal identification number, given according to the chronology of patients admitted with stroke over the study duration on each hospital site. (For example, there were 104 stroke patients admitted to study site a through the study period. Out of the total admissions, 11 were recruited to the study but were given an identifier based on their admission number.

For example, **a16** refers to the sixteenth patient admitted with stroke on study site a, over the recruitment period.

Verbatim text has been used in order to preserve the context and integrity of the data. This includes repetitions in statements, use of linguistic 'fillers' (such as um.....) and use of (.....) to indicate pauses in expression. The length of pause will loosely reflect the relative pauses in expression. This is essential to preserving the nature of articulatory 'struggle' observed when participants were trying to express beliefs or views that were complex or difficult for them.

The use of 'clinician' will be used generically to encompass all clinical professional staff engaged in this process. Where there are significant differences in views or beliefs between clinical professional groups, this will be made clear.

8.7. Analytical Procedures

The three data sources (observations, documents and interviews) generated a considerable amount of qualitative data. The approach to analysis in this study was informed by the principles, processes and procedures of Grounded Theory, as described by Strauss and Corbin (1998, op cit).

8.7.1. Iterative Mode and Constant Comparative Analysis

Grbich (1999 op cit) describes iteration in qualitative research as the process of

> *'going out into the field, collecting information by observing or interviewing, transcribing this information, reflecting upon it and subjecting it to an initial analysis of 'what is going on', then using the information gained to guide the next venture into the field.'*

This process occurs within each transcript and between all respondents and is central to Grounded Theory methodology as used in this study.

Strauss and Corbin (1998 op cit) describe this as moving between induction and deduction, whereby the researcher initially takes an inductive stance to data collection, and through iterative processing, moves to interpretation (hence, they argue, deduction) which is 'tested' in the field.

Analysis followed the definitive pattern of open and axial coding, as will be described in section 8.7.4. The aim of analysis was to reduce the raw data into codes, then group these into related categories, with the ultimate development of substantive theory. Despite its appeal as a sequential set of 'stages', this cannot be the reality if the ultimate substantive theory is to hold true. For example, a researcher cannot select a core category and have faith that it is valid, until it is further verified by reviewing it in context of categories, sub-categories, and even with new data acquisition. The process of 'checking' and verifying analysis is achieved through a process of constant comparison between the data and the conceptual framework developed. Following this approach, a theory will emerge that will satisfactorily explain and predict phenomena relating to the research question.

The process of analysis in this study commenced early in the exploratory stage as my initial views and interpretations were sharply challenged by my observations and experiences. Given the inevitability of the 'human' impact on analysis and

interpretation, it was necessary to ensure processes for maintaining methodological rigour and analytical objectivity at all levels.

8.7.2. Methodological rigour

Mays and Pope (1995) highlight the need for methodological rigour in qualitative research when they cite Britten and Fisher (1993) as saying 'there is some truth in the quip that quantitative methods are reliable but not valid and that qualitative methods are valid, but not reliable'. Mays and Pope state that 'the basic strategy to ensure rigour in qualitative research is systematic and self conscious research design, data collection, interpretation, and communication.'

There were a number of ways that this was addressed in this study.

- All tape recorded data was transcribed by an independent transcriber in order to ensure a true account of the language exchange. The first reading of the transcript was accompanied by listening to the audio tape in order to check for accuracy, and to add contextual information recorded in the field diary. The data was therefore subject to a number of levels of scrutiny to ensure that it accurately represented the observed events.
- A research diary was maintained throughout the study in order to provide both an audit trail and an account of reflexivity issues during data collection and analysis. Reflexivity, the process of reflection and self awareness was maintained throughout the study in order to ensure that my personal experiences or interpretations were not assumed to reflect those of the participants involved.
- Micro-coding and analysis of data was carried out by both supervisors at various and regular intervals through the study. This 'sharing' of perspectives was essential to provide the challenges to subjective interpretation that is inherent within qualitative data analysis.
- Some sources (Lincoln and Guba 1985) advocate 'member checking' (face validity) where the researcher asks participants to view the data findings for 'resonance' (Popay, Bennett, Thomas, Williams, Gatrell and Bostock 2003). This was felt unnecessary in this study owing to the process of constant comparative analysis. Blumer (1969) raised the need for research to both generate theory and to verify it. He reported that a theory could be verified based on 'its internal consistency, in the character of its assumptions, in its

relations to other theories, in its consistency with what seems to be 'human' or in other kinds of data than those provided by the human documents.' Glaser and Strauss' (1967 op cit) adopted this view in their development of grounded theory methodology, as they used constant comparative analysis to address this very issue.

- Triangulation of data collection methods has previously been described. This encourages rigour in methods, as it necessitates cross-referencing of theory and interpretation across different data sources. In addition, wide ranging methods of data analysis, as described in section 8.7.4, provided further systematicity, hence rigour, within the research design.

8.7.3. Theoretical sensitivity

Strauss and Corbin (1998 op cit) assert that theoretical sensitivity 'grows throughout a research project' as familiarity with the data allows the researcher to recognise indicators of concepts in the data. They maintain that sensitivity is fundamental to Grounded Theory methods, as the researcher adopts a combined process of data collection and analysis, which leads to identifying sources of comparative data for theory building. Before commencing the study, I was anxious about how I could maintain a 'naïve' and neutral view of events, given that I had worked as a SLT in the NHS for fifteen years. I questioned whether my background would limit my potential for objectivity in analysis. Through a process of reflexivity, however, I realised that I was moving into an aspect of the decision process that I had previously never considered. In particular, my emphasis of interest shifted from my original view to look at the PEG decision, to that of investigating the end-of-life issues that are debated when decisions are made to withhold feeding. It became evident that the ultimate decision for PEG placement is a culmination of events from day one of admission and that understanding the constructs relating to ANH withholding and withdrawal were essential to investigating the decisions to initiate feeding. An entry in my research diary on 25/01/03 stated:

> *'The 'poorly' patients are making me think. One patient at (site A) has been NBM & 'dying' since 11/01/03 & yet he is still alive....I need to think about including this group of patients, and how to approach them. They may be a useful group? I feel that I need to unpick the decisions that are made NOT to feed as well as the decisions to feed...this is a patient group I have never*

before considered. What happens to make the clinical team sure that they either should or shouldn't feed?'

In this way, it is clear that my own theoretical sensitivity was developing to explore concepts that were relevant, but had not been developed in my past clinical experience.

8.7.4. Stages of Coding

Strauss and Corbin (1998 op cit) describe qualitative data analysis as both a science and an art. They maintain that the science is ensuring a degree of rigour, with the art relating to the creativity required for comparative analysis. Successful qualitative analysis relies on a balance between the two. Strauss and Corbin developed procedures for qualitative analysis 'to help provide some standardisation and rigour to the process'. This approach has been the subject of some criticism (Glaser 1992; Charmaz 1995) when it is applied in a 'cookbook' manner to research data. In their defence, Strauss and Corbin warn against following procedures without allowing creativity. They state that 'these procedures were designed not to be followed dogmatically but rather to be used creatively and flexibly by researchers as they deem appropriate.'

The approach to data analysis in this study adopted all of the main 'stages' as described by Strauss and Corbin, but the process was cyclical and non-linear. The reality was a process of moving from one stage to another, generating questions, and then moving back again in order to allow concepts to evolve.

8.7.4.1. Microanalysis

Boyatzis (1998) states that social sciences research that is based on thematic analysis, requires acknowledgment of the 'unit of coding' at an early stage in the analysis process. He defines the unit of coding as 'the most basic segment, or element, of the raw data or information that can be assessed in a meaningful way regarding the phenomenon. He further states that 'the unit of coding should have a theoretical justification, given the phenomenon of interest and the unit of analysis, and should provide the opportunity to establish and observe a 'codable moment'. Grounded Theory methodology as described in chapter 7, has its roots in the sociological theory of Symbolic Interactionism (Blumer 1969; Annells 1996). Central

to this theory is the belief that language use is the key symbolic communication process used by humans in order to construct social 'meaning.'
Glaser and Strauss (1967 op cit) and Strauss and Corbin (1990 op cit) based their grounded theory methodology on the classic representation of symbolic interactionism, that of investigating the microprocesses of interpersonal interaction. Their method of analysis starts with 'microanalysis,' the 'line-by-line analysis necessary at the beginning of the study to generate initial categories and to suggest relationships among categories.' Charmaz (1995, op cit) amongst others highlights the limitations of this approach, in that the 'macroprocesses' in any given phenomena (such as power, culture and gender) are not accounted for.
As previously identified, this study incorporates both aspects of microprocess and macroprocess analysis, in order to investigate the socially constructed decision process under study.
The initial approach to the research data took the form described above. All transcripts were subject to micro-examination and line-by-line analysis. The process requires that the researcher continuously questions and challenges the data, in order to explore the meanings that they might represent for the participant. Microanalysis continues throughout the open coding and axial coding stages, with the process developing theoretical sensitivity as later described.

8.7.4.2. Open Coding

Open Coding is defined by Strauss and Corbin (1998 op cit) as 'the analytic process though which concepts are identified and their properties and dimensions are discovered in the data'.
At the early stage of coding, line-by-line analysis encourages the researcher to generate the micro level 'building blocks' of a concept. Data is 'fractured' into the smallest unit of coding possible, in order to 'deconstruct' the perceived social constructs. Conceptual labels are given to these fragments of data in order to represent the issues in an objective and systematic way.
I approached open coding in a consistent manner with each transcript; My first step was to read the transcript in order to 're-live' the context of the data source. The next step was to read the transcript in depth, highlighting the chunks of text that I felt were interesting or relevant, and these were given a label or 'tag'. Labels were varied, serving a variety of purposes and functions.

Conceptual labels were the most commonly used, and these labels were used when a layer of interpretation had been applied. For example, 'balancing act' was used when participants talked of making difficult decisions and factors that they took into account. My description of the code for 'balancing act' is recorded as

> *'the idea that there is a thin line to walk in some types of care. This may link to lack of research or clinical evidence. How do they know what is the right thing to do when both sides of the scales can be equally weighted? They are often describing the balance between intervening and not intervening – in terms of the consequences of risks/benefits and good/harm. 12/01/04'*

In-Vivo Codes referred to labels that adopted the participant's own words. Glaser and Strauss (1967) identified the strengths of in-vivo codes as they are often 'catchy' and capture the cultural meaning underpinning the term. An example of an in-vivo code used in the study was 'holding your nerve'. This related to situations where a doctor had made an earlier decision to withhold feeding, owing to her view that the patient was dying. When the patient was still alive over a week later, the doctor reported being concerned that she had made the 'wrong decision'. Advice from a more senior doctor was for her to 'hold your nerve'. My description of what this label represented was recorded as

> *'How long are they comfortable with OBSERVING the process of dying if that patient hasn't or won't die?! At what point do they review and decide to intervene rather than let die? Is there a suggestion that the clinical decision is right, and that emotional aspects should be kept separate? The emotions and conviction are represented in the 'nerve'....'holding your nerve' therefore seems to suggest that they shouldn't let emotions distract them from sticking to their original plan 15/01/04'*

Descriptive labels were used when a label gave a description of what was discussed, rather than attributing any interpretation to this. For example, the 'FOOD Trial' refers to the international research study as described in chapter 3. This code was used every time a participant mentioned the FOOD trial in either interviews or context. My decision to 'tag' references to the FOOD trial allowed for 'searches' that gave insight into professional groups awareness and use of related research literature.

Linguistic labels such as 'verb' were used when participants used a linguistic class of word in an unusual way. For example, frequent references were made to patients 'being PEG'ed'. Whilst this may have been colloquial use, I wanted to remain open-

minded to the possibility that transforming the noun/acronym to a verb may have been symbolic. For example, 'PEGing' suggests an active intervention and may have relevance in the context of 'acts or omissions' in decision making.

The initial process in open coding is described as 'conceptualising' where a researcher identifies an abstract representation of an event, object or interaction that is significant in the data. This stage often generates a large volume of conceptual units.

Management of the codes was achieved using two methods. Firstly, I recorded all codes/labels on separate index cards, detailing the label and the description of the term, Use of index cards allowed for tangible movement between categories at a later stage in the analytical process. In addition, I used a qualitative analysis software package, NVivo, which facilitates data management in a number of ways. NVivo is a re-write of an earlier software package, NUD*IST. It has been refined and continuously developed for over a decade, and is increasingly respected within the qualitative research community. My rationale for choosing NVivo was that the software was developed following the principles of Grounded Theory hence it had the theoretical underpinnings necessary to support my chosen methodology. The NVivo software does NOT have an analytical purpose other than to allow data storage, access and retrieval. Gibbs (2002) describes the benefits of NVivo within Grounded Theory studies as follows:

> *'These programmes.....provide a variety of facilities to help the analyst examine features and relationships in the texts. They are often referred to as theory builders – not, it should be noted, because on their own they can build theory, but because they contain various tools to assist the researcher to develop theoretical ideas and test hypotheses'*

All codes that I identified through open coding were transferred on to NVivo as 'free nodes.' These represented the microscopic conceptual label, and facilitated quick access to the data supporting the code.

As seen in the definition by Strauss and Corbin given above, the open coding stage identifies concepts, but is also the stage when relationships between codes begin to emerge, and properties and dimensions of codes are described. They state that

> *'Although events or happenings might be discrete elements, the fact that they share common characteristics or related meanings enables them to be grouped'*

This 'grouping' is the process of re-constructing concepts to tentative categories, with properties and dimensions of categories being identified.
Properties are defined by Strauss and Corbin (1998) as 'characteristics of a category, the delineation of which defines and gives it meaning'.
Dimensions are defined as 'the range along which general properties of a category vary, giving specification to a category and variation to a theory'. The analytical process at this stage therefore involved a constant method of comparing and contrasting concepts in order to fully understand the complexity of each phenomenon. A number of analytical 'devices' were employed to facilitate this process, and these are described further in the next section.
By definition open coding is not undertaken in isolation from the subsequent stages of axial coding and selective coding. The process becomes cyclical and iterative, moving between microanalysis and macroanalysis interchangeably. The process of constant comparison generates further concepts, and this ensures that open coding cannot cease until the final core category is identified at the closing stages of the analysis.
In my study, open coding continued across all data sources throughout the study, resulting in a total of 595 conceptual codes. These represent the individual 'building blocks' from which the substantive theory was developed.

8.7.4.3. Axial Coding

Strauss and Corbin (1998) defined axial coding as

> *'the process of relating categories to their subcategories, termed 'axial' because coding occurs around an axis of a category, linking categories at the level of properties and dimensions'*

Axial coding is the stage where categories generated through open coding are further developed by gaining an understanding of the conditions and context of the data. In particular, this stage identifies issues relating to causal conditions, (why does the category exist?) contextual conditions, (what are the specific circumstances relating to the condition) interaction/action strategies, (what do participants do to affect the condition?) intervening conditions (what other factors mitigate to changing the circumstances of the condition) and consequences (what is the outcome of the previous trail of events?). Deconstructing and then reconstructing data in this way generates an organisational scheme that is termed the *paradigm.* A number of analytical devices were used to identify these conditions,

including writing memos, generating matrices, time-line development and drawing diagrams. These will be further explained with examples, in order to relate the process of analysis to the data under discussion in this study.

8.7.4.3.1. Use of memos

Strauss and Corbin (1998) describe three types of memo that are essential to the process of theory development.

Operational memos are kept to direct data collection, and often relate to structural or practical issues of the data. For example 'who is the lead physician for stroke care?' served as a reminder to me that I needed to ask this in future visits to the hospitals.

Theoretical memos relate to analytical questions or insights that generate further concepts. For example, at one stage in analysis, I wrote a memo relating to participants' descriptions of defining 'Quality of Life'.

> *'In defining Quality of Life, people talk about patients who lack capacity.....some people describe physical independence, others describe emotional 'personhood'.....do they ever talk of determining Quality of Life in patients who have capacity?'*

Further analysis then followed to look at the concept of Quality of Life in people who had capacity.

Reflexive memos are an acknowledgment of the dynamic nature of interactions occurring between the researcher and the participants. Following one interview, I wrote in my research diary

> *'I am struck by how 'open' participants are about saying they don't know what they should be doing. The consultant I saw today seemed apologetic that he couldn't give me definite answers....but I was also aware of my need to 'rescue' him and reassure him that he was not the only one'.*

This memo was key to developing a more reflexive interviewing style in the subsequent sessions.

8.7.4.3.2. Generating matrices

I used matrices at a number of points in data collection for different purposes. As defined, axial coding requires the researcher to take a viewpoint at any intersecting 'axis' within data. For example, within my analysis, I produced a matrix for the decision points for nutritional interventions (eg NBM, IVI, NGT and PEG placement)

against each participant recruited. This allowed for patterns and differences to emerge across the study sample. This matrix is further discussed in chapter 9.

8.7.4.3.3. Time-line development

Time-lines or 'critical pathway' analysis is a technique where key 'moments' in the data are mapped in a temporal sequence. An example of using this analytical technique in this study relates to the development of each participants 'journey' through the hospital admission. Using both observational and documentary data, I was able to 'map' interventions and discussions for every day of their hospital admission, from day 1, to the point of their discharge. This developed an insight into patterns as described above for nutritional interventions, but also highlighted overall commonalities and divergent points across the study sample.

8.7.4.3.4. Drawing diagrams

Diagrams, or models, illustrate the complexity of relationships between categories in a symbolic and manageable form. Strauss and Corbin (1998) recommend this approach to both 'stimulate the analyst's thinking' but also as a means of organising the huge volumes of data generated. Diagrams in my study, often took the form of flow diagrams, based on the data given about causal relationships. For example, a diagram was produced to explore the NGT decisions by highlighting the individuals involved, alongside the place and timing of the decision.

8.7.4.4. Selective Coding

Strauss and Corbin's (1998) definition of selective coding is that it is the 'process of integrating and refining the theory'. To achieve this, the categories previously generated are placed in a conceptual hierarchy, culminating in the identification of a central or 'core' category. The core category represents the main theme underpinning the research findings.

In generating the core category, Strauss and Corbin recommend that a 'storyline memo' is used as a key technique for objective viewing. To do this, they suggest that the researcher writes a few sentences to describe 'what is going on here'. I outlined a storyline memo on 17/10/04 and this is discussed further in chapter 9. As can be seen, this developed analytical thinking to indicate a key theme and to relate

this to different patient presentations. I returned to the technique of storyline memos at intervals over the subsequent progression of selective coding.

8.7.4.5. Theoretical saturation

Theoretical saturation is described as

> *'the point in category development at which no new properties, dimensions, or relationships emerge during analysis' (Strauss and Corbin, 1998).*

This stage in the analytical process represents the point when data collection is drawing to a close. Analysis at this point serves to validate and verify theoretical schema, rather than fundamentally challenging the hierarchy developed. At this point in my study, I was aware that participants were raising very few 'new' issues, and that I was becoming increasingly able to 'predict' their reasons and explanations given for decisions and phenomena observed.

8.8. Study Findings

The study findings will be described in detail in chapter 9-13. At this point however, it is appropriate to consider some issues relating to data collection and analysis that support the quality of the interpretation and findings presented.

8.8.1. Trustworthiness

Lincoln and Guba (2000) assert that as constructionists are aiming to present 'reconstructed understandings of the social world', the traditional positivist criteria of internal and external validity should be replaced instead with terms such as trustworthiness or authenticity. Trustworthiness is the term used to 'ascribe rigour to the qualitative research process' (Ball 2001). Lincoln and Guba (1985) suggest the four main criteria for ensuring trustworthiness are transferability, dependability, credibility and conformability.

Dependability and conformability relate to an internal 'audit' of the process and procedures adopted. The 'auditability' of this research is achieved through systematic mechanisms for data collection and analysis, as previously described. Transferability mirrors generalisability within quantitative research, in that this refers to ability to relate findings to other similar contexts. Within transferability, a researcher aims to demonstrate sufficient flexibility of the ultimate theory for

explaining similar processes in different, but related contexts. The degree to which my findings can achieve this are described in chapter 14.

Credibility refers to the degree to which the study findings take account of the variability within a social context, and represent this variability within the ultimate findings. Within my study, this was achieved through mechanisms such as triangulation, but also through 'prolonged engagement' as described by Guba and Lincoln (1985). The duration of the data collection period was in excess of 18 months, and this allowed sufficient 'immersion' in the data context to accurately represent the inherent diversities observed.

There are criticisms (Sandelowski 1986) concerning whether these strategies and views adopt a stance that is unnecessarily positivist. However, for the purposes of my research, I adopted the view that I needed to demonstrate methodological rigour for a number of reasons. First, my inexperience with qualitative research methodology required that I took a comprehensive and logical approach to data collection and analysis. Having an educational background underpinned by predominantly positivist research, I needed to equate issues such as bias and validity, to my developing knowledge of qualitative research. Second, I felt that it was important to ensure that possible criticisms of the research findings should relate to the substance of the theory, and not to criticism over methodological issues. My research findings may be relevant for a number of professionals in different settings. It is likely that this will include professional groups from within medicine and healthcare. This context traditionally adopts a positivist perspective, hence my research will be required to 'convince' novices that the relativist view is credible and applicable. It is hoped that ensuring a transparent and rigorous approach to both data collection and analysis will achieve a basis for this.

8.8.2. Resonance in context

In many ways, this research study draws on principles established within ethnography, hence the approach for ensuring trustworthiness of findings is based largely in the degree to which the findings are 'recognised' by participants. Hodgson (2000) describes the increasing use and relevance of ethnographic approaches within healthcare. He acknowledges that ethnographic studies are diverse, but share some essential characteristics that are useful for healthcare analysis. Atkinson and Hammersley (1994) describe ethnography as a form of social

research with the aim of looking at social phenomena using naturalistic data from small sample groups. Analysis depends on interpretation of meanings of human action within a given 'culture'.

Culture can be defined as the rules adopted by individuals within a particular group or society. The rules

> *'tell them how to view the world, how to experience it emotionally, and how to behave in relation to other people to supernatural forces or gods, and to the natural environment' (Helman 1994).*

For a piece of work to be successful in describing social processes, the findings must have relevance and be recognised by participants themselves as a meaningful representation of the phenomena in context. This is referred to be some researchers as 'resonance' (Popay, Bennett et al. 2003).

Maykut and Morehouse (1994) recommend 'member checks' as a means to verify whether the researcher has produced a 'recognizable reality' of the participant's view. My own view is that asking an individual participant to reflect on information they have previously given does not provide this assurance as the interactions and events they have experienced since this date would affect their *current* view of the phenomena. I concluded that member checking was not compatible with the philosophical perspective of symbolic interactionism, hence I avoided this method of verification. Instead, I adopted an approach in the final stages of analysis where I discussed the ultimate core category and broad findings with clinicians who were not immediately engaged in the study. This allowed for assessing resonance in an objective manner, but still in-keeping with Grounded Theory methodology.

Section Three : Findings and Discussion

9. Presentation of the Findings

This section of the thesis will provide an account of the research findings and the discussion.

The iterative nature of constant comparative analysis is a complex and often intangible process, combining a variety of techniques and 'stages' as previously outlined. In this study, the complexity of the interpretative stage was further compounded by the variety of different data types, sources and contexts. Presentation of the research findings is therefore a similarly complex process when attempting to capture the 'journey taken' and the ultimate interpretations.

For simplicity, one way of presenting the findings, might have been to focus on individual components of the data and the process of analysis. For example, types of data could be discussed according to their source (in this case, observations, interviews and documents). Whilst this approach has its merits, it is 'at odds' with the purpose of substantive theory development. As stated in section 7.3.4, Strauss and Corbin (1990, op cit) define theory as:

> *'A set of well-developed concepts related through statements of relationship, which together constitute an integrated framework that can be used to explain or predict phenomena'*

In order to achieve this, I have chosen to present the findings in the following way. This short chapter explores the analytical process, and gives examples of how key themes were identified in the data. This is not intended to be an exhaustive account, but instead gives examples of defining moments in theme development.

Chapter 10 summarises the findings, allowing a view of the 'whole picture' to orientate the reader. A model will be presented in order to illustrate this, as well as to provide a framework for the thesis structure.

The chapters that follow (11-13) will give both the detailed explanation and 'evidence' from the data.

Chapter 11 will set the context of nutritional decision making within stroke care. This will outline the fundamental beliefs that underpin feeding after stroke.

Chapter 12 has four main subsections, and will deal with each of the main identified influences that affected nutritional decisions. These will be presented as chapters 12.1 – 12.4)

Chapter 13 will pull the above strands together in order to discuss the process and potential outcomes of nutritional decisions.

Chapter 14, the discussion, will evaluate the research project in terms of its contribution to current knowledge.
It should be remembered throughout, that the ultimate conceptual model was generated inductively from the data using the approach to data analysis outlined in section 8.7.

9.1. The process of analysis

During the analytical process there were moments of clarity when key themes emerged. This section will describe a selection of these moments in order to illustrate how theme development occurred.

9.1.1. Identification of themes

As described in chapter 8, constant comparative analysis took place alongside contemporaneous data collection in an inductive and iterative process. Analysis was conducted at both macroscopic and microscopic levels, using a variety of techniques to 'fracture' and 'reconstruct' the data.
Some key 'moments' will be described in order to illustrate the iterative nature of the process and its contribution to the key findings. Through analysis, there were many influential 'moments' that contributed to an 'insight' or consideration of a 'theme' that changed the course of the subsequent analysis. To illustrate this, three key 'moments' will be described that arose from pattern (matrix) analysis, typology analysis and the use of storyline memos. These examples serve to highlight the impact of some significant steps in analysis and to provide an insight into how the stages of analysis developed.

9.1.2. Pattern Analysis

As described in chapter 8, matrices were used in an early stage of the analysis to map the 'journey' of the patient participants from day one of admission through to various nutritional decision points. The matrices provided a visual representation which promoted analysis of patterns in the data.
By drawing up a matrix it was immediately clear that intravenous fluids were commenced on day one of admission without exception for all patients who were Nil By Mouth. In contrast, there was huge variability in the timing, consideration and implementation of nutritional interventions such as NG Tubes or PEG's.

This visual representation raised fundamental questions about the distinction between nutrition and hydration and highlighted the discretional nature of nutrition interventions.

Interestingly, when this observational data was compared with what the clinicians said in interview, a slightly different picture emerged. Clinicians reported 'average' timescales within which NGT or PEG tube feeding was considered. Surprisingly, these were significantly shorter periods than those observed in the patient data. This analysis highlighted differences between data sources and raised the possibility of difference between belief and practice. These issues will be further discussed in chapter 14.

9.1.3. The Absence of Patient Typologies

At a later point in the analysis, and having familiarised myself with the 'pathways' of the patient participants, I was curious to examine whether there were similarities in groups of patients that affected the timing or nature of interventions. From the observational data, it was evident that clinicians consistently referred to two main factors in the early stages of decision making about nutritional interventions. These were the patient's level of consciousness and the patient's ability to participate in the decision making process. This was coded during analysis as 'capacity' although it was acknowledged that clinicians rarely used this term themselves.

Having identified these two aspects, the observational data were revisited in order to establish whether there were any links between consciousness, capacity, and the timing (or delays) in nutritional interventions. The patients were grouped according to four simple 'states' i) Mostly conscious and having capacity ii) Mostly unconscious and having capacity iii) Mostly conscious and lacking capacity and iv) Mostly unconscious and lacking capacity. Although these groupings were over simplistic because the patient's levels of consciousness varied over time, they were useful in identifying the level and timing of interventions.

For example, there were 'clear-cut' cases where the issues of consciousness and capacity had a marked influence.

Those who were conscious & had capacity were generally perceived to have a good prognosis and this resulted in more active and urgent nutritional interventions in most cases. This applied to 6 out of the 20 recruited patients on admission.

Those who were unconscious & lacked capacity were generally perceived to have a poor prognosis, resulting in the withholding of nutritional interventions. This applied to 2 out of the 20 recruited patients on admission.

These two clinical presentations, albeit simplistic, gave insight into some situations in which clinicians experience less uncertainty over what their plan should be.

This contrasts with the more difficult cases where patients had fluctuating consciousness, questionable capacity and where prognosis was uncertain, or patients who were conscious but lacked capacity. In these cases, nutritional intervention plans were subject to a 'wait and see' approach. This applied to 12 out of the 20 recruited patients on admission.

In this context, the uncertainty was generally more pronounced than the aforementioned 'clear-cut' cases, and this was associated with less explicit planning.

Interestingly, patients could cycle between states of consciousness creating uncertainty in their management. Although failing to identify 'neat' groups of patients, the search for typologies had proved to be a useful process in highlighting the importance of uncertainty on decision making.

9.1.4. 'Standing back' – the storyline memo

As suggested by Strauss and Corbin (1990), a necessary step in constant comparative analysis is periodically to 'stand back' from the data and consider what it is telling you 'in a few words'.

This allows a 'macroscopic' view in order to summarise key themes 'of the moment'.

One key storyline memo in this research is detailed in an extract from my research diary below. In this example, I reflected on how each professional group contributed to the overall decision process.

> *17/10/04 – Research Diary*
>
> ***Doctors** – Are they acting as clinicians or social agents? There is a tension between their paternalistic past & the climate of being client centred. This is challenging when 1) the patient cannot contribute & 2) the doctor has responsibility to make the decision. They are dealing with competing aims. When they are making a decision, they are not really clear about whether they consider clinical benefits & harms...or social benefits & harms. They want to make decisions that will not allow suffering - & it's open to*

interpretation about whether they are creating suffering if patients are 'kept alive' with a tube & a view of poor QoL[1]*....*

***Nurses** – They are a go-between...The gatekeeper of the information....The silent witness...or the indirect manipulator....quite a powerful position in terms of helping a decision or sabotaging it.*

***Dietitian** – Very much a passive role! They wait to be told when to intervene – they don't really seem to problem solve.*

SALT[2] *– A Fence-sitter! The SALT's seem to be fearful of unquantifiable risk & therefore are cautious about stating their opinions. The SALT also seems to be a bit 'spineless' at times – they are very factual.....but also appear to consistently raise the social conscience.....so in fact, the SALT creates some of the procrastination that is evident in the doctors....the SALT gives the clinical, but also poses the QoL question....Almost an agent provocateur role???*

It was evident that the clinicians were not always clear about the extent and limitations of their roles, or their aims for the stroke patient. The result of this storyline memo was that a major subsequent theme, that of 'juggling hearts and minds'. This referred to the dual importance placed on both clinical facts and emotional/social views in the decision making process.

In this set of examples, the aim has been to demonstrate both the use of data and the development of analysis through integration of differing analytical techniques. These were some of the many evolutionary steps during the interpretative process. The chapters to follow will describe the product of analysis : the resulting themes and concepts in terms of the study findings.

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[1] QoL = Quality of Life

[2] SALT – Speech and Language Therapist

10. The Key Findings

This chapter will summarise the research findings using models for illustration. The purpose of the models is to show the interrelationship of some key aspects of the decision making process, and to serve as 'touchstones' throughout the findings section of the thesis.

The starting point for this research was a simple recurring question – why do some patients have enteral feeding after stroke and others don't?

In the early stages of the study design it became clear that in order to answer this question, data on all nutrition and hydration decisions (to include oral intake for example) would be required. This was necessary in order to fully understand the fundamental beliefs underpinning enteral feeding decisions. From the data, it was evident that clinicians have some shared beliefs about nutrition and that this influenced their behaviour when making decisions. It is clear that they make the decisions within a particular context and set of circumstances. The findings are duly presented to reflect the issues of

- The Baseline Position : Do not feed
- The Influences on decision making
- The process and outcome of decision making

Each of these aspects will now be summarised.

10.1. The Baseline Position : Do Not Feed

The clinician's beliefs about nutrition after stroke provides the basis on which decisions are made, and this will be described in chapter 11. Key underpinning beliefs were that artificial nutrition and artificial hydration were distinct interventions, that nutrition is not essential immediately post stroke, that aspiration risk outweighs the benefits of providing nutrition and that prolonging a poor quality of life through feeding is problematic.

In the stroke context, the provision of *artificial hydration is routine*, quick and relatively straightforward. The *normative pathway is 'to hydrate'* - to initiate artificial fluids as soon as possible after stroke. In contrast, the provision of artificial nutrition varies for each individual patient in terms of both the method used and the timing of the intervention. In short, *nutritional decisions are highly discretionary*, based on the views of clinicians in each patient situation. From the data, it is evident that the

normative pathway in the early days after stroke is 'Not to feed' – unless there is clear and convincing evidence (such as patient's being fully conscious or having a certain good prognosis) to persuade the clinicians otherwise.

10.2. The Influences on Decision Making

In each individual patient situation, the clinicians consider a range of issues that contribute to the decision process. From the data, there were four recurring themes which contributed to the beliefs held by clinicians as outlined above.

Views on Prognosis - The clinician's view about the patient's possible prognosis is the starting point in decision making for nutritional interventions. Prognosis broadly incorporates the likelihood of physical recovery and survival, along with the nature and extent of the physical recovery in the context of future 'Quality of Life'.

Beliefs about Nutrition or Hydration Interventions - Clinicians hold very different beliefs about the harms and benefits of the possible interventions for feeding and hydration.

Perceived Responsibilities – There are a number of people involved in the case of each patient. Some of these people have formal, designated professional responsibilities, while others have a personal connection with the patient that may bring with it a sense of responsibility for the patient. The views over who has (or should have) the key responsibility in influencing the decision process can be variable and this can result in variability in the process itself.

Personal Conscience – this final, but extremely powerful component refers to the influence of personal beliefs or values held by those involved in the decision process.

Each of the four themes outlined above, encompass both clinical issues (scientific or professional) and social issues (those elements that underpin what the participants think and feel). Both were seen to carry equal weight in different scenarios depending on the information gathered, the timing of decisions and the collective beliefs of those involved.

A model illustrating the influences on decision making is shown as figure 1.

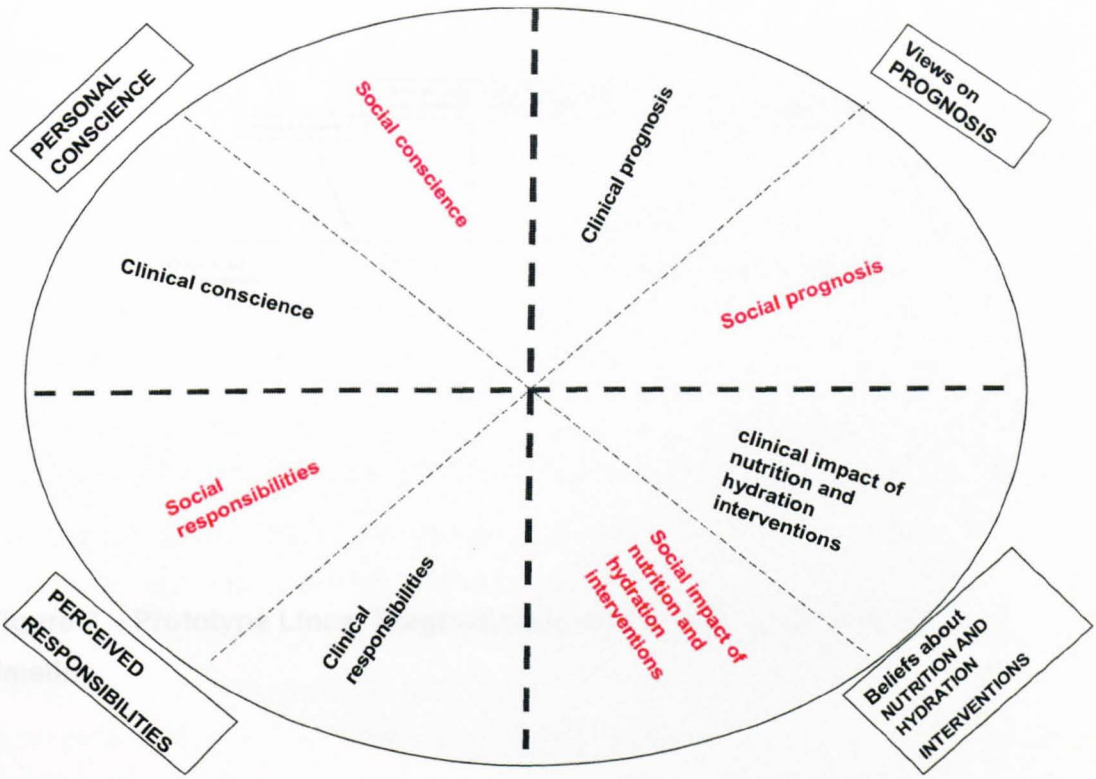


Figure 1 – A model illustrating the themes that are influential to maintaining or challenging the 'Not to feed' position.

This model was generated to provide a diagrammatic representation of the key themes. Initial diagrams in the analytical stage took the form of flow charts or timelines (such as that shown as Figure 2), although the limitations of these early diagrams became quickly apparent. For example, although showing the potential impact of these influences at varying points in the patient's admission, the timeline approach failed to demonstrate the multidimensional interaction of influences at any given point in time. A number of other 'linear' diagrams were attempted and rejected on the basis that the decision process itself did not follow a logical or linear pattern.

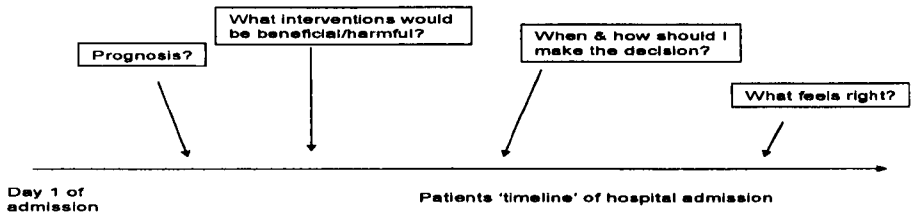


Figure 2 – Prototype Linear Diagram showing the Influential themes on a timeline.

It was clear that a model representing the complexity of the decision process needed to allow greater fluidity of interaction between the influencing factors. This led to development of the model shown previously as Figure 1. This model offers the following advantages

- the key themes in decision making are represented without specifying the relative weight or influence of each aspect towards the decision outcome
- The influence of each 'pie segment' may be individually significant, or may be combined with another segment, as highlighted through the use of 'dotted' lines within the model itself

Attempting to generate a model that implied causation or consistent weighting of influence based on the key four themes would have denied the complexity of the process. Instead, the model acknowledges the potential influences, whilst allowing variability in each individual case.

Blok (2004), described the need to demonstrate complexity in models, without placing boundaries on them to constrain their interpretation or use. He illustrates this using Douglas Adams' quote on reductionism.

> *'if you try to take a cat apart to see how it works, the first thing you have in your hands is a nonworking cat' (Adams, 1998, cited by Blok, 2004)*

In other words, models devised to explain complex systems must attempt to illustrate (and also acknowledge their limits in illustrating) the individual components of the phenomenon, and the possibilities of relationships between them. The model shown as Figure 1, is helpful in stripping the process into core elements without oversimplifying the complexity of the process.

The four themes identified as recurring influences will be described in detail in the four sections that make up chapter 12.

10.3. The Process and Outcome of Decision Making

The four themes identified form the basis of decision making in terms of *what* is considered, but they do not fully explain *how* the decisions are made.

At different points in time, feeding may bring benefits or pose risks to the patient. Similarly, not feeding may bring benefits or pose risks. The clinician's judgment of whether to feed or not relies upon an assessment of these risks and benefits. This assessment requires the clinician to differentiate between what is known, what is likely, and what is not known. Any decision to move from the 'not to feed' normative pathway must demonstrate convincing certainty that this would be the 'best thing' for the patient. In contrast, maintaining a 'not to feed' position is either considered to be the best thing for the patient on grounds of some known certain facts, or conversely may be the 'safest' position in the absence of information or certainty.

The issue of doing the 'best thing' for the patient was a recurring theme throughout observations and interviews. When asked about the basis of decisions for nutritional interventions, clinicians acknowledged that there was no specific guideline to lead or inform them, but that decisions were made in the *'best interests'* of the patient. In this study, it became evident when examining the process by which clinicians stated they determined best interests, that each case was unique. The term best interests was used to reflect the outcome of a process which was different in each individual case.

Given the lack of definition, it is tempting to relegate the significance of the term 'best interests' to the level where it is not influential to the decision or process under study. This would be inaccurate, however, as the term is an extremely relevant and powerful factor within the clinicians 'cognitive' analysis of their role. For the clinicians, the term serves to encapsulate the 'struggle' they have with competing

issues in this complex decision process. In addition, 'best interests' implies an acceptable contemporary 'paternalism' that is largely defensible during and after the event.

In reality, the ultimate decision to start enteral nutrition was not a one-off or definable moment in time, but was part of a process that evolved as information was gathered over time. A plan emerged (either explicitly or 'passively') as elements of the four key influences became known, and this generated a view on the relative harms/benefits of the options to initiate, withhold (actively or passively) or withdraw nutritional interventions. These decisions were then subject to review based on further intervening events or anticipated outcomes.

These issues relating to the process and outcomes of decision making will be described in chapter 13.

A diagram to illustrate the process is shown as Figure 3.

This diagram is not intended to be a tool to predict the 'next steps' in the decision process, but instead shows a cumulative (although non-linear) sequence of events towards the 'ultimate' decision. The diagram also recognises that decision makers can revisit their decisions at any point in time as further information is made available.

The diagram is viewed starting from the left side and moving to the right – whilst acknowledging that at any point, a return to the previous steps could be necessary as further information emerges or as the situation develops.

The diagram highlights key issues in the process of decision making and links these to possible clinical outcomes.

The diagram starts from the premise that the clinicians adopt a 'not to feed' approach in the acute stages of stroke care. Information from a number of dimensions is considered as shown under the heading 'influencing factors' within the diagram. This represents the role of the clinician's beliefs in influencing the process, and therefore the model shown as Figure 1 is subsumed within Figure 3.

The resulting picture is one of either review or change. That is to say, based on the information gathered, clinicians consider the relative harms and benefits of the possible interventions and generate a view on what is in the patient's best interests. The view on best interests results in either maintaining the do not feed position or instead to challenge it by commencing nutrition.

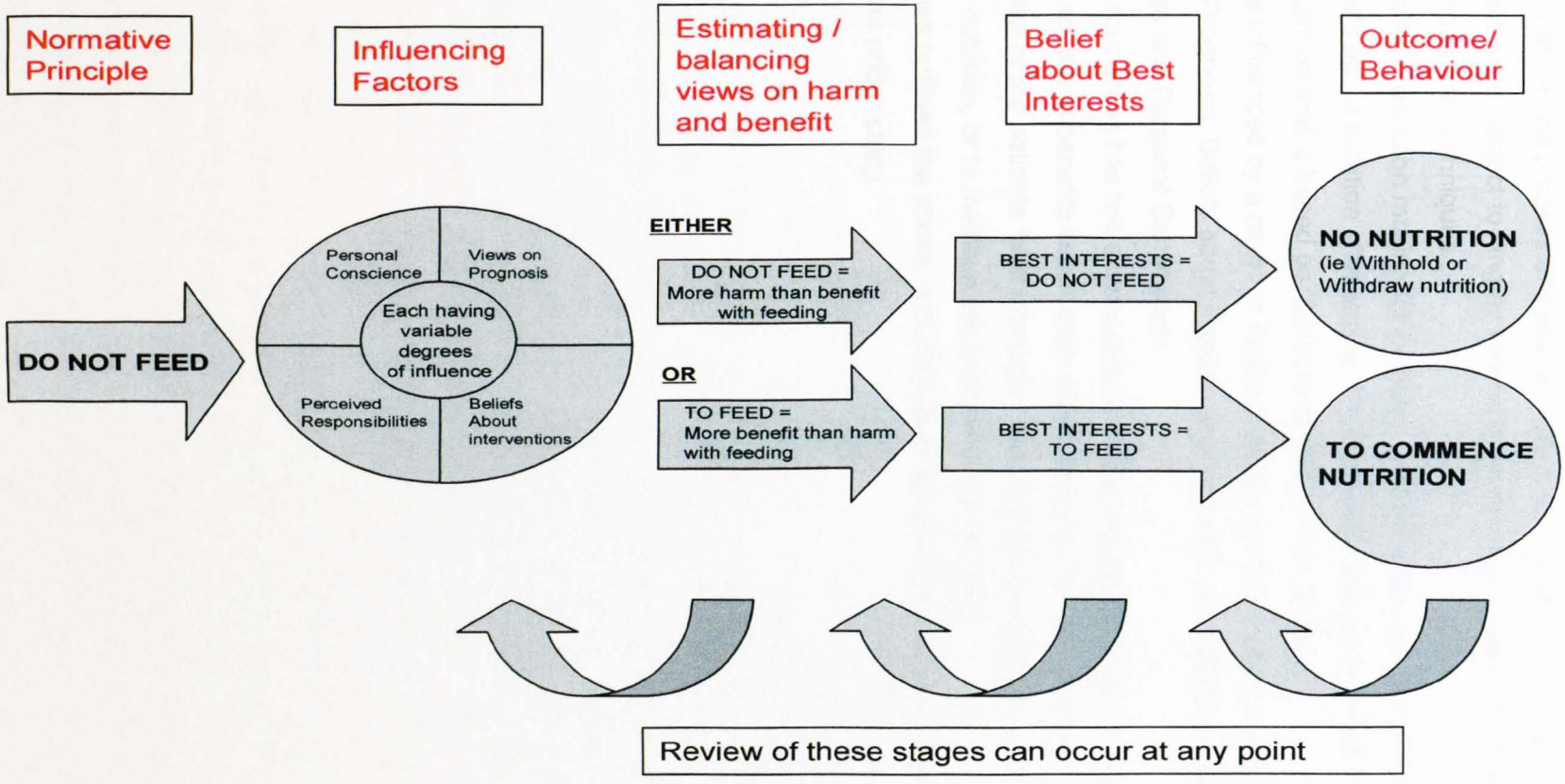
The arrows beneath the diagram illustrate the fact that this is a non-linear process, and that revisiting information or reviewing a 'decision' can occur at any point, based on information that emerges on route.

In short, the diagram aims to map the core elements, whilst allowing fluidity and flexibility to account for the decisions that get made.

The diagram does not attempt to predict 'cause and effect' in decision making. Instead, it highlights that the perceived harms/benefits (and therefore best interests) vary at any point in time for each individual patient.

The diagram can be useful for both representing the views or approach of an individual clinician or the collective views/approach of a team.

Figure 3 – A diagram to illustrate the process and outcomes of nutritional decision making after stroke.



10.4. Summary

The triangulation of methods for data collection generated a rich and diverse account of the content, nature and process of decision making for nutrition and hydration after stroke. The data were subject to lengthy and comprehensive analysis employing a variety of methods and techniques.

Despite variability in decision making for nutrition, analysis revealed key themes in the clinician's beliefs about nutrition after stroke. These beliefs create a normative pathway for nutrition that is based on 'not to feed' rather than 'to feed'.

The clinician is influenced by a range of factors that fall into four main themes. These are Views on Prognosis, Beliefs about nutrition and hydration interventions, Perceived Responsibilities and Personal Conscience.

Each of these four areas has two dimensions, a clinical aspect and a social aspect. Considering harms and benefits within each area takes the clinician to a point where they have a view of the patients 'best interests'. This results in a decision to either intervene with nutrition, or to maintain the position of 'not to feed'.

This chapter has outlined the above, with models to illustrate the research findings and phenomena under study.

11. The Baseline Position: Do Not Feed

A pervasive theme throughout analysis related to the clinician's beliefs about nutrition after stroke and how this influenced their approach to the provision of nutrition. Analysis revealed a recurring theme - in contrast to the routine provision of hydration for a patient, the 'normative pathway' for nutrition after stroke was 'not to feed'. This was the 'baseline position' from which clinicians considered their options.

Key universal beliefs underpinning the practice of 'not to feed' were as follows

- nutrition and hydration were viewed as distinct and different interventions, with nutrition not being considered as essential to recovery after stroke,
- the perceived risk of aspiration outweighed the benefits of providing nutrition,
- nutrition was seen to be detrimental in situations where it was felt to prolong a poor Quality of Life for a patient.

These issues will now be discussed.

11.1. The value of nutrition and hydration after stroke

One of the first key beliefs was that the value of nutrition and hydration for recovery after stroke were seen to be fundamentally different.

From both observational and interview data, it was evident that hydration is provided via an IV drip in all of those patients admitted to hospital with signs of a stroke. It was the expressed view that fluids are essential to recovery, and it was widely accepted that artificial fluids should be provided as soon as possible.

In contrast, nutritional interventions were seen as non essential. There was a general belief that maintaining NBM in the 'early days' after stroke was not harmful. Further, withholding food was seen to have the potential benefits of both limiting aspiration risk and minimising the outcome of prolonging a patient's poor quality of life. The resulting pathway was one of withholding feeding, at least in the early stages.

The flow diagram (Figure 4) illustrates a typical, but very simple account of the baseline views to nutrition.

On admission, the national and local stroke care pathways suggest the position that 'Do not feed orally' should be adopted until the patient has a swallowing assessment. The rationale for this lies in the perception that aspiration is a significant risk to a patient after stroke, and the result is a precautionary approach to avoid or minimise any risk of pulmonary aspiration through maintaining a Nil By Mouth (NBM) position. As is evident, this sets the scene that NBM is perceived to be a 'safe holding position'

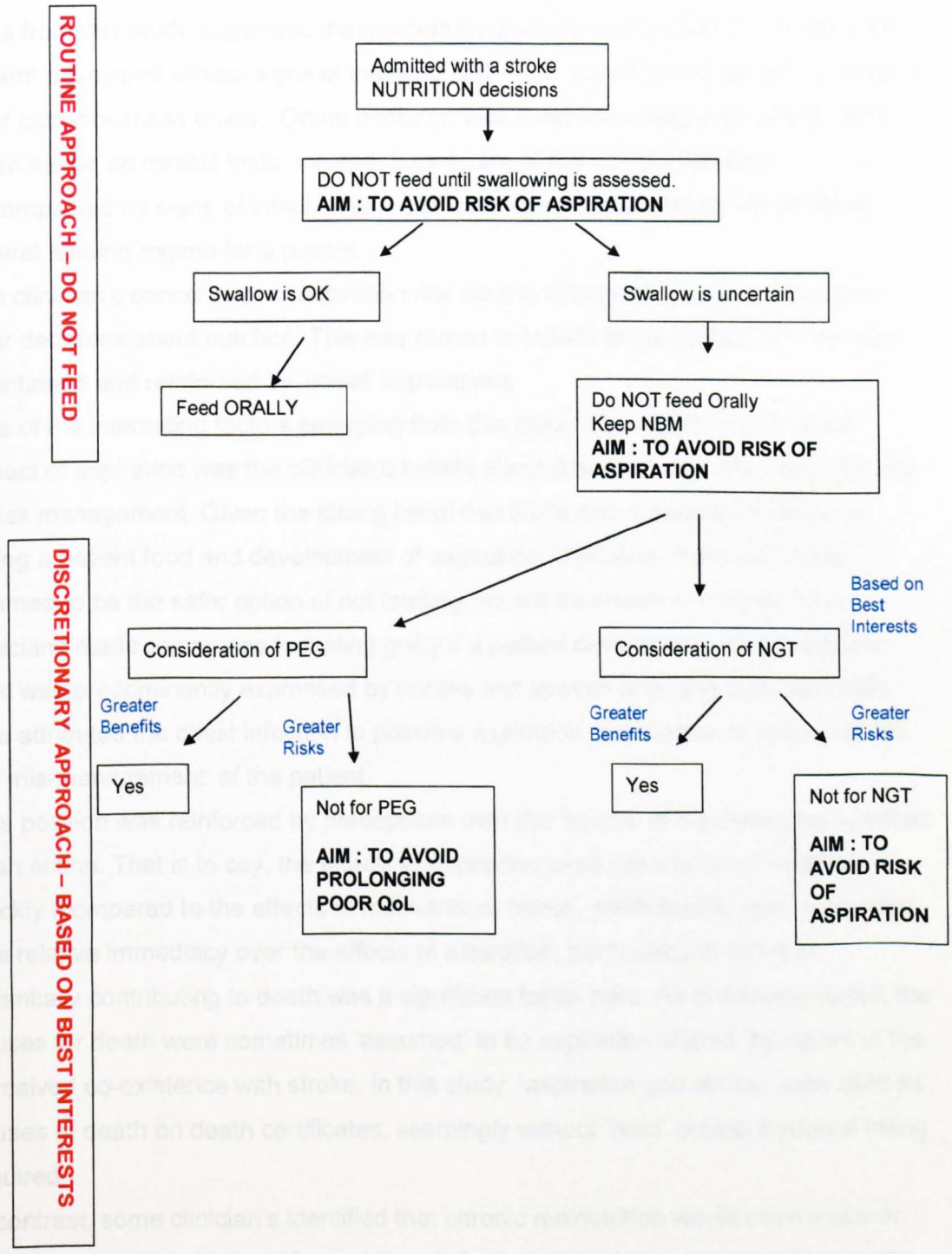
until the risks of aspiration are assessed, starting the pathway with the baseline position of 'not to feed'. From the data, once swallowing was assessed, oral feeding commenced if there was certain evidence that swallowing was safe. In contrast, any persisting signs of aspiration risk resulted in maintenance of the 'not to feed' position. Consideration of enteral feeding was a discretionary decision based on the perceived harms and benefits of the interventions available at any given time. It is evident from the data that the 'not to feed' position also applied to NGT feeding where there was a perception that tube feeding carried an aspiration risk, thereby reinforcing the normative position with regard to nutrition.

When considering PEG feeding, the 'risk' was seen to focus less on aspiration, and more on the perceived 'harms' associated with prolonging a poor 'Quality of Life'. In either case, the result was that tube feeding was either delayed or avoided, in preference to maintaining a relatively safe 'not to feed' position.

There were cases where decisions were made to institute feeding, hence deviating from the normative pathway. In these cases, there was clear and convincing evidence that the benefits of feeding outweighed the harms of not providing nutrition. Typical examples of this from the data were those patients who were alert, conscious and had capacity to be involved in the decision process. Where patients had a variable or low level of consciousness, with or without the capacity to be involved in the discussion, the process of assessing the harms and benefits of feeding was more complex.

In summary therefore, one of the most significant beliefs underpinning the baseline position is that, in contrast to hydration, nutrition is not viewed to be essential for recovery in the early days after stroke.

Figure 4 – Flowchart illustrating the typical approach to nutritional decisions



11.2. The risk of pulmonary aspiration

As previously stated, underpinning the baseline position of 'do not feed', was a belief that nutrition was not critical to recovery in the early days after stroke. In addition, there was view that pulmonary aspiration was a risky side-effect of feeding.

Data from this study suggested that pulmonary aspiration was often suspected if the patient developed clinical signs of infection such as a raised temperature or change in their consciousness levels. On no occasion was a definitive diagnosis of aspiration given based on clinical tests. Instead, knowledge of the risk of aspiration accompanied by signs of infection was sufficient to instigate a Nil By Mouth/Nil by enteral feeding regime for a patient.

The clinician's concerns over aspiration risk were a strong and pervasive basis for their decisions about nutrition. This was rooted in beliefs about clinical risk, but was maintained and reinforced by 'social' implications.

One of the interesting factors emerging from this study with regard to the 'social' impact of aspiration was the clinician's beliefs about their own role and accountability in risk management. Given the strong belief that there was a causal link between giving a patient food and development of aspiration, clinicians chose what they deemed to be the safer option of not feeding. As will be shown in chapter 12.3, clinicians made references to feeling guilty if a patient developed a chest infection. This was predominantly expressed by nurses and speech and language therapists, who attributed the chest infection to possible aspiration, and further to accountability for 'mis-management' of the patient.

This position was reinforced by perceptions over the 'speed' of a problem being linked to an action. That is to say, the effects of aspiration were seen to occur relatively quickly (compared to the effects of malnutrition) hence, attributability was more overt. The relative immediacy over the effects of aspiration, particularly in terms of potentially contributing to death was a significant factor here. As previously stated, the causes for death were sometimes 'assumed' to be aspiration related, by nature of the perceived co-existence with stroke. In this study, 'aspiration and stroke' were cited as causes of death on death certificates, seemingly without 'hard' clinical evidence being required.

In contrast, some clinician's identified that chronic malnutrition would have a slower rate of progression, hence this would rarely be considered as a cause of death in the context of post stroke complications.

Given this backdrop, it was clear from the data that fear of aspiration, hence a desire to minimise or manage the perceived 'risks' of aspiration was a driving force behind the 'not to feed' position. This belief contributed to both creating a baseline context, as well as serving to maintain it.

11.3. The influence of anticipating a poor 'Quality of Life'

The baseline position of 'not to feed' was significantly influenced by the clinician's beliefs about 'quality of life' and the patient's prognosis. As seen in the data, clinicians felt a responsibility not only to manage the patient's clinical condition, but also to bear in mind the likely social consequences of any interventions. In cases where the clinician anticipated a 'poor quality of life', their clinical duty extended to avoiding the perceived 'entrapment' of enteral feeding. Despite acknowledging the subjectivity of quality of life as a concept, all clinicians were in agreement that they should not 'prolong' life of poor quality. This, in itself, was sufficient to justify withholding of feeding in some cases.

As will be discussed throughout chapter 12.1, this belief was both generated and reinforced through a range of experiences and values.

In summary, there were three fundamental factors underpinning the baseline position of 'not to feed' after stroke. These were the perceived low value of nutrition, the possible risks of aspiration and the effects of anticipating a poor future quality of life for the patient.

This chapter has outlined the background context relating to the clinician's beliefs about nutrition after stroke. In each patient situation, this underpinning belief was influenced by emerging factors as will now be discussed in chapter 12.

12. The Influences on Decision Making

From the data, there were four key recurring influences that were considered in each patient situation. The 'evidence' to support each of these themes will be given in detail throughout subsections 12.1 to 12.4.

The order of presentation in these chapters mirrors clinical practice, whereby there was a consistently observed sequence of events in the decision process. Often the starting point lay in the clinician's views about the patient's prognosis. This is therefore presented as the first key component in chapter 12.1. Having established some initial view on prognosis, clinicians considered the relative harm or benefit of the possible nutrition/hydration interventions and these beliefs are presented in chapter 12.2. The influence of having responsibility for the decision was another major factor that emerged as information was gathered and these issues will be explored in chapter 12.3. Arriving at a decision was then subject to an 'emotional barometer', whereby the decision had to ultimately 'feel right'. This aspect is explored within issues of personal conscience, and will be presented as chapter 12.4.

It is necessary to consider each of the four themes in isolation in order to preserve the integrity of the categorisation during analysis. However, it is acknowledged that in reality, each theme mutually interacted to build a holistic view of the key issues.

To reflect this, each theme will be considered separately within the subsections of chapter 12, but with necessary cross referencing between chapters. Within each of the four themes, there is a further subdivision, that of considering the clinical and social implications of each. Once more, it is acknowledged that these neat divisions were not observed in reality, but recurrent patterns during analysis support presentation in this way.

In order to illustrate the evolutionary 'process' of decision making, the four influences will be drawn together in chapter 13.

12.1. Views on Prognosis

As previously indicated, data analysis revealed that there were four key influences to either maintaining a position of 'do not feed' or challenging this position to commence feeding. The first of these key areas will be discussed in this chapter. The view on the patient's prognosis was often the 'starting point' for the clinicians when considering nutritional interventions. This is an unpredictable, complex and inexact science, hence it presents a challenging premise on which to make decisions. The chapter will consider the concept of 'views on prognosis' and how this emerged through analysis.

12.1.1. Assessment of Prognosis

A clinician's view about the patient's prognosis had a major influence on nutritional interventions. The starting point in considering patients' best interests largely related to the clinician's views of the possible outcomes for the patient. In broad terms, this could relate to the expected outcome in terms of clinical survival, as well as the possible outcome for the patient's future 'lifestyle'.

Determining the influence of a patient's prognosis was a complex and subjective process and this chapter will highlight the factors involved, alongside the intervening events that were seen to generate, maintain or develop the clinician's views.

Assessing prognosis in acute stroke was acknowledged by most of the participants to be a complex and difficult process. Despite this, there was widespread agreement that one of the starting points in nutritional decision making after stroke was the need to consider the patient's prognosis.

> ***Consultant IM7a*** *: the overriding principle would be...you know...what is the prognosis for this patient...*

The variable nature of the patient's presentation in the 'early days' after stroke proved challenging for the clinicians when attempting to arrive at a prognosis. Despite having experience in stroke, clinicians indicated that they could never state with certainty which patients would improve, and which would deteriorate. This is expressed by Dr IM5b below, where the 'benefit' of experience is seemingly negated in some cases when predicting stroke recovery.

Specialist Registrar IM5b *: but I think the more you see of...the more you see of the patients the more you.....get a feel of the ones that are....not going to do too well.....on the other hand...you know...I have seen patients who...must have had some kind of like cerebral stunning and over the next day or two they do pick up quite quickly...*

The unpredictability of stroke recovery, and the resulting difficulties in assessing prognosis was a recurring theme throughout the clinician's responses. In the following, Dr IM10a presents a view expressed by many, that often the exceptional cases influenced care for the majority. That is to say, previous situations in which patients had unexpectedly lived, died, recovered or deteriorated set a precedent by which other cases are judged.

Consultant IM10a *: so you see such exceptional cases where you become even more open minded to the possibilities I think...*

The prognosis for patients after stroke was expressed by a number of participants as broadly twofold. From the day of admission, it was clear that clinicians attempt to consider not only the chances of the patient surviving, but also the degree of disability or 'dependence' that may result. However, their ability to predict this in the 'early days' of a hospital admission was clearly challenging.

Consultant IM2b *: It's very difficult to make a prognosis about stroke in the first 24 hours...there are certain things which.....make it unlikely that the patient is going to recover enough to be independent.....if the patient is still unconscious 24 hours after their stroke or if they are still having incontinence.....more than 24 hours after their stroke they are less likely to.....recover enough to be independent.....apart from that you can have some.....some.....erm..... surprises.....and just because someone has a severe disability.....doesn't mean that....they may not recover in the future.....erm.....a lot depends.....on the patient's previous physical and mental status.....and that's something that you need to know about...*

Clinicians often referred to the element of surprise when considering prognosis. The use of the term 'surprise' was interesting in that it intimated the possibility of a positive

outcome emerging unexpectedly from circumstances which had previously been judged to be poor.

> ***Consultant IM4b*** *: there are no sort of objective markers that tells you which patient is likely to survive a stroke or which patient is likely to die or which patient is likely to do well or do badly……stroke is full of surprises….patients who we think will not survive or who will not regain function within a few months can give you a surprise…*

> ***Consultant IM7a*** *: Erm….until I suppose they die or they wake up and improve…and you know we have had patients…..who….erm…..go on like that for three weeks and then they've woken up and started to gradually eat and drink….which has been a bit of a surprise to us….*

The clinicians generally expressed the need to keep 'an open mind' in that patient's can unexpectedly improve. Even in cases where the clinicians did not feel optimistic about recovery, the powerful impact of hindsight encourages reflection on individual cases that may ultimately serve as a rule of thumb. In the following, Nurse IN7a and Dr IM3b gave different examples of the impact of hindsight on assessment of prognosis

> ***Nurse IN7a*** *: because we have a woman now (on the stroke unit), she has been PEGged and we just thought oh my god…why are we PEGging her….and she is really bright now, she is up taking note, she knows when her son visits, which she didn't do two weeks ago…..and you just think oh my god what would have happened if she wasn't PEGged now she would have just wasted away…..*

> ***Consultant IM3b*** *: you know…..you're absolutely sure (that they are going to die)…..and if he perks up…then you restart the feeding…and you say…..bloody hell wasn't that another miracle…*

The use of the terms 'surprise' and 'miracle' reinforce the unpredictable nature of stroke in that some patient's survive despite poor clinical indicators. Clinicians referred to the relative lack of medical interventions for stroke, and the resulting emotional impact of this helplessness for clinicians.

Consultant IM1b *: the problem is that the treatment for…stroke…is not being given the same …you know…we don't have the same ability…..erh….as reversing things such as thombolysis….though that will come within the next year…few years…and I think the whole attitude to stroke will change…when you have a treatment….it's partly…I think it's related to doctors feelings…of…erm…impotence…really to put it like that….I think you feel that you can't help these people so you want to walk away…*

Given the tentative nature of prognosis, the clinicians estimate and generate their views based on a number of factors. These include the perceived likelihood that the patient will live or die (referred to as 'clinical' prognosis), as well as the view on possible disability or dependence experienced by the patient in the future (referred to as 'social' components of prognosis). These issues make up one quadrant of the 'Influential Factors' model, as previously highlighted. The focus for this chapter is therefore shown diagrammatically as Figure 5.

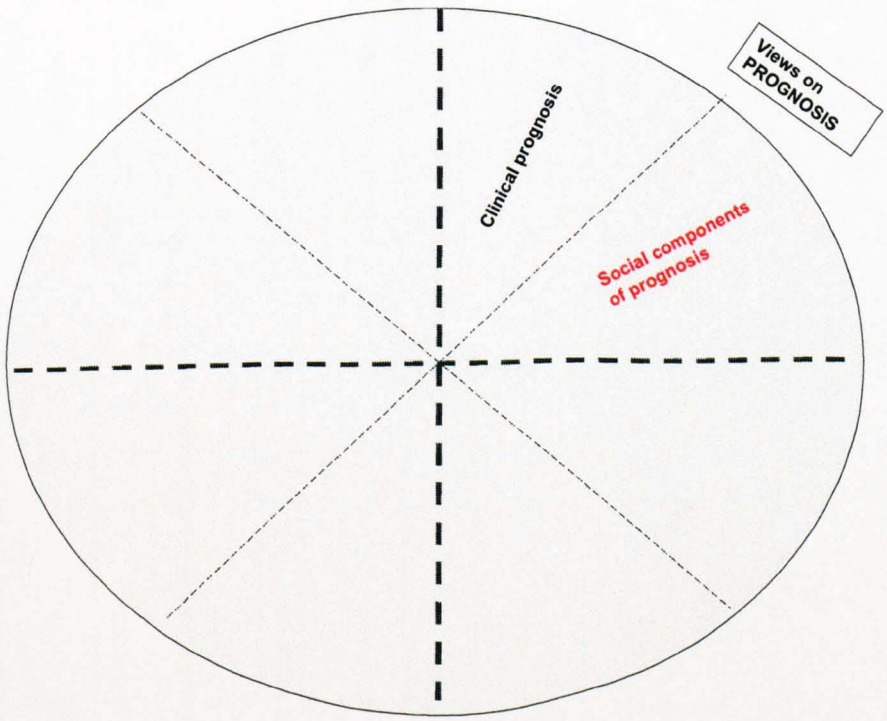


Figure 5 – Views on prognosis as an influencing factor in nutrition decisions after stroke

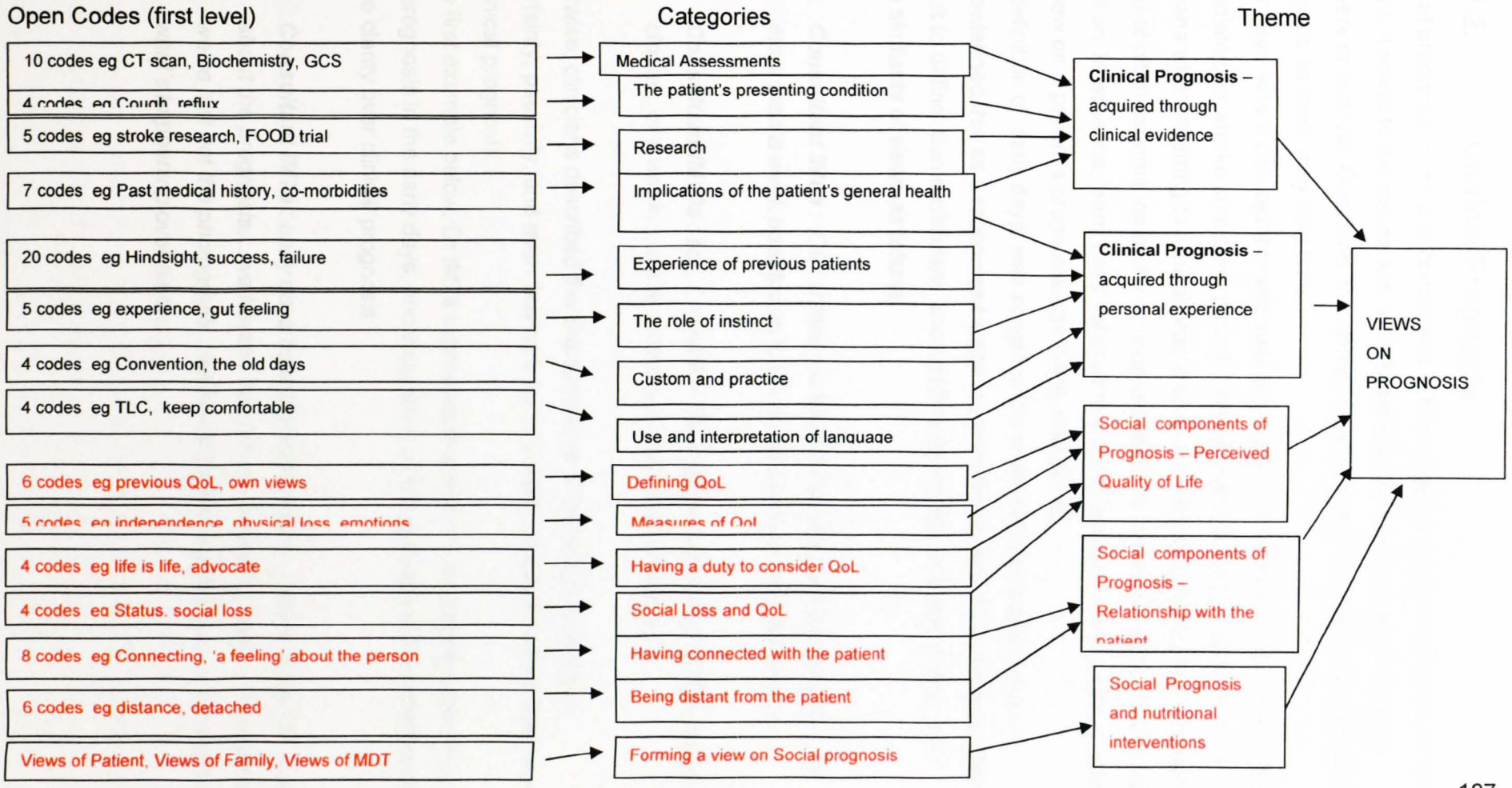
Figure 6 shows the analytical stages moving from open coding of data, through to developing 'Views on Prognosis' as a major theme in the decision process. The diagram should initially be viewed from left to right, showing the progression through analysis from the first level open codes, to developing categories, and ultimately, to the development of the theme.

The diagram also serves to lead the reader through the headings and subheadings within chapter 12, by working from right to left. The chapter heading is the main concept discussed, and this will be explored through considering the clinical and social themes of prognosis. The categories will form section headings throughout this chapter, with the 'evidence' for the issues being illustrated through the basic level codes generated from the data. Examples from the data will be provided to illustrate each point made.

These issues will now be further explored in order to understand how clinicians arrive at a view for prognosis after stroke within the two following dimensions

- clinical prognosis
- social components of prognosis

Figure 6 – Theme development : Views on Prognosis



12.1.2. Clinical Prognosis

Clinical prognosis forms one component of the overall prognostic assessment of the patient. It refers to the issues and factors that indicate the chances of physical recovery or survival. Over time, the clinical prognosis may fluctuate and establishing prognosis, in itself, may take time.

'Early days' was a concept that was regularly applied to a patient's condition in the immediate post stroke admission period. This term was used by nearly all of the clinicians when referring to clinical prognosis and it was evident that this reflected a period of often extreme variability or unpredictability in terms of the patient's clinical condition. In essence, 'early days' referred to a pre-prognosis 'holding stage', where the view on a patient's prognosis was being established.

The definition of 'early days' was sought in the study interviews and clinicians acknowledged this as a recognised stage in stroke illness but felt that it was often difficult to define. Some clinicians attempted to define this in terms of time, with some similarity of views as follows.

> ***Consultant IM6a*** *: Ok....I think we would probably be talking there....no more than a week possibly up to five to seven days that sort of thing...*

> ***Consultant IM10a*** *: so.....a patient for example within four or five day of a stroke...or a week.....we're...we say it is too early to know...*

Otherwise, clinicians described the characteristics of this stage in terms of uncertainty, passivity, and even 'buying time' to enable clinicians to form their views on clinical prognosis.

In the first example below, Dr IM7a expresses the inherent uncertainty associated with prognosis in the early days, and suggests that the passage of time itself serves to give clarity over clinical prognosis.

> ***Consultant IM7a*** *: early days basically means that.....we're really not sure about the prognosis....we haven't had time to evaluate....erhh....to basically we've just got the photograph...we haven't got the video yet.....we can't see what's happening over time.....*

The relative passivity of this stage in terms of allowing time (without intervening) for the patient's prognosis to emerge was expressed by others. In the following, the use of 'waiting to see what happens' indicates that an acceptable course of clinical management in the early days may in fact, be to do nothing.

> ***Dietitian ID3a**: early days means...they've maybe just been admitted..... and we are just waiting to see what happens...*

Some clinicians recognised that they used the term 'early days' to indicate to relatives that clinical prognosis is uncertain.

> ***Specialist Nurse IN6a** : Well I think early days when somebody first has their stroke means that we haven't a clue how it is going to go, I use the term when I am speaking to relatives and I am honest and I'll say.....I probably use the term early days with someone who has had a more major stroke.....rather than with someone possibly with a minor stroke...*

'Early days' had the advantage of both holding out hope to relatives without commitment to a particular prognosis.

> ***Specialist Nurse IN6a** : It means....give us longer we haven't got a clue really....yeah.....(laughs)....with those where I am more sure I don't use it, I think it is a term we hide behind in some ways....*

The early recovery after stroke was therefore critical to the development of the clinician's views on prognosis. In these early, relatively passive days post stroke, clinician's gathered clinical evidence through a number of mechanisms to be discussed. This information was combined with a less scientific body of evidence, that of intuition and gut feeling.

12.1.2.1. Clinical Prognosis – acquired through clinical evidence

On admission to hospital after stroke, there were some key aspects of the initial assessment that formed early opinions about the patient's likelihood of survival. Clinicians sought some routine and standard objective measures to guide the initial predictions of prognosis. This information included

- Medical Assessments
- The Patient's Presenting Condition
- Research
- Implications of the patient's general health

Each of these aspects will now be discussed in order to explore the basis of clinical 'evidence' for estimating clinical prognosis.

12.1.2.1.1. Medical Assessments

On admission, routine medical assessments were requested or carried out on all patient participants. The standard medical 'clerking' included routine 'observations' such as the patients temperature, blood pressure, pulse and routine requests for 'tests' such as blood biochemistry (Urea and Electrolyte's and Full Blood Count). This was observed in all patient participants on day 1 of admission. Requests for chest X-rays were also noted in the medical notes of most of the participants on day 1, indicating the clinician's views on chest status as a prognostic indicator. The initial 'problem solving' that contributes to views on clinical prognosis is highlighted in the extract below, where a Specialist Registrar provided her rationale for interpretation.

> ***Specialist Registrar IM9a*** *: now if she's got a high temperature....that could be just part of the acute stroke....or it could be that this woman has aspirated....now if she's aspirated..she's going to be in a worse prognostic category anyway.....get a chest X-Ray...does this woman have aspiration pneumonia?...is it pulmonary oedema?.....*

Computerised Tomography (CT) scans of the brain were identified by clinicians to be the standard assessment after stroke in order to identify the nature of the stroke and treatment interventions.

> ***Consultant IM3b****: Well.....usually my approach is...erh...you know...you get.....obviously you'd have a CT scan to confirm the nature of the stroke...and treat any underlying cause...*

Despite this being stated as a routine examination, clinicians indicated some practical constraints in obtaining CT scans as quickly as they would have liked. In the following, Nurse IN3b refers to national guidelines[3] which give timescales for carrying out CT scan investigations. Although she does not state the suggested timescale, she later implies that CT scans should take place within 48 hours of admission to hospital. The guidelines indicated actually suggest that CT scans should be conducted within 24 hours of admission.

> ***Nurse IN3b*** *: Yes.....there are national guidelines but they are very basic.....I mean as soon as patients come in they should be CT'd.....alright there is some evidence that if it's haemorrhagic it's going to show later rather than sooner....but we are not....we are not going to have a slot for CT scans at 9.30 in the morning...so they have to wait for scans....*

The clinician's requests for CT scans varied. CT scans were requested for 15 out of the 20 patient participants within 3 days of admission, with the remaining 5 requested between day 3 and 10. In these cases, CT scan request was deferred due to the clinician's belief that the patient was dying.
The CT scans enabled clinicians to establish their views on prognosis, and were influential in intervention plans. In some cases, CT scans indicated the need for more active interventions such as instigating referrals for second opinions, and this was observed where one patient who was initially managed 'conservatively'[4] was transferred urgently to another hospital for neurosurgical intervention. Where CT scans indicated a massive or severe stroke, there was a shift towards adopting a more palliative care approach.

> ***Nurse IN3b*** *: It depends on the CT results.....if the CT results shows a massive stroke....an absolutely massive stroke we would be looking at quality of life there wouldn't we.....because how much of that is recoverable.....not a lot....I wouldn't have said.....*

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[3] The Royal College of Physicians (RCP) - National Clinical Guidelines for Stroke, Revised 2004.

[4] 'conservatively' – suggesting limited interventions : with the aim of maintaining stability

CT scan results were also found to be important for giving the relatives more concrete indicators of prognosis. This is clear in the following, where the result of a CT scan gives Dr IM3a greater confidence about estimating prognosis.

> ***Consultant IM3a*** *: you know...it's a terrible stroke on the CT scan...and you call in the family and say look.....he's had a stroke...this is the natural history....defences are down.....we're not going to get him any better....I don't really think we should treat this.....quite honestly...*

In the case of patient 68a, the initial care of the patient was dominated by uncertainty. After the CT scan, there was a greater degree of certainty that the prognosis was poor, and the emphasis shifted towards overtly communicating plans for withholding interventions. These were recorded explicitly in the notes as follows.

> ***Medical Notes entry – Patient 68a***
> *Day 2 – written entry by Medical SHO*
> *Chase FBC[5] & U&E's[6]; Maintain IVI fluids; Awaiting CT scan. Patient still poorly, but still for resus.*
> *Day 3 – written entry by Medical SHO*
> *CT results noted – Large (L) frontoparietal haematoma with subarachnoid extension. Discussed with Neurosurgeons at (regional hospital) – has seen the plates – not for surgery.*
> *Keep comfortable*
> *Discussed with family – explained the diagnosis and prognosis. Agree NOT for resus. Keep comfortable. TLC[7].*

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[5] FBC – Full Blood Count; A blood test giving information about the features of the blood and therefore, the patient's health status

[6] U&E's – Urea and Electrolytes; A blood test giving information about the body's general condition, kidney function, metabolism etc

[7] Tender Loving Care; Suggests a palliative approach to symptomatic relief rather than active interventions towards recovery.

In the above example, the CT scan results changed the patient's prognosis, and with it, the plan for resuscitation.

Another routine clinical assessment contributing to the view on clinical prognosis was the Glasgow Coma Score (GCS). The GCS scores a patient's level of consciousness, based on three parameters – eye response, verbal response and motor response. On these responses, the patient is graded as having a mild brain injury (scoring over 13) a moderate injury (scoring 9-12), or a severe brain injury (scoring 8 or less).

The GCS was recorded in the medical notes on day 1, for 15 out of the 20 patient participants. The GCS assessment was then only repeated if the patient subsequently deteriorated, but not otherwise. The GCS scores were not cited to be perfect prognostic indicators, but it was clear that they provided some powerful measures for clinicians. For example, in the two cases where the GCS was low on day 1, (65a had a score of 4, 68a had a score of 5), the medical notes also record the clinician's pessimism over likely survival with a decision against resuscitation or any other interventions. An example is given from the medical notes of 65a below.

> ***Medical notes 65a – day 1 of admission***
> *Specialist Registrar medical note entry*
> *GCS 4/15, reduced gag, brainstem signs, poor prognosis*
> *Not for 2222 (resus)*
> *Liaise with relatives asap*
> *CT brain if survives the night.*
> *(Later that afternoon)*
> *Discussed with son – he agrees for TLC. Please keep NOK informed of progress*

The observational data and documents were analysed to compare the immediate clinical implications of having a higher GCS compared to a lower GCS. In particular, this analysis aimed to compare the GCS with the speed and nature of decisions, in order to see how much this reflected certainty or uncertainty.

Interestingly, most cases where GCS was recorded as 13-15, resulted in decisions to feed with an NGT within 5 days, with the actual placement of the NGT occurring without delay once the decision had been made. Conversely, patients with a variable GCS, or GCS below 12, had NGT considered between days 6-16, with an additional average of 3 days delay between the decision to place an NGT and the

act of placing it. It would seem, therefore, that the patients with higher GCS scores are more likely to receive ANH sooner that those with low or variable GCS scores. In essence, uncertainty about prognosis (gained from the GCS amongst other factors) resulted in greater indecision about nutritional interventions. This created some delay in both planning and implementation of nutritional intervention.

12.1.2.1.2. The Patient's Presenting Condition

Alongside the objective medical assessments as described above, clinicians based their view on clinical prognosis on the patient's clinical presentation. This referred to the patient's clinical signs and symptoms, and the implications of these for stroke recovery. The clinician gathered information relating to symptoms, the trend for recovery, and the degree to which medical intervention can influence change. Discussion about 'symptoms' gave clinician's additional information about the presence or possibility of secondary complications after stroke.

There was an expressed view that maintaining stability was the next best outcome to seeing recovery in the early stages after stroke. In the following statement by Dr IM10a, the value of aiming for a stable medical condition is clear. This was echoed by many other clinicians when describing their clinical aims, particularly in the early days after stroke.

> ***Consultant IM10a*** *...is there any chance that things could be improved....or at least.....the stability maintained.....so if that's the case...yes...I mean.....you go for it...*

A recurrent issue relating to post-stroke symptoms and complications highlighted the priority given to managing dysphagia in the early stages after admission to hospital. Clinicians considered that the 'risk' of aspiration needed to be managed in order to improve a patient's chances of recovery. The presence of a cough or a raised temperature often led the clinicians to adopt a 'precautionary' approach, whereby the patient was kept NBM if there was any suspicion of a chest infection. Clinicians viewed aspiration as a major risk after stroke, and aspiration pneumonia was considered to dramatically reduce the likelihood of a good outcome after stroke. This is evident in the words of Dr IM1b below.

> ***Consultant IM1b :*** *the real problem with people with strokes is when they have a pneumonia...if they have a pneumonia the prognosis goes*

down...erm.....how vigorously you treat their infection.... their pneumonia .....determines their outcome

This belief was so strongly held, that there was a pervasive view that maintaining NBM in these situations prevented aspiration. There was an expressed view that pneumonia is ultimately preventable by following this maxim.

***Consultant IM10a** : first...Nil by Mouth...I mean that is the safest approach against aspiration....*

In these situations, the clinician adopted a role to 'prevent' further complications and this provided an active focus in the context of feeling generally helpless to influence outcome in stroke. In the following statement, Dr IM1b described the proactive approach to preventing aspiration. The expressed *active* approach is in contrast to the passivity previously identified, and it is clear that the clinicians appreciated the move away from 'helpless' waiting.

***Consultant IM1b :** so it's very important...so if you can prevent that pneumonia by preventing aspiration I think that's important...*

It is clear that views on clinical prognosis, and in this example, the extent to which clinicians can influence this through their management, have a major impact on nutritional decisions.

In addition to the presentation of clinical signs and symptoms, clinicians view the patients 'trend' for recovery or deterioration as a main prognostic indicator for survival.

This view is so strongly held, that clinicians adopt what could be viewed as a 'watchful waiting' approach in the early stages. What presents as a passive monitoring approach serves the functions of giving inherent indicators for the patient's clinical prognosis. As with other examples of watchful waiting in healthcare, (for example, as a recognised stage in the management of prostate cancer) this approach legitimately allows time to monitor the severity of symptoms, the progression of the problem if not treated, and the risks and benefits of waiting rather than intervening. The progressive nature of building a view on clinical prognosis is, therefore, evident, as was supported throughout the observational data. In the case of patient participant 9b below, the changes in his clinical condition and the impact this has on planning is clear.

Patient participant 9b – ward round observation

Registrar *: he's improved a lot actually...this man.....*

SHO *: he has...yeah.....amazingly....*

Registrar : *(to team) when he was admitted.....he was very ill.... very unresponsive.....and...erm...not communicative at all....he could not sit up.....and so we decided then that....CT scan has confirmed it was cerebral bleed.....on top of a progressive .....and we talked to family....and we agreed that we would not do anything active.....but he's erm.....improved.....although he's still confused.....and disorientated.....and swallowing ...yeah.....has returned.....*

The impact of intervening events such as a change in the patients clinical presentation are seen to be key features of establishing both a view on prognosis and best interests for interventions. Where interventions (such as antibiotics) are given, the clinicians acknowledge that they need time to see how the patient progresses, based on the treatment they are receiving. As seen in the words of Nurse IN3b, this may be directly related to a decision about a nutritional intervention such as a PEG.

Nurse IN3b *: is her body coping with the stroke?.....is she responding to antibiotics or is the pneumonia getting worse?....if she is still unconscious but her GCS is coming up....if she is responding to antibiotics.....if in every way she is getting better....then I would be looking at a PEG.....but if there is a worsening in the scenario then maybe I would be saying....no is it time to look at resus.....*

One of the fundamental uncertainties for clinicians in the early days was distinguishing between those patients who were temporarily severely ill, and those who were in the process of dying. The combination of presenting signs and the trend for recovery are essential to this deliberation, but the uncertainty is further compounded by the clinician's fear of making the wrong decision. This dilemma is clearly expressed by Dr IM1b as follows

Consultant IM1b *: I think it can be very difficult to know if someone's...I think you can suspect that people are dying...that they're gradually fading away...that they're not...their responses change from being one thing to*

another...but I think within reason...that's within reason...but I think it's very hard...to know...because they often come back...and then where do you draw the line...I think it's a dangerous slippery slope...and I think people are wrong as often as they are right about someone...

As shown, clinicians held a clear view that monitoring and reviewing a patient's clinical condition contributed to an assessment of prognosis. In essence, there were occasions where watchful waiting was an active part of managing the patient after stroke.

Clinicians were clear that during this 'waiting' stage, nutritional interventions had little or no impact on the patient's outcome.

***Specialist Registrar IM5b**: Yes.....now if she....if she didn't have a chest infection but she remained unconscious then I would have to say I would look at the 4 days previously and I would say right....has she improved or deteriorated over those 4 days.....and if she has got worse over those 4 days then she hasn't got worse because she has not had food...*

***Consultant IM8a** : this lady has got a massive stroke..... she is now so many days down the line....she has shown no recovery in fact she is getting worse and there isn't any point in putting a PEG tube down.....I think she should just be kept comfortable.....we are going to submit her to another procedure....which isn't going to make her better....it's not going to cure her.....some people think that putting a PEG tube in is going to make them better....but it doesn't.....it doesn't affect the original pathology....*

Where this view becomes complex, is determining the point at which nutrition does become important to prognosis. The reference by IM3b to lingering, hints at a range of other issues, besides prognosis, that might lead to feeding. These issues are to be discussed further in chapter 12.2.

***Consultant IM3b :** Yes...first few days...you know...if...three or four days into it... he's still going down the nick... then I think you have to take it that things are not going.....you know...I wouldn't probably feed him.....but if he recovered...and he's lingering.....then you'd have to feed....*

12.1.2.1.3. Research

Although the clinicians in this study recognised the importance of research in determining clinical prognosis, research was rarely quoted in those discussions that were observed. The 'live' application of research in practice was therefore difficult to determine.

For stroke care, many clinicians cited the relative paucity of research evidence on which to base their views on prognosis or interventions.

> ***Consultant IM7a*** *: in terms of research....erh...coronary artery you know research is...is ...way ahead of stroke.....I mean that data around stroke units was really the first data.... erm....it's just not as sexy as coronary heart disease so it doesn't get....it hasn't got the money...it hasn't had the money put into it...*

This position affected the clinician's levels of confidence when estimating clinical prognosis and contributed to their levels of uncertainty in managing the early stages of stroke in particular. Although CT scans were influential when assessing prognosis, there was no reference to the type of stroke or site of lesion in determining clinical prognosis (as per the Oxford Stroke Scales research, (Bamford, Sandercock, Dennis, Burn and Warlow 1991). The following views from a Specialist Registrar highlight that, even in cases where evidence is available, it may be difficult to apply to individual cases.

> ***Specialist Registrar IM9a*** *: based on research...if you just look at anybody who presents with focal neurology due to a stroke...you know 33% ish are going to get better in 24 hours...33% are going to have major disability but improve.....and the other 33 are going to die....you know ...within two weeks....Erm...I think there's an increasing recognition that in the early days...particularly if you don't have experience of stroke.....you can't ascertain which group they're going to be in.....and we have had patients who have sort of....erm.....who'd dwindle on the general medical wards...who are not having....erm.....you know....appropriate.....acute....action taken...*

Despite the expressed difficulties in use of research for practical application, a number of participants expressed the view that the relatively recent development of stroke unit care was evidence that research was being put into practice in the NHS.

***Nurse IN3b** : Langhorne is one of the researchers who has shown that ....patients in an acute stroke unit with rehabilitation...are out within 6 weeks...with less infirmity....*

Participants stated that stroke unit research had changed their views on a patient's prognosis after stroke and there was a feeling that patients now stood a better chance of surviving a stroke. The impact of research on service organisation, and hence on the 'culture' of patient care was raised by Dr Im9a.

***Specialist Registrar IM9a**: Erm...I would say...increasingly....because.....in the past...people who were brought onto the stroke unit....I think, were viewed as people who were capable of being rehabilitated.....nowadays....the type of patients that we're seeing is anybody who's had a stroke....and also I think that we are less ageist....erm.....in our approach to stroke as well.....they're not written off before they come down (to the stroke unit).....*

The issue of research relating to the management of swallowing is interesting. Some clinicians cited a degree of certainty that there is research evidence to support a precautionary approach to the management of aspiration.

***Consultant IM7a** : Because...people die of dysphagia and erm....infection and whatever....and I think now...with research...once we appreciated how big a problem that was....that's what's taken over....*

In contrast, however, there was no mention of research or evidence to support the initiation, withholding or withdrawal of nutrition, or the effects of this on prognosis. It was widely acknowledged that there is currently limited research evidence to indicate the relative harms or benefits of maintaining Nil By Mouth over a prolonged period. Most stated that they 'did not know' what the evidence was in this area. This view was also echoed by the dietitians in the study.

***Dietitian ID2b** : I can't say I have done that much into the effects of being nil by mouth....apart from the general that you are going to become malnourished and weight loss....*

The broad view that omitting to provide nutrition will ultimately lead to malnutrition appears vague and unscientific. There was equally little clarity regarding the point at which NBM status could become 'harmful'.

> ***Dietitian ID3a*** *: mmm...I'm not sure there IS any evidence (about the effects of NBM)...I mean it's weeks.....do they not say anything between six and seven weeks....it's making sure you're hydrated.....it's the hydration that's.....you know.....obviously...it's not ideal...if you're an inpatient...obviously you'd....for them.....but you know...if someone was to be on hunger strike.....they obviously could survive maybe up to six or seven weeks...*

This perceived lack of evidence may underpin the belief that not feeding a stroke patient has relatively little impact on their outcomes. Further, it raises an organisational issue about importance of monitoring and 'owning' the responsibility for the NBM period.

While the majority of clinicians involved in this study were unaware of research evidence on nutrition and stroke, there was one exception. Consultant IM10a's views on feeding ran counter to the knowledge and views of the majority of participants in this study

> ***Consultant IM10a*** *: I think the evidence has emerged..over the years that earlier nutritional involvement...you know...support...improves the outcome...and the Japanese were..I think I remember being in some meeting three years ago....they were coming up with evidence to support that.....so....we all know now that earlier intervention in terms of nutrition is a positive thing...at least if you want...you don't say essential but..at least it's a positive contributor to a good outcome...yeah...*

A significant research study on nutrition and stroke (the FOOD trial) was taking place at the same time as data was collected for this study. Despite this, there was little reference made to it by clinicians in this study. Interestingly, the one consultant who referred to the FOOD trial, did so with some scepticism about whether the results would benefit patient care. This highlights some of the difficulties when applying research evidence in practice.

***Consultant IM7a**: Well…I don't think the evidence is there…I mean that's why we need the FOOD trial really…it'll be interesting when the FOOD trial sort of…reports as to you know….if we're…..if that suggests that we should be giving them food within 24….48 hours then…..that will create…well…..that'll create pressures within the …..within the service as well as…….further ethical dilemma's down the line…*

This latter point is interesting in that it raises the potential conflict between prolonging life and improving prognosis.

12.1.2.1.4. Implications of the patient's general health

When establishing the patient's prognosis in terms of survival, clinicians do not consider the stroke in isolation. Clinician's placed stroke in the context of other diagnosed co-morbidities and past medical history and it was this combination of factors that set the scene for prognosis after stroke. In establishing this view, clinicians generated their expectations of the patient's likely survival, and decisions over interventions. There was consistency between views expressed in the interviews and what was observed in practice. The first quote is from IM9a in an interview, followed by an excerpt from a MDT meeting in which IM9a was discussing a patient.

***Specialist Registrar IM9a** : the other thing is what premorbid….erm….problems they've had…..if you have got somebody who's suffered from……severe dementia……or heart disease or respiratory problems….who then has had a stroke….erm…..or has got an underlying cancer……and they're going into multi organ failure…..it then becomes absolutely apparent that there is no way that they're going to survive this acute insult…*

MDT meeting – Patient participant 65a

***Nurse** : OK…next to discuss is Mr 65a…*

***Specialist Registrar M9a** : he's really poorly……he's got right upper lobe pneumonia….AF…previously known heart failure, poor pleural function …...been in type two failure….and now a stroke….spoken to his family…they know he's very very poorly…..*

***Consultant M7a** : Ok…next patient please*

When making nutritional decisions in the context of unpredictability with stroke, clinicians were unanimous that having an accompanying medical diagnosis (with a clearer prognostic outcome) was extremely influential. For example, if the patient had a stroke in the context of a terminal illness (eg cancer), many clinicians stated that the approach to the nutritional decision is significantly more 'straightforward'. In some cases for example, the bleak clinical prognosis automatically excluded the options for ANH for patients. This is evident in the words of Dr IM5b, who states his view that artificial nutrition or hydration would not be a major consideration when a patient is terminally ill.

> ***Specialist Registrar IM5b*** *: now in someone who is terminally ill with cancer I.... personally....and I am sure there is no evidence on this....I have spoken to a lot of people....there is nothing really to suggest that by giving intravenous or sub-cut fluids to the terminally ill patient we are doing nothing more than treating ourselves and not the patient....so.....I don't think there is a great deal of evidence to suggest that we should be NG feeding terminally ill patients....*

Although a patient's age was not directly cited as being influential on views of prognosis, it was evident that there were features associated with increasing age that were factored into estimates of survival. As expressed in the following example, there is a view that the older population bring with them associated increased co-morbidities and a lower baseline from which to recover.

> ***Speech and Language Therapist IS1b*** *: I suppose the prevalence of really poorly people is higher in older people isn't it.....*

> ***Specialist Registrar IM4b****: but there is a group of people who do come through the doors who have very dense strokes...usually elderly.....quite elderly people....and you look at them and you just think....it's not looking too good....you know...blood pressure's through the roof and they're at risk of re-infarct and everything else...*

As explored throughout the previous section, clinicians use a number of information sources, acquired through clinical 'evidence' in order to support their views on clinical prognosis. Whilst some of the issues require interpretation on the part of the clinician, on the whole, they are based on what clinicians perceive to be more

scientific or objective sources of information. The following section will now explore how past clinical experiences affected views on clinical prognosis.

12.1.2.2. Clinical Prognosis – acquired through personal experience

Individual experiences also provided clinicians with a view of clinical prognosis. Most participants acknowledged past experiences that had shaped their views about a patient's clinical prognosis, and the impact of interventions such as ANH. The experiences cited were wide-ranging, but were identified as falling into the following broad categories :

- Experience of previous patients
- The role of Instinct
- Custom and Practice
- Use and interpretation of language

12.1.2.2.1. Experience of Previous Patients

Clinicians expressed a view that their previous experiences of patients who had ANH commenced, withheld or withdrawn influenced their beliefs about prognosis and the benefits of interventions. In general terms, clinicians 'match' the patients to a number of criteria drawn from their experience with previous patients. In effect, these experiences become clinical 'evidence' for each individual clinician as they develop personal 'baselines' to guide future practice. This has a sense of 'trial and error' based on personal experience.

> ***Nurse IN2b**: You have got to use everything as a learning curve....and so....you do sort of tend to think back and think that scenario we had like this and we did it that way so we will do it this way this time...and see what is the outcome....*

The observational data similarly indicated instances where past events or experiences contributed to developing views on an individual's prognosis. In the following MDT meeting about patient participant 82a, there was direct reference to a previous patient who had a similar clinical condition and whose family had behaved in a similar manner to 82a's. In this case, there was a view that they should base their views on clinical prognosis on the *outcome* of the previous patient, rather than being influenced by 82a's family.

MDT meeting – Patient participant 82a

Nurse : he really reminds me of the chap we had in that bay a few weeks back...do you remember, the one with the family....they wanted everything done...

Specialist Registrar : Hmmm...and you know what happened when we DID all that they asked for....

Nurse : Hmmm

Specialist Registrar : I think we should play this differently...and hold back.....I'll speak to the family tomorrow....

Although providing much more subjective 'evidence', these examples highlight the role of hindsight as a legitimate indicator for clinicians when establishing views on clinical prognosis.

12.1.2.2.2. The role of Instinct

Clinicians acknowledged that the variable nature of their education generated diverse approaches to patients. It was evident that personal views and experiences contributed to views on clinical prognosis, and that over time, clinicians developed an 'instinct' over the likely outcome.

Specialist Registrar IM5b *: yeah...the more patients you see.... the more you.....get to know....I think it's the fact that ..... there are certain things in life that you can't form flow tables for and you can't form strict guidelines...and medicine is one of them.....and we try and create....we try and put patients in boxes and we are....we're never going to succeed and this is why....it is so important to realise how much experience counts...*

Of particular significance to this study was that clinicians developed an instinct about what would 'be best' in terms of nutrition. In the absence of formal scientific 'training' about nutrition, doctors used past experience and 'gut feeling' when making nutrition decisions.

Specialist Registrar IM5b *: I don't think there's anything mentioned at medical school....I think there's a little bit about vitamins and things like that but... ...but clinical relevance of nutrition and guidelines and how to look at*

patient's and assess them....you know to give you an idea it's something you only pick up with working....I don't think I have ever been taught it.....

This view was echoed by the dietitians who stated that despite receiving formal education about clinical nutrition, the most 'practical' learning was gained from experience in the clinical setting. Dietitian D2b described relying on 'feelings' more than education, suggesting that her practical experience had prepared her more for the reality of the clinical setting than she had gained from formal training.

***Dietitian ID2b**: You obviously have the base knowledge of what you have learnt in lectures but then you kind of carry that through and obviously when you go into hospital it doesn't follow what you have learnt in lectures either a lot of the time....(laughs)....because you have those protocols for NG and PEG feeding and then you go into hospitals and it just doesn't work like that....*

As seen, therefore, clinicians acknowledged 'instinct' to be a powerful factor in determining prognosis and views about nutritional interventions. This once more highlights the variability of determining prognosis for patients after stroke

12.1.2.2.3. Custom and Practice

Custom and Practice refers to the 'way things are done' (and have always been done) in a particular context or setting. Within this, is the notion that clinical practice is steeped in history and this has the effect of preventing flexible thinking in a particular context. One clear example of a 'convention' observed during this study, was that the timing of ANH was partly based on custom and practice. In stroke care, this consultant states the convention to be a 'wait' of 72 hours (with the patient kept Nil By Mouth) before considering NGT insertion.

***Consultant IM2b** : My views on artificial feeding and hydration are that.....if the patient's going to recover...that we should be getting on with it....I think conventionally we wait for 72 hours before we start artificial feeding....*

This was in marked contrast with the practice relating to ITU and acute neurology wards. In both of these settings, it was stated in the interviews by the consultants that it would be 'customary' to insert an NGT for feeding on the day of admission in cases where patient's presented with reduced consciousness.

Further examples of variability according to the context were seen in the interview data, observational data and the medical notes. It was evident for example, that clinicians formed a view on a patient's clinical prognosis based on a previous action or activity of another member of the clinical team.
In the following example taken from the medical notes of patient participant 68a, the 'query' from a Specialist Registrar about commencing a diamorphine pump, triggered a change in approach from the rest of the multidisciplinary team. Although not explicitly stating a shift to terminal care, this 'query' was clearly given this interpretation, as is evident in the subsequent withdrawal of intervention by SLT and other Allied Health Professionals. The implications of SLT withdrawal are such the patient may not have further swallowing assessments, hence a trigger for nutritional review may be omitted.

> ***Medical notes - Patient Participant 68a***
> *Day 21 – Physiotherapy entry*
> *Suction applied; Thick secretions.*
> *Day 22 – Specialist Registrar entry*
> *? for diamorphine pump. To discuss with family*
> *Day 22 – Physiotherapy entry*
> *Not appropriate for suction – suspect it would not alter prognosis*
> *Day 22 – Speech and Language Therapy*
> *In view of diamorphine pump, suspect SLT will no longer be required. Please recontact the dept if necessary*

Through the interview process, some clinicians identified that their approach is often based on what 'happens' rather than what 'should happen'. This is evident in the following reflection by one of the consultants.

> ***Consultant IM6a*** *: I think we pay quite a lot of attention to what we should be doing but....I mean you've highlighted a point for me today where I think I'm going to be having to think a little bit more about why don't we put a nasogastric tube down a bit sooner in some patients....and I mean just having this discussion with you has made me think on that point.....*

Beliefs about prognosis may also be influenced by cultural or attitudinal factors within healthcare generally. A commonly expressed view throughout the data was that many general medical clinicians anticipated a poor prognosis in all cases of

stroke. This could affect ultimate outcome for patients if the diagnosis itself brings with it an inherent pessimism. Dr IM3b's pessimism about stroke recovery is clearly expressed in the following statement.

> ***Consultant IM3b**: the first thing is...can I make it better or not?.....now I can't do that...if it's a stroke.....and it has....it has led.....to feelings of therapeutic nihilism.....in so much that you know...can't do stroke...can't do anything for you...*

As can be seen, therefore, markers for views on clinical prognosis can be based on custom and practice in subtle, but hugely influential ways. This theme is developed in the next section, where the impact of language use is discussed.

12.1.2.2.4. Use and Interpretation of Language

The way in which prognosis was discussed and communicated was very important in this study. The terms used to convey the nature of the prognosis varied according to whether it was considered to be a good or a poor prognosis.

Throughout the study, it was clear that there were frequently used terms in the stroke setting to indicate prognosis. Many of these were 'lay' terms, and in some cases they were ambiguous. Where they were observed, they exclusively related to a suspected poor prognosis.

The key terms relating to a poor clinical prognosis were 'poorly', 'keep comfortable' and 'TLC' (Tender Loving Care). These are seen in a variety of contexts, as shown through the examples below.

> ***Ward round – patient participant 34a – Dr M7a (Consultant) and Nurse N5a***
>
> ***Dr M7a** : so....there's no drip up now....*
>
> ***Nurse N5a** : no*
>
> ***Dr M7a** : no drip up?.....*
>
> ***Nurse N5a** : no...'cos she's been on diet and fluids.....oral diet and fluids.....*
>
> ***Dr M7a** : that's until when...this morning?.....*
>
> ***Nurse N5a** : up until....well...up until this morning...yeah.....*
>
> ***Dr M7a :** right....well....(breath sounds increase again) ...I think we'll have to erh..... I think we'll need to drip her now...she's poorly.....I think we need to see how the next twenty four hours go....*

***Nurse N5a** : OK....we'll get it set up...*

***Dr M7a** : clearly there's not a .....well....the question is...why has she deteriorated.....have you spoken to the relatives?.....*

Medical notes after the ward round above - recorded by SHO

Not communicating. Has deteriorated

Cheyne-stoking[8] lasting 15-20 minutes. Sats 37-95% on 24% air

On mashed diet previously.

Not for 2222[9]. TLC.

For IV fluids

In the following example taken from a meeting with the patients' relatives, Dr M9a sensitively indicates that if the patient's condition doesn't improve, they may need to 'keep him comfortable'. It was difficult to establish what the patient's relatives understood by this term, but it is evident that the doctor was preparing them for the worst case scenario.

Meeting between Dr M9a and the wife of patient participant 68a

***Dr M9a** : we just need to .....give him a couple more days...and see if we can get him through this.....the worst case scenario....if we can't improve his condition with antibiotics....and only if we're 100% certain.....it might be time to talk about..... giving him medication just to keep him comfortable.....and...I know this is so hard...because....you've been through this....you've been through the initial upset.....and you're desperately hoping.....hoping he'll get a bit better.....*

***Mrs 68a** : we went out of here last week feeling good didn't we....(looks to son).....*

***Dr M9a** : mmmmm*

***Mrs 68a** : .....(tearful).....I don't know.....I just don't want him to suffer.....*

---

[8] Cheyne-Stoking – a pattern of respiration where the respiratory rate increases, then decreases and is followed by periods of not breathing

[9] 2222 – referring to the 'crash call' telephone number. In this case, 'not for 2222' indicating that the patient would not be appropriate for resuscitation

Dr M9a *: .....(takes Mrs 68a's hand)....he's really fighting at the moment....isn't he....*

Mrs 68a *: yeah....*

Dr M9a *: if we can't overcome this.....this chest infection....and his condition.....*

I promise you .....that.....there's definitely a move to be about keeping him comfortable....

What was uncertain from the observational data, was the degree to which participants had a 'shared' interpretation or understanding of these terms. For this reason, during the interviews, participants were asked to define some terms. Further, they were asked to indicate what the terms meant to them about clinical prognosis, and subsequent interventions.

Generally, clinicians agreed that 'poorly' was the most ambiguous term, although all admitted to using this term themselves. There was divided opinion in interpretation, with some clinicians feeling that this term indicated that active treatment should continue, some feeling that this suggested an uncertain prognosis, and others stating that this would mean terminal care. This variety of viewpoints is expressed in the examples below.

Dietitian ID1b *: Poorly, well....that can just be that someone is generally unwell and unless stated otherwise people can feel poorly and be perfectly fit and healthy. To me that's active treatment....*

Speech and Language Therapist IS2b *: Poorly. I think I would interpret that as being possibly not appropriate for assessment but I would want to go and see....I think it's suggested that they are not medically so well.*

Specialist Registrar IM9a *: Poorly.....to me that means terminal phase....yes.....erm....probably means in your heart of hearts you think they're going to die....but they're not showing all of the features of terminal illness yet.....but that you're guarded....*

Requesting a definition for the terms 'keep comfortable' and 'TLC' revealed complete consensus that both of these terms related to the terminal stages of the patient's illness. Where they differed however, was in the perceived implications of this in terms of the interventions that would be offered. This variability also applied to

views on whether nutritional interventions should be offered. In some cases where a patient was for 'TLC' or to be 'kept comfortable', clinicians felt that nutrition and other interventions would be offered or would continue. In the following, Nurse N1b expresses that interventions to alleviate suffering would be the focus, and that this could include nutrition.

> ***Nurse IN1b*** *: with TLC and keep comfortable...you might even give radiotherapy because that doesn't have.....that doesn't have the same effect.....because that can make them more comfortable.....and any treatment that would make them more comfortable you would go for.....yeah.....including nutrition...*

Some clinicians disagreed with this position, suggesting instead that 'TLC' or 'keep comfortable' would indicate that interventions such as ANH would not be offered. This was expressed by both SLT S1b and Dr M7a below.

> ***Speech and Language Therapist IS1b*** *: keep comfortable and TLC would mean to me that they are palliative, they are end stages and they are not for alternative feeding....*
>
> ***Consultant IM7a****: you will not be putting in a PEG in somebody who you're giving TLC...or you're keeping comfortable....*

In summary, there was greatest consensus over the terms 'keep comfortable' and 'TLC' where these terms were seen to be essentially synonymous, and referred to terminal care. The greatest difference in interpretation related to 'poorly' whereby clinicians had a range of views incorporating transient illness through to progressive deterioration. The language used in the clinical context can be extremely powerful in influencing the clinician's views on clinical prognosis and the level or types of intervention that is offered. As can be seen, there are some differences in interpretation, based on each clinicians past experiences. The variability of views can create some ambiguities in determining the predicted prognosis for a patient.

12.1.2.3. Forming a view on clinical prognosis

The previous accounts provide an insight into the views held by clinicians about clinical prognosis, and the factors that generate or form those views. It is important

to see these in the context of the processes within which these judgments are made. This section will further explore these issues, but with direct reference to events occurring in practice that changed or maintained these views.

Views on clinical prognosis were seen to be raised as a predominant and consistent theme across all data sources. As shown in previous examples, there were numerous references to clinical factors in ward rounds, MDT meetings, medical notes and interviews. The events contributing to changes or maintenance of viewpoint for clinicians were seen to be intervening conditions (uncontrolled events) and strategic actions (plans and activities). These events contributed to the perceived level of uncertainty over prognosis held by either individual clinicians or across the team.

Broadly, the factors triggering a review of clinical prognosis included

- A change in the patient's clinical condition
- Time running out
- A crisis

Each of these issues will now be discussed.

12.1.2.3.1. A change in the patient's clinical condition

Not surprisingly, there were numerous observed incidents where intervention was triggered by a change in the patient's clinical condition.

Where the change was seen to represent improvement, there was a view that the clinicians were managing the patient well, and management plans would be maintained. This is expressed by Dr IM1b below

> ***Consultant IM1b*** *: if they got better.....(laughs)...if they got better there's nothing....more you need to do.....just carry on with what you're doing....*

This position contrasts with the situation where a patient is perceived to have deteriorated, where a change in intervention is required in order to minimise further 'damage'. Patient participant 82a had both PEG feeding and oral intake, and was observed to have deteriorated. It was thought that he had aspirated on oral intake, hence oral diet was withheld.

> ***Patient 82a – MDT meeting***
>
> ***Nurse 1*** *: right.....he's not...he's not so well actually...he's a bit chesty this morning.....I mean he's on small amounts of puree and he was coughing*

afterwards...so I said just lay off....just continue with the PEG at the moment.....and keep an eye on him....

***Dietitian** : continue with the PEG...but not the diet?...*

***Nurse 1**: yeah.....but no more diet....*

Examples to support this 'reactive' rather than proactive approach were numerous through the data. It was clear that particularly in the 'early days' of stroke care, the patient's condition determines the next stages in management rather than an active long-term plan.

12.1.2.3.2. A crisis

This issue is an extension of the aforementioned points. As it relates to a more dramatic and urgent review of the patient plan, it warrants particular mention in terms of the impact on nutritional decisions.

Throughout the observational sessions, there were changes in the patient's condition or situation that required a more immediate plan to either feed, or not to feed. Crisis situations forced a review of treatment and prognosis.

In the following example, the patient participant (34a) suddenly and dramatically deteriorated. This generated a significant change in view about the patient's expected clinical prognosis and in consequence, the interventions offered. It is interesting to note that the shift in this case was made from a situation of active intervention, to one where an active decision was made not to resuscitate 34a.

9.45 am – Ward round patient participant 34a

***Consultant M7a** : clearly there's not a .....well....the question is...why has she deteriorated.....have you spoken to the relatives?.....(no response from staff nurse (N5a)*

***Consultant M7a** : (to 34a) .....I'm just going to stroke your...the bottom of your foot....(Dr M7a uses his key to stroke the bottom of 34a's foot. 34a flinches and pulls foot back.....sorry.....she's got quite a marked.....(unintelligible)*

***Medical SHO** : she's had surgery....*

***Consultant M7a** : has she.....right.....so.....we....have.....do you know whether we've sucked her out....has she been getting any phlegm up...*

***Nurse N5a** : no...*

***Consultant M7a** : you've not had to..... (looks at observation charts).....any temperature at all....*

***Nurse N5a** : not this morning.....no..... I need to transfer some information from this piece of paper to that chart.....*

***Medical SHO** : she had a temperature when she came to the ward....*

***Consultant M7a** : (takes his stethoscope and listens to the front of 34a's chest on both sides).... air going into the left base... a few crackles on the right...erm.....so we're probably ought to (unintelligible).....can you check her white cell count.....I wouldn't have thought she's well enough for x-ray.....what relatives has she got?.....*

***Nurse N5a** : nephews and nieces...*

***Consultant M7a** : tell them she's erh.... taken a turn for the worse....*

***Nurse N5a** : OK....*

***Consultant M7a** : at the minute....erm.....she'll be not for resus.....we can review that when the cheyne-stoking stops..or after forty eight hours.....*

***Nurse N5a** : can I just ask (unintelligible)*

***Consultant M7a** : erm....yeah...try another five hundred....*

***Nurse N5a** : OK.....*

***Consultant M7a**: (to 34a) let's just put this back on your.....(replaces oxygen saturations monitor probe on finger)...right.....(draw curtains back around her).....let's see the next one.....*

After the ward round

I was standing at the nurse's station, and the SHO asked the SN (N5a) for a 'do not attempt resuscitation' (DNAR) blue form.

***Nurse N5a** : are you filling that in now?*

***Medical SHO** : as opposed to when*

***Nurse N5a** : I thought Dr M7a said to fill it in when the cheyne-stoking stops...*

***Medical SHO** : oh...is that what he meant.....*

***Nurse N5a** : I think so.....that reminds me, I must ring the relatives*

Although the change in 34a's condition provoked a change in her management, this was not clearly communicated to all parties as evidenced by the differing perceptions between the nurse and the SHO relating to DNAR. The SHO in fact defers to the nurses interpretation, and 34a's DNAR status was delayed until a later point.

Another recurrent example of a 'crisis' that changed subsequent events, related to the management of suspected aspiration. It was observed with a number of patient participants that when pulmonary aspiration was suspected, an *immediate* decision

was made to place the patient NBM. In the following example, the rationale for stopping NGT feeding for a period of time was explained to the distressed family of 68a by the Specialist Registrar M9a. It was clear that the suspected aspiration of NGT feed drastically changed the clinician's view on the patient's clinical prognosis.

Specialist Registrar meeting with family of 68a

Specialist Registrar M9a *: mmmm....what we know is that.....as I said before.....when the swallowing muscles are poor....you're always at danger of having....food...or saliva....come up...(indicates with finger upwards on her throat) and go down into the lungs and cause a pneumonia....and it's something that always makes us very twitchy....because...if you or I got a pneumonia.....it could take us six months really to get back....up to speed again.....so you can imagine...what it's like if it happens with a major stroke...plus diabetes.....at the moment he's on two antibiotics.....*

68a's wife *: mmmm*

Specialist Registrar M9a *: one is called cepharoxin and the other is metradianozole.....and they....* ***can*** *be helpful with aspiration pneumonias.....*

68a's wife *: do you think he's got pneumonia....yes?.....*

Specialist Registrar M9a *: he does....*

68a's wife *: right....*

Specialist Registrar M9a *: he does clinically have a pneumonia.....****even*** *with the tube going all the way down to the tummy...even if you have a tube put in..straight into the tummy....you can still get....reflux of the stuff from the stomach.....up the gullet....and into the lungs.....*

68a's wife *: mmmm*

Specialist Registrar M9a *: and that's what's happened here.....*

68a's wife *: mmmm*

Specialist Registrar M9a *: it's much....it's much safer.....than allowing somebody to....to eat....if they're conscious..... but it still can happen.....and it does tend to be a bit more of a problem with diabetics.....because....with diabetes.....the nerves that make the stomach open and empty....can be erh....slowed up.....and....basically....what's happening...is that he's getting fluid collecting...and it's not emptying...as quick as it would be with you or I.....and then....some of it's trickling back up...where it's falling into his lungs....at the moment he needs his oxygen on....mmmm....when that comes off...his oxygen levels* ***do*** *go down.....*

12.1.2.3.3. Time running out

While change was a primary trigger for intervention, there were instances in this study where the absence of change over a prolonged period of time also provoked review and intervention. This was clearly expressed in the statement below.

> ***Consultant IM3b**: 'say we've been muttering about feeding for say...you come to the end of the week and someone's unconscious.....if they're unconscious and going down the nick...I don't think you'd feed....but if they're unconscious and everything else is hunky dory....then you're going to have to feed in some form or another....'*

In the following example, this position was observed in practice by the SLT's who were assessing patient participant 58a. Although the patients clinical condition remained unchanged from day 4 to day 11, the SLT suggested that waiting and seeing what might develop was no longer appropriate. Artificial nutrition was proposed, albeit tentatively.

> ***Ward observation - 3.30pm***
> *Two SLT's, (S6a & S4a) have just assessed 58a's swallow and exit from the bay together.*
> ***SLT S6a** : we're not getting very far with assessing her are we?*
> ***SLT S4a** : no...although she was more alert today....she does seems a bit better.....*
> ***SLT S6a** : when did she come in again.....(looks through notes)*
> *SLT S4a approaches Staff Nurse (Nurse) who has just put the telephone down after a conversation about another patient*
> ***SLT S4a** : .....can we have a word about 58a?....*
> ***Nurse** : mm...yes....she's one of mine.....*
> ***SLT S4a** : did she ever have an NG tube?....*
> ***Nurse** : erh.....no....*
> ***SLT S4a** : it's just that we're still not happy for her to have anything orally....*
> ***Nurse** : er....(taking a piece of paper from her pocket)...I'm trying to think now....did she have it?.....*
> ***SLT S4a** : we've seen her before....she came in before....she's the lady with severe learning difficulties isn't she?....*

***Nurse** : that's right...lives at (name of residential home) (still looking at paper)*

***SLT S4a** : mmm....well she's brighter now isn't she?....*

***Nurse** : yeah....whenever we do anything to her you'd think that we were going to murder her...*

***SLT S4a** : oh...well she kept laughing at us.....*

***SLT S6a** : (still looking at notes).....yeah she liked you S4a...she thought you were very funny.....*

***SLT S4a** : mmmm....not sure how to take that...(laughing).....her swallow is all over the place though isn't it?...*

***SLT S6a** : mmmm...she's variable isn't she?*

***SLT S4a** : she practically inhaled that first one I gave her....*

***SLT S6a** : how long has she been.....we might need to think about alternative feeding with this lady....*

***Nurse** : right.....OK...we'll try an NG with her....but I don't know whether she'll keep it down.....*

***SLT S4a :** I think we have to at least try..*

***Nurse** : yeah....well Dr M9a is back in tomorrow so I'll ask her...*

***SLT S4a** : Ok....we'll put something in the notes..*

***Nurse :** if you could.....(turns to an auxiliary who is walking past)...have you got a minute?....let's get the hoist and try 58a out.....*

***Auxiliary Nurse** : OK....*

***Nurse** : we can give her a go with an NGT anyway.....*

SLT's S4a and S6a write in the notes and then leave the ward.

It is clear, therefore, that at certain points, the lack of nutrition becomes important in terms of a perceived negative impact on clinical prognosis. The point at which this happens however, is variable, as is further described in chapter 12.2.

These examples from the data give insight into the effects of intervening conditions on changing or maintaining the clinician's views of clinical prognosis. These events could not be predicted, but the responses were generally consistent as described above.

This section has considered the impact of clinical prognosis on nutrition decisions. The next section will outline the social components of prognosis on nutrition decisions.

12.1.3. Social Components of Prognosis

In this study, the 'social components of prognosis' refers to the 'non-clinical' aspects of prognosis. As previously described, it is clear that both objective and subjective indicators formed views on whether the clinicians thought the patient would live or die. In addition, clinicians also formed views about the patient's future life experience. This concept was particularly complex, based largely on emotions, value judgments and personal views about the patient's future life. It was clear from the data that these social components of prognosis had direct links to views on nutritional interventions and whether they should be provided. These issues will be discussed further in chapter 12.2.

The social components of prognosis will be discussed under the following headings

- Perceived Quality of Life (QoL)
- Relationships with the patient
- Social prognosis and nutritional interventions

12.1.3.1. Perceived Quality of Life

It was evident that the majority of clinicians viewed 'Quality of Life' (QoL) aspects to be an important component of prognosis.

When considering prognosis in the 'early days' of the stroke, clinicians placed dual emphasis on establishing the patient's likelihood for survival, as well as on how life would be for the patient should they live. All clinicians used the broad term 'Quality of Life' when attempting to express this.

One particularly interesting aspect about QoL in this study was the fact that it was mostly raised when QoL was considered to be poor. In these cases, a relatively large amount of time was spent considering the patient's QoL. In contrast, QoL was rarely discussed in those cases where there appeared to be potential for a 'good' future life experience.

In this study, standard QoL scales were not used. Instead, clinicians adopted an individual approach to their assessment and determination of QoL. The majority of clinicians in this study recognised the difficulties this posed.

> ***Nurse IN3b** : we do make assumptions and we do make judgments....but it's very difficult to put it down into what is....what makes one quality of life acceptable....and what isn't.....I suppose everybody has got different ideas as well.....*

Consultant IM2a *: and then of course you have to define what you mean by recovery….. What is meaningful life?…..*

The clinician's use of QoL within prognosis was evident in interview data, but also in observational and documentary data. However, there was little consensus over core definitions or parameters for QoL. There were some overlapping and recurrent themes that will now be discussed under the following headings.

- Defining QoL
- Measures of QoL
- Having a duty to consider QoL
- Social Loss and QoL

12.1.3.1.1. Defining Quality of Life

When attempting to establish a view on a patient's QoL, clinicians considered the 'future' in the context of the patient's past and current 'lifestyle'. In particular, the baseline for QoL was the patient's previous levels of activity, social integration or interests. Often, this information was based on judgments linked to their past medical condition (for example, any dementia or ill health), or the views expressed through carers or families. In some cases, clinicians attempted to define QoL according to what the patient 'would have wanted'. Most however, acknowledged the difficulties in defining a patient's wishes and expectations in the absence of a formal advanced directive (living will).

The influence of QoL was generally evident when the clinician formed an initial view on the patient's clinical prognosis. For example, if the patient was believed to have a poor clinical outlook coupled with a poor baseline QoL, the clinicians surmised that future QoL would worsen. These combined influences lead the clinicians to query whether active intervention would be in the patient's best interests. If however, the patient had a life that was previously felt to be of a good quality, clinicians were more likely to intervene and 'give them a chance' to regain this. There were many cited examples of this, with the following giving insight into the factors that were influential. Dr M1b and Dr M2b both present a view that the 'starting point' would be to gather information from the relatives about both the patient's physical and 'mental' status before admission.

Consultant IM1b *: I think it's important to talk to the family when they come into the hospital…explain what's going on….try and find out what the quality of life of these people was like before they came in..what we should do…you*

know should we go on…I mean if they've had four strokes before, they can't see out of one eye…they can't see out of their eyes…they…you know….and they're….mentally…you know….have a very poor quality of life…..these decisions have to be brought into the overall decisions that you make on these people….and you have to bring the family into that decision making….

***Consultant IM2b** : but….erm……we'd hope that the medical or the nursing staff would meet the family…in order to ascertain their views and find out what the patient was like…..when they were previously well…..physically and mentally…what they would have wanted….*

Dr M2b's words also highlight another influential factor, that being an attempt to ascertain the patient's previous expressed wishes about future life choices. This indicates that the initial views about QoL are often generated through discussion with relatives or carers where possible. Clinicians acknowledged the limitations of this in terms of maintaining objectivity, and clearly expressed some discomfort about asking relatives to give information about QoL issues. However, clinicians also acknowledged the limitations of attempting to determine QoL *without* considering the views of those who 'know the patient well'. The obvious challenges associated with QoL judgments were expressed during the interviews, when clinicians were asked to describe how they would approach this. It was clear that there was no 'standard' approach, with clinicians considering a variety of factors based on their personal experience. Dr M6a indicates the need to respect individuality, whilst recognising personal limits to judge others. He describes the quality of 'experience' linked to physical abilities as follows.

***Consultant IM6a** : that's where you are playing God….of what is going to be the quality of life…who are you to judge the quality of life…and that's where people will argue with you….but you've got to look at it with the wealth of experience that you've had and again taking everything in…..in to note….what to somebody would be no quality of life….to another one might be a quality of life and they are exactly the same….so someone who is completely paralysed and who can't speak but might be able to smile if they hear some music or something might have some quality of life whereas another person like that may have made it quite clear that if they ever end up like that they want everything pulled….*

The fact that clinicians have no objective measures for defining QoL was an aspect that was acknowledged by some. When asked to define QoL, some clinicians, such as nurse IN3b below, referred to physical ability and life experiences. It is clear that her account of a good QoL was aligned with being both physically and mentally active.

> ***Nurse IN3b*** *: before that she had a good Quality of Life....a good social life...she was active....she was fit....she was a normal person....yes.....she had only got something like osteoarthritis in her spine...one area of her spine and she was having treatment for that....and she had gone for injections and various other things only a few days prior to this...and she was very vocal....she has a good sense of humour....*

Other attempts to define QoL were directly associated with clinical conditions. Dietitian ID1b for example, saw the cognitive decline in dementia to be synonymous with a poor QoL.

> ***Dietitian ID1b*** *: patients who have a poor quality of life...for example, where they are confused with dementia.....*

Although the concept of QoL was explored in the interviews, no overt discussions about how to measure QoL were observed during the course of this study.

12.1.3.1.2. Measures of Quality of Life

As previously described, clinicians defined QoL in relation to the patient's physical or mental status. The implications of these issues will now be discussed in terms of how the value of QoL was measured by those involved.

The physical measures of QoL predominantly reflected the degree of perceived disability and, therefore, dependence experienced. Where clinicians raised physical issues, it was generally seen that a higher level of dependence was linked to poor QoL, with a higher level of independence suggesting a good QoL. Despite this maxim, clinicians acknowledged the limitations of this value judgment, although they appeared unable to separate their personal feelings from the analysis. It is interesting that most discussions about QoL resulted in clinicians defaulting to their own views of how they would want themselves or their family to live.

Dr M5b gave clear insight into this perspective when he described his personal views on QoL being linked to severity of disability and dependence. He used the

phrase 'common sense' implying that this should be a pragmatic response rather than a medical judgment.

> ***Specialist Registrar IM5b*** *: Yes.....I don't know what my views are on that...or.....but I would like to think that if I suffered severe brain damage to the point that I was....completely incapable and completely dependent and had no quality of life I would hope that somebody would use their common sense on me and just say you know....enough is enough....I think its very difficult....but that is what I would like for me...*

In the following, dietitian D1b gives an alternative view on the physical measures of QoL when she describes this in terms of hobbies. The implication here is that QoL would be poor if a person is unable to physically carry out their interests.

> ***Dietitian ID1b*** *: I know from my family, they wouldn't want enteral feeding for example if they had a severe stroke, and, I know from my father specifically....if he couldn't do his activities of daily living, especially if he lost the use of his hands....because he does model trains, that kind of thing, he wouldn't be interested, because he has always said, I wouldn't want to continue on being like that because my life wouldn't be of an appropriate standard to myself.....*

The individual nature of measuring QoL was echoed by many other participants, with an acknowledgment that each person has different expectations or needs. However, there was also a sense that the 'relative value' of QoL was a significant factor. Many clinicians talked of being unable to 'guess' about QoL in some patients whose baseline of QoL would be different to their own. This is starkly expressed by Dr M3b below, where there is an implication that patients have a lower threshold of expectation about QoL than might be held by health professionals, as they may have already experienced 'limitations' on their physical or social existence. Dr M3b's contrast of a 'disaster' for him (and me) and a 'fantastic life' for the patient clearly expresses the inherent value judgments that create difficulties in these decisions.

> ***Consultant IM3b*** *: when you've been as I have been to their (patients) support groups where they're in their wheelchairs with oxygen cylinders...erm...nasal prongs....having a pint and a steak and kidney pie in the local British Legion.....which to you or I would be a disaster...but for him*

would be a fantastic life.....then...we...you sometimes wonder...well....I certainly think that some of my assessments of what is a meaningful life....erh...may have been.....not erroneous but.....erh.....you know...each for his own...

The views about QoL were also reported to be echoed by families, and created a further consideration for clinicians in terms of the possible burden that the patient may place on carers if physically dependent. In the following example, it is suggested that a patient's physical dependence carries an emotional but also a practical consideration for the relatives. Dr M9a suggests that a measure of QoL may also be the degree to which a patient becomes a 'burden' for families, and the extent to which the family or the patient can accept or embrace this. This social aspect of prognosis is hence influential in shaping clinicians views.

***Specialist Registrar IM9a** : that's the second question that the relatives ask.....the first question is are they going to die.....the second question is....nursing home or home...really....*

Issues on perceived QoL were frequently discussed in the MDT meetings, although this was often 'ad hoc' rather than routinely planned. In these forums, views on QoL appeared to contribute to a general consensus on whether the patient was perceived to have a good or a poor QoL. In the following example from a MDT meeting, the consultant's initial views on the patient's future QoL changed after discussion with the rest of the MDT. In this case, the potential shift from considering a nursing home placement for patient participant (6b) to residential care suggests greater independence, and hence a much more optimistic tone about future QoL.

MDT Meeting – Patient participant 6b.
***Consultant Dr M7a** : right...how is she ....how is she doing.....she's not doing very much is she...I'm not sure how far we're going to get with her.....nursing home if we're lucky?*
***Physio** : well....we hoisted...we're hoisting her out in physio.....is she being hoisted out on the ward? (to staff nurse)....*
***Nurse** : I can't remember...have we hoisted her out?....*
***Student Nurse** : No....*
***Nurse** : I know we didn't.....*
***Physio** : she's been in quite a lot of pain....*

***Nurse** : I know we didn't do it yesterday.....because she.....(whispers) had the runs...*

***Physio** : oh alright.....*

***Nurse :** and I mean **really** had the runs.... (facial grimace)*

***Physio** : yeah...but when her pain's settled ....and that she can be....she still needs the hoist.....erh...she's got quite a bit of RA[10] as well hasn't she...*

***Nurse** : yeah....*

***Consultant Dr M7a** : oh yeah....well...*

***Physio** : she creaks....*

***Consultant Dr M7a** : oh yeah....quite a bit...she's got quite deforming RA.....*

***Nurse** : yeah....*

***Consultant Dr M7a** : I don't know where we're going to get with her.....*

***Nurse** : no...*

***Physio** : but she's a bit better medically than she was?....*

***Consultant Dr M7a** : I suppose so...yes....*

***Physio** : well...it's early days yet...*

***Consultant Dr M7a** : yes...I suppose.....Ok....so she's doing better than I thought.....she might go to a residential home then...we'll just have wait and see.....OK.....*

Another recurring theme when considering measures for QoL was expressed as the degree of emotional or 'mental' distress experienced by the patient. Many clinicians expressed a view that these emotional aspects were often the hardest to witness and that 'prolonging' this distress would never be seen to be compatible with a good QoL.

In the example below, nurse N1a describes tangible discomfort when nursing a patient who is 'desperately unhappy'. She indicates that a patient in this situation would experience a poor QoL, and that she would find this difficult to 'observe' without being personally affected. This clearly indicates the difficulties in establishing whether it is the patient's discomfort or her own discomfort that generates the view on poor QoL.

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[10] RA = Rheumatoid Arthritis

***Nurse IN1a**: A good Quality of life...being..pain free.....a quality of life....erm.....and mentally...erm....serene.....I don't mean that they are not desperately unhappy or.....do you understand what I am saying..... that they are peaceful I think is the word....that they are at peace with themselves to a certain degree.....does that sound....yes.....and I think other than that....I think we are just not in a position to judge really.....but that would affect me I think.....when....when....they are obviously miserable....*

This concept is broadened by nurse N4b when she implies that patients who are frightened, not only have a poor QoL, but in these cases, their lives should not be prolonged. Her personal angst over clinicians 'going too far' to keep patients alive, is apparently worsened when she feels patients are experiencing 'mental pain'.

***Nurse IN4b** : people should be made comfortable, pain free, fear free but sometimes I think things are taken too far for too long.....I think sometimes when you see little old men and little old ladies who are frightened of what is happening to them, and they will struggle and pull every NG tube out, on a daily basis....whether they know what they are doing when they get to that stage, I don't know....I don't know but sometimes I think things go on too long for people.....I'll get shot for saying this....I don't want you to think I am horrible because I am not.....I think if someone has a PEG and they are quite happy about it and they are aware...that is the right word I am looking for, they are aware of what is going on around them and what is happening more or less.....to them....well that is different again.....I think sometimes, as I said its carried on too long, people go too far....*

It can be seen therefore, that the measures for QoL are highly personal and varied. There were recurring themes relating to changes in a patients physical, emotional or mental status, but there was little consensus on which aspects would be the most influential factors.

12.1.3.1.3. Having a duty to consider Quality of Life

Having considered some of the factors that underpin a clinician's views on QoL, it was clear that they did not have a standard 'proforma' on which to base their assessment and views. However, clinicians perceive that their professional role gives them an inherent duty to ascertain a view on social prognosis. This includes a

duty to 'balance' quantity of life against quality, as well as a professional duty to 'advocate' for the patient's absent voice. This latter point is interesting in that the role of 'advocate' was equally expressed by doctors and nurses but with a different emphasis. In the study sample, doctors often talked of advocating for 'allowing to die' when patient's had a poor QoL, with nurses adopting an advocacy role to encourage proactive treatment of patients with a good QoL. It was clear that when considering what would be best for patients, clinicians perceived QoL determination to be an integral part of the decision process.

Dr M7a talks of his duty to balance aims for 'sustaining life' with aims for good quality of life. He suggested that he considers both clinical and social aspects of recovery when making decisions.

> ***Consultant IM7a*** *: the view that I've expressed a number of times is that...you know...I don't think....that you.....as doctors...we as doctors should be expected to sustain life....just because it's life.....and not consider quality...*

The influence of expectations was further highlighted by Dr M9a when she describes her concerns over situations where QoL is not considered. In her view, being an 'advocate' for the client should raise consideration of QoL to an equal priority in terms of her duty to the patient. In this case, the advocacy role may indicate withholding ANH in respect of the patient's QoL.

> ***Specialist Registrar IM9a*** *: I have concerns about artificial feeding and IV fluids...erm.....being implemented in patients who really are dying or require palliative care.....and I have grave concerns about....erm.....people practising defensive medicine because they're concerned about.....being sued....erm....and not being the patient's advocate....so starting it when it's inappropriate....*

Having a duty to consider QoL was also significant when the patient was perceived to be very unwell, but might have 'potential' to recover. This was raised by many non-medical clinicians, perhaps reflecting their primary role in rehabilitation. In the words of Nurse N1b, if the patient demonstrates a 'certain', (although undefined) QoL, this would be instrumental in raising the 'duty' of the nurse to advocate for active care. In this case, the nurse indicates that she would make more 'forceful'

attempts than she might otherwise, in order to ensure that other clinicians were considering QoL issues.

> ***Nurse IN1b*** *: I am not saying we are asked but we certainly give our opinion……especially when you think that obviously there is a certain quality of life you would then you would be an advocate for your patient…..yeah…*

As seen therefore, despite the variability in definition and assessment of QoL, clinicians used the idea and discussions around QoL (particularly when there was a poor clinical prognosis) to gauge the extent of feeling of those involved. In doing so, this gave an opportunity to reflect on the patient's 'social' circumstances. It was clear that any competent clinician would be expected to consider a patient's QoL as part of the clinical plan.

12.1.3.1.4. Social loss and Quality of Life

Social Loss, as described by Glaser and Strauss (1964), refers to the status or position of the patient in society, and the degree to which their death would affect those other than the patient's family. This was evident in the data, expressed by clinicians but also observed in context. This issue has some overlap with the consideration of how the clinicians related to the patients (to be discussed in section 12.1.3.2) but in this context, it was a 'societal loss' rather than a personal identification with the patient. In the following examples, the complexity of this issue is stark.

Dr M3a provides insight into social loss when he indicates that clinicians are unknowingly influenced by a patient's social status when planning interventions. In this case, he links the degree of activity ('tried hard' with resuscitation) with the patients social standing ('Managing Director'). In addition, he highlights the profound contrast between what the patient 'had been' and what he had become. This reinforced the sense of loss experienced by those in a caring role.

> ***Consultant IM3a*** *: I don't think we should keep life going at all costs…. I think we should keep life going for meaningful existence….but when there's no…when there's no prospect of a meaningful life…and that's a very grey thing isn't it…… I remember…there was someone down here that was…that was resuscitated…..but a bit late…and he was brain damaged afterwards…they tried hard….because….you know…he was a managing director…but then gone to being an imbecile sort of thing…and that was very*

hard to take.....erm...I think...there is a very.....(sighs)...fine point with say...how...how good an existence in someone who's badly disabled...are you doing them any good...

This measure of QoL is clearly a covert heuristic, and one that is extremely powerful in clinical decision making. This was observed within context in the study, when the influence of social loss was also observed in the case of patient participant (58a). In this case, Dr M9a met with the nephew in order to gain information about the relative social loss for the patient and family. There had been a initial view expressed in the clinical team that 58a should not be a candidate for ANH as she had a 'learning disability'. The influence of social loss to establishing this view on intervention is clear. However, through discussion with the nephew, Dr M9a gained further insight into the measure of QoL in terms of the social loss for the patient *herself* if she was to have a PEG. The degree of 'loss' of QoL was considered to be negligible in her case, with the result that both Dr M9a and the nephew ultimately agreed that a PEG would be 'worthwhile'.

58a's nephew *: Well....58a all her life has been.....sort of....kept at home*
Dr M9a *: right...*
58a's nephew *: her sister...was the breadwinner....if you like*
Dr M9a *: right*
58a's nephew *: my dad's...eurh.....sister.....*
Dr M9a *mmmm.....*
58a's nephew *: and....erm....58a just....kept house....*
Dr M9a *: right.....*
58a's nephew *: so really.....she's been.....she was very very shy...and retiring...obviously*
Dr M9a *: quite sheltered....*
58a's nephew *: yes...very sheltered...yeah....*
Dr M9a *: yeah.....*
58a's nephew *: and because of her speech impediment....*
Dr M9a *: mmmmm*
58a's nephew *: and she had ....erm .....an operation on her leg when she was young...she was born with a deformed leg....*
Dr M9a *: right.....*
58a's nephew *: 'cos her father was crippled you see.....*
Dr M9a *: right.....*

58a's nephew *: you know so.....and.....so she's not had a ....an easy life.....*

Dr M9a *: it's not a full life.....no.....*

58a's nephew *: well.....who are we to say....you know.....we all have different challenges don't we?....*

Dr M9a *: absolutely....yeah...but she has already lived with disability and wouldn't see it as a bad thing?*

58a's nephew *: precisely....*

The concept of social loss was further evident in the role played by families to ensure that clinicians were aware of the 'person' within the patient. This will be further discussed in section 12.1.3.2.1. This aspect was raised by one nurse in particular, who had personal experience of her father having had a stroke and subsequent PEG feeding. Nurse N7a described the profound effect on her father in terms of his loss of status. This frank account highlights the impact of social loss to individual patients, family's and society.

Nurse IN7a *: It certainly is.....because my dad he had a stroke at 57....no at 47 he had a stroke...and he was PEGged after a couple of weeks and he lived for 2 years after that with a PEG and no improvement at all.....he was in a wheelchair, nil by mouth, and I just think, I don't know I just think would he have wanted that if he had thought all he is going to do is be in a wheelchair for 2 years.....so I think maybe that is.....at the back of my mind.....when I see like families, and I always tell them, I say from personal experience a PEG isn't always the best thing, and maybe I shouldn't maybe the Drs would shoot me if they heard me say it but.....I just think I have been on the other side of the fence as a relative so.....and it has an impact on the family...because my brother was 12 and he thought the PEG would make dad better and it didn't.....so I think he was like waiting for my dad to get up and walk and talk and things and he never did.....and I think oh well, my dad was like a very proud man who was doing his degree and he couldn't bear for anyone to come and visit him and see him in that state and I just think maybe he would have been better just....like.....being left to it really and just.....it sounds horrible....to pass away rather than have that, he was so distressed all the time.....*

Social loss and its contribution to determining QoL is, therefore, significant in terms of establishing intervention, but also the potential impact on the future of those involved.

Throughout this section QoL as a factor within social prognosis is seen to be an instrumental, but hugely complex factor when determining a patient's best interests.

12.1.3.2. Relationships with the Patient

Within the social components of prognosis, the clinician's relationship with the patient was an extremely personal and influential issue affecting the decision. For the clinicians, the degree to which they could 'identify' with the patient, or saw them 'as a person' was extremely powerful. In some circumstances, clinicians were given information or made a 'connection' with the patient such that their views were influenced by how they would personally value their life. In other situations, clinicians maintained a distance or detachment from the patient. In these cases, there was often less personal investment attached to seeing the patient as a person. These aspects will be discussed under the following headings

- Having 'connected' with the patient
- Being 'distant' from the patient

12.1.3.2.1. Having 'connected' with the patient

In this study, 'connectedness' between individuals was observed when a clinician related to the patient, in a way that generated some personal emotion or responsibility for the patient's future life experience. In many cases, where the clinician had 'connected' with the patient, there was an increase in clinical activity or intervention.

This social component of prognosis was particularly evident in the observational settings.

In some cases, the 'insight' or connection was made through direct communication with the patient.

In the following example, patient 6b was unwell with a severe chest infection, and views on her clinical prognosis were uncertain. Despite this, she remained alert and interactive, and sufficiently connected with the clinicians for them to assume an active treatment plan. This may have been influenced by the fact that she had

presented as a sentient being, and could communicate with the clinical team, hence leading to more positive views about her social outcome.

> ***Consultant M2b*** *: I'm going to squeeze your leg...sorry if it hurts.....alright.....(M2b moves around bottom of bed to stand on 6b's left side) coming round this way....(looks at 6b's mouth).....can you stick your tongue out....(6b nods)....can...you...stick...your...tongue ...out.....right.....can you understand me.....show me you understand.....can you take your finger...and rub your nose.....rub your nose...with your finger....can you lift your arm up.....alright.....ok.....you know you're having trouble...problems swallowing....don't you.....we were going to try.....and put a tube....into your....into your tummy.....through the skin.....under anaesthetic....to help you with your feeding.....is that what you want.....(6b nods) ...Ok....you won't feel it.....that'll be in a few days now.....(6b coughs) .....can we request chest physio...*
>
> ***Medical House Officer*** *: he's here at the minute.....*
>
> ***Consultant M2b*** *: if she's more cooperative.....she might...you might have another go at an NG tube.....*
>
> ***Nurse*** *: right....we'll see how it goes.....*

It can be seen that in the above example, the intermittent communication from 6b, albeit limited, was sufficient to assume some awareness and on behalf of the patient. The contribution of 'connectedness' largely required the patient to show a degree of awareness or fleeting consciousness. There was a recognition that once they had 'identified' with the person, it would be difficult to remain detached. This is illustrated in the words of Dr M3b below, where he states that a patient showing some attempt at verbal communication, or otherwise opening their eyes, would demonstrate sufficient levels of consciousness to consider ANH.

> ***Interviewer*** *: what would somebody need to be doing in order to be...conscious.....enough to be fed.....*
>
> ***Consultant IM3b*** *: (Imitates in slurred voice)...hello doctor ..... awake...awake...yeah so not...not unconscious...but awake....doesn't have to.....*
>
> ***Interviewer*** *: So opening their eyes?....*

Consultant IM3b *: Opening their eyes....yeah...if they're awake....if they're awake...*

Many clinicians acknowledged the practical difficulties of establishing a patient's level of consciousness in the acute stages after stroke. This issue of consciousness links to views on clinical prognosis, as previously discussed. However, it was clear that consciousness was also a subjective measure of levels of social 'awareness' as expressed by nurse N6a below.

Specialist Nurse IN6a *: she isn't in a position to say, but she is conscious and I do think it's a very difficult decision and I suspect if someone is conscious you couldn't* ***not*** *feed them really unless they have said no.....you know, as opposed to those where you get..minimal or no response when you try to rouse them.....so you could have someone who is drowsy and you go near them or you touch them and they can open their eyes and you see...some response and can see, you can see something happening in the brain.....you can see....because they're sort of.....all you have in the middle between the two, where someone might be drowsy but if you wake them up they can speak to you or even if they can't speak they are aware that you have woken them up and they are in these circumstances, and they know there are things are happening, you couldn't do nothing....and then.....but if someone is unconscious you don't get much response or maybe might get a stir when you move a painful leg or something like that but then that is it.....you could do virtually anything to them and you wouldn't get much from them.....you'd hold back...*

In many cases, it could be argued that connectedness was merely related to levels of consciousness. However, there were occasions where connecting with patients transcended their consciousness levels. This was clearly observed in the case of patient participant 22a. In this case, the fact that the consultant Dr M7a had spoken to her when she was alert some weeks previously held an immense 'hold' for him in maintaining a view of a good prognosis. Despite patient 22a becoming unconscious as her clinical condition worsened, her expressed views when she was alert were respected to the point where the clinician felt a duty to overrule the views of the family. This may, in part, be attributable to respecting autonomy rather than connectedness, but was interesting in that the change in her clinical prognosis and consciousness did not affect his view of her potential social well-being.

Medical Notes – patient participant 22a – day 20 after admission

Entry recorded by consultant Dr M7a.

Long discussion (45 minutes) with niece and nephew. She indicated that she thought her aunt would not want a PEG tube. I told them that I had a conversation with her a week ago where she indicated to me that she wanted to get better and that she understood to have a chance of doing that, that she would have to have the PEG tube. Whilst I have every sympathy with the niece's opinion, I told her that I have a duty to respect 22a's wishes and therefore felt that the PEG should be inserted.

As well as identifying 'direct' connections with patients, clinicians spoke of connecting with patients through the words of relatives, or even where the connection may be more with the relatives. Once more, views on the 'value' of the patient and their QoL were seen to influence clinician's views on interventions, including those relating to nutrition. In the following, Dr M7a describes a current case where the relatives 'painted a picture' of the patient as being a 'gentle and caring' person as evident in the scenario of looking after an injured bird. As Dr M7a himself says, having been given a picture of this person, he could no longer remain detached to the impact of the clinical decisions on the person and their family.

***Consultant IM7a** : what is the prognosis for this patient....if the prognosis is poor...I mean I would probably be saying under those circumstances... I don't think we should be going down....I think the prognosis is very poor...if they said...as it was said in this case....but my father.....you know...if he saw an injured bird in the road would pick it up and nurture it back to health...that's the sort of person he was...therefore....I think you should treat him.....how.....how do you say no to that.....*

The issue of connectedness is one that presents itself to clinicians rather than them actively seeking it. In the last example, it appears that in some instances, this additional insight further complicates the situation, and may result in clinicians compromising their clinical judgment in order to respect broader social values or aims.

12.1.3.2.2. Being 'distant' from the patient

As described, there are some situations where the clinicians connect with a patient, to a level where they inadvertently place a greater value on their 'personhood'. It was also clear from the data that some situations generate a sense of detachment or distance from the patient, and this can influence a clinician's view on their future life.

There were a number of examples in the data where clinicians were detached from patients for a number of reasons. In some cases, this was observed when the clinicians faced difficult emotional situations, such as a patient's probable death. In other situations, this was observed when objectivity was required, such as those occasions where second opinions were sought. These examples were relevant for nutrition decisions in that there was a 'knock-on' effect over the level of subsequent interventions. Where 'connecting' with a patient encouraged a more positive approach to nutritional interventions, being detached generated a less active approach.

The following example from the medical notes of patient participant 3b reveals the combination of factors that might create a sense of detachment. The medical notes entry reveals that the patient is deeply unconscious (hence no sense of 'connection') and has 'distant' relatives. There is an implication that in this case, the clinician's view of social (as well as clinical) prognosis is poor.

> *Medical Notes entry – patient participant 3b*
> *Day 2 of admission*
> *Remains unconscious and unwell.*
> *Lives in sheltered housing.*
> *NOK (Next of Kin) are old – live in xxxxx (Ireland)*
> *I don't anticipate that 3b will recover from this latest incident. If he does, he will likely be severely disabled.*
> *Keep comfortable at present.*

It was interesting to note that in situations where clinicians appeared detached, there were further mechanisms employed (albeit perhaps unknowingly) that further maintained their distance. In some cases, this was through use of language, for example, referring to a patient by their disorder rather than by name. This is shown in the example below from a MDT meeting.

MDT meeting – Patient participant P1a

***Specialist Registrar M9a** : She's another poorly stroke....in bed 3.....just monitor....*

Where brain damage was extensive, essential human characteristics were removed, rendering the patient vulnerable. Dr M5b referred to these patients as sitting ducks, targets for other infections or co-morbidities.

***Specialist Registrar IM5b** : I think...you know if you've got that much damage done to the brain in one fell swoop then generally speaking if it isn't the fact that....there has been extensive brain damage it's the fact that they are just a sitting duck for something to land on their chest...or an infection or a clot or you know....a further stroke or something....*

***Specialist Registrar IM5b** : but if you are talking about somebody who is severely ill.....severe stroke....bedbound they are more likely to succumb to recurrent infections much much earlier than....whatever feeding is....erh.....no matter what nutritional support they are getting....and these are the.....the things that that tend to terminate life so....erm.....I would be aware of the fact that the patient is likely to succumb to other complications....*

Although there were many references to age and its impact on prognosis, few were as explicit as the views expressed by Dr M2b. In this case, it is evident that age sometimes allowed an objective distance from the patient when making decisions.

***Consultant IM2b** : there are some people I think very strongly....say a young person who I hope we can get better....erm I feel very strongly we ought to be doing everything and some older people in which I...I feel it would be futile to push...*

In summary, when considering the social components of a patient's prognosis, it is clear that issues relating to personal 'connecting' with the patient may influence the view taken. The implications of some of these factors in the eventual management plan will be further described in chapter 13.

12.1.3.3. Social prognosis and nutritional interventions

The aforementioned social components of prognosis showed direct links to views on nutritional interventions after stroke. In simple terms, if the patient had a poor QoL, nutritional interventions would be less readily offered than if the patient had a good prognosis.

In the first example below, poor QoL is directly cited as a reason to 'let' a patient eat orally (with an acknowledged aspiration risk), rather than considering enteral feeding. In this case, there is an implication that the patient (7b) has an anticipated poor clinical prognosis but that they should aim to improve her social situation by allowing her to do what she has requested. That is to say, although there is a view that allowing oral intake may increase her risk of aspiration (thereby potentially contributing to a poor clinical outcome, possibly death), improving the social outcome for the patient should override this aspect. There is an implication that aspiration might be a 'lesser evil' for 7b than prolonging life with a NBM status. The inconsistency in management and complexity of these cases is clearly expressed in the following.

> ***Ward Round – Consultant M1b reviewing Patient Participant 7b***
> ***Senior House Officer*** *: well....if someone like that aspirates...anyway.....well...her quality of life and being able to drink a little bit for a short while is probably better.....than making her nil by mouth.....for a longer time....*
> ***Nurse*** *: and making her feel uncomfortable*
> ***Senior House Officer*** *: so if you are weighing up quality of life aspects.....*
> ***Consultant M1b*** *: you can't really make someone choke.....that's not acceptable*
> ***Senior House Officer*** *: no you can't....but if she wants to drink.....and she feels better for it.....for let's say two months...it's better than being tube fed and nil by mouth for two years.....*

Clinicians expressed general views on providing nutritional interventions for patients with a perceived poor QoL. Overwhelmingly, throughout the data, there was a presumption that providing artificial nutrition for a patient with a poor QoL would not be in their best interests. In the following, Dr M7a relates consciousness, 'connectedness' and QoL issues directly to his plans for feeding. In this way, he appears to have developed heuristics for feeding, based equally on clinical and

social aspects, but with the relative weight of each aspect varying in each patient situation.

> ***Consultant IM7a*** *: Erm.....previous quality of life...erm.....potential....in terms of prognosis....erm.....previous expressed wish if you can find that out...erm.....I think they're the main things....you know.....where have you started from....if you've started from end stage dementia....erh....with no quality of life...I wouldn't put a tube down that sort of person...if you're starting from good quality of life....erh...in somebody who has an attitude of ....you know.....we'll get through and fight whatever comes....then I'm more likely to put a tube in that sort of person...erh...if they've had a large bleed or a large infarct that's taken off...you know....half their brain.....erh....and they're semi-comatosed and.....they've got a chest infection and don't seem to be responding...I won't be putting a tube in that sort of person...*

Dr M5b reinforced the view that ANH decisions are directly linked to views on QoL by providing his personal view on what would be 'best' for him. It is unclear how much his statement would impact on the decisions he would make for *others*, but it is clearly expressed in terms of his baseline for a beneficent (and arguably 'best interests') approach.

> ***Specialist Registrar IM5b*** *: I wouldn't want to be fed no.....we need to.....in my opinion differentiate between living and existing and I would rather have.....two good quality years of life than 5 of just merely existing....*

In conclusion, issues relating to the social components of prognosis are seen to be complex, challenging and extremely influential for clinicians when making decisions about best interests for nutritional interventions after stroke.
It is clear that views on prognosis are influenced by clinical and social aspects, and that these are subject to change as events occur during the patient's hospital admission.

12.1.3.4. Forming a view on the social components of prognosis

As previously discussed, the views on the social components of prognosis lay both in the perceptions of QoL, and the clinician's relationship with the patient.

Throughout the study, it was evident that the social components extended beyond the patient, to include the carers and the multidisciplinary team. Views relating to each individual were formed over time, and these aspects will now be discussed under the following headings.

- Views of the patient
- Views of the carers or family
- Views of the Multidisciplinary Team

12.1.3.4.1. Views of the patient

Decisions for the majority of patients participating in this study were made in the absence of the patient's views. However, there were some instances in which a patient had either previously expressed a view prior to becoming incapacitated or was able to contribute a view to their management.

In the following example, Dr M6a describes a situation where the views of the patient were given priority as he was conscious and had capacity to be involved. In this case, his level of consciousness reinforces the perception that he had a good clinical prognosis, hence the decision to offer ANH is fairly 'straightforward'.

> ***Consultant IM6a*** *: Well if you've got somebody who can't...I mean the vast majority are fairly straightforward....I mean we just had one this week or rather a month or so ago....a rather unusual one with a guy who'd had a brain stem stroke such that he couldn't swallow...but he could still walk around the ward...amazing really....so he could still walk around the ward....and he could still speak although his speech was a bit affected but he was mentally all with it...but he couldn't swallow....so one just talked to him and I asked him what he wanted and all the rest of it and said to him 'well look.... if we don't feed you some way you are going to die' and he didn't want to die so there was no problem there.....*

On occasions, clinicians acknowledged the difficulties associated with considering second hand accounts of the patient's wishes. In the following example, a stated 'living will' believed to be put forward on behalf of the patient is seen as an intervening condition to affect judgment on social prognosis.

> ***Specialist Registrar IM5b*** *: relatives statements about....erm.....the wishes of the patient before....their illness.....whether they have expressed clear wishes not to be....sort of.....given active treatment like living wills things like*

that.....the opinions of the relatives in terms of what they feel may be....erm.....proper or important for the patient....although that is not binding but one would take that into consideration....

However, as will be discussed in chapter 12.3, 'going against' the views of the family (especially if the views are strongly held) would be a rare event.

When establishing a patient's previously expressed views, some clinicians referred to use of 'living wills' or 'advanced directives'. Most clinicians stated that these are not used to a large extent with the older generation, with a view that patients of this age trust the doctors' opinions in decision making. Where living wills had been used, clinicians were keen to emphasise that they were rarely simple and straightforward to apply. Questions needed to be asked about the circumstances in which the living will had been written, the intentions of the individual when recording their wishes and further clarity was required about the circumstances in which the individual would want their wishes to be enacted.

***Consultant IM2b** : Erm.....the document is usually deposited with the GP so it gets faxed to us and it's in the patient's notes and we have to have.....a discussion with the patient or the relatives in the light of what their known views are.....because.....you never know when....erm.....people make these directives whether they have foreseen the exact situation that they are in.....and you've got to make a sort of decision on their behalf....whether this is the kind of problem that they visualised that they wanted their views to be carried out in.....*

12.1.3.4.2. Views of the carers or family

The views of the patient's carers or family shaped and influenced the views of the clinicians. This was often not in the context of the patient's social outlook directly, but in terms of ensuring that the carers/families views on the patient's future were taken into account. This is a subtly different point to that which will be discussed later in chapter 12.3, as in this context, the 'needs' of the carers take precedence over the needs of the patient.

As previously indicated, this issue often sees a 'blurring' of views based on what the relatives think the patient would have wanted, alongside what they think would be best for the patient. This is starkly acknowledged by Dr M5b, in contrast to his earlier statement in section 12.1.3.4.1. He identifies here that the family 'want what's best for him' but that he struggles to separate this from an 'advanced directive'.

Specialist Registrar IM5b *: but this guy in my opinion....you know...his....his....his care has been affected by....the feelings of his relatives and that is worrying.....that's quite worrying I find.....*

The views of relatives in terms of their own social 'needs' was a recurring factor in determining best interests. In some cases, this appeared to relate to the 'value' placed on the patient's life by their relatives. If the carers expressed a view that the patient's 'value' was high, the level of social prognosis was perceived to be similarly high. In the following example, the patient's previous QoL was perceived by the clinicians to be lower than the perception held by the patient's husband. Although the husband's needs were also influential, it was clear that his judgment of her QoL was respected and it was his view that determined subsequent interventions. The complexity of issues underpinning this are illustrated through providing Dr M6a's description in its entirety. As can be seen, Dr M6a detailed a number of competing interests that need to be balanced.

Consultant IM6a *: Ok....before she came in....she was still eating.... she was being fed by her husband.....so she was already dependent and she couldn't take anything.....she had to be fed.... so without her husband diligently shovelling the food into her....but she could swallow....then....ok....so she was already very dependent.....now.....and then she had the stroke so she couldn't take anything at all...right.....then we were looking at the quality of life beforehand and it's always difficult to.....because the patient can't tell you much because they are demented you see.....so all you are going on is the husband and we both agreed (both doctors) that here was someone who perhaps couldn't leave go what he knew was the inevitable decline with his....the prognosis.....even if there hadn't been the stroke....is likely to have been less than 12 months because the decision.....the next decision would be....like with a dementia patient they get to the stage where they can no longer swallow....what do you do.....erm.....in that case I feel it's right for nature to take its course.....right.... and I think this has just been brought forward by three or four months by the stroke.....so it was on that basis you see.....but on the other hand it's a very upsetting time for the husband and all the rest of it so it's not an easy situation....and you can really.....why should we put a PEG down on someone to make them.....to keep them.....and it's a very ethical*

situation and different people will do different things and have different views on Quality of Life....and I know that.....so whatever decision you make you know there are going to be a load going one way and another load going the other way.....so you are not wrong whichever way you go...but.....so in the end you've got to make a judgment.....

As can be seen therefore, the views of the family in terms of their 'own needs' are extremely influential in decision making. It was acknowledged by some clinicians (as seen in the above example) that broadening 'best interests' to consider what the family might need is essential to an holistic approach.

12.1.3.4.3. Views of the Multidisciplinary Team

The views of the other members of the multidisciplinary team were also seen to be influential in forming views about the social components of prognosis. The medical clinician ultimately has responsibility to make the clinical decisions for a patient who lacks capacity to contribute. However, it was evident that the decisions were made with some degree of consensus across the team. Even with good clinical insight, the responsible clinician sought the opinions of the team as a measure of determining the majority view on the best interests of the patient in terms of social prognosis. This aspect was clearly observed in the MDT meetings, and in the expressed views of the clinicians themselves. In the first example below, the consultant stated the need for consensus before making a decision, and cited the MDT meeting as one forum to ascertain the views of the team.

***Consultant IM6a** : when you are in the multi-disciplinary meetings you find out more.... and it's the consultant at the end of the day who leads the decision.....but I like to think I would never make a decision if there were people...well I would make a decision...but I would never make a decision against what a significant number of other people thought....*

The direct influence of the MDT on decision making was observed in the meetings, where consultants were seen on occasions to change their view of management based on the views of others. In the following example, the consultant directly asked for opinions regarding the patient's (16a's) future QoL, and what they should plan for her care.

MDT Meeting – patient participant 16a discussed by Consultant Dr7a

Dr 7a *: yes.....have there....has she got relatives....have we....*

Nurse *: she's got the sons....*

Dr 7a *: have they seen her?.....*

Occupational Therapist *: I don't think they realise how she's going to be..*

Dr 7a *: in a treatment session?.....*

Nurse *: he comes in...I mean he does work...but he comes in at night time....and he's certainly seen her when she's been.... you know.....been....very agitated and everything.....*

Occupational Therapist *: she's alright when they're in...she's good when they're in.....*

Nurse *: but they can calm her down...where as we can't....*

Nurse (2) *: yeah...as soon as they go she starts again....*

Physiotherapist *: well...we probably need to get them in to therapy then...to calm her down.....and see.....*

Dr 7a *: So what should we do?*

Occupational Therapist *: I don't think we can plan discharge yet...she's going to be so dependent on them....*

Dr 7a *: Ok...so she's medically more stable...but we're going to have to see how she copes...let's review again next week....*

One of the issues underpinning the need for consensus and a MDT approach was seen to relate to 'damage limitation' for complaints or major disagreements. In the following, Dr M3b directly refers to this issue as an influencing factor when he makes clinical decisions. In the context of decision making based on best interests, it is clear that the interests of the 'team' require consideration as much as those of the patient and family.

Consultant IM3b *: but you'd want to take the nurses on board with you.... and you know...that we were all agreed that this was the best way forward.....erm...because sometimes they can report you.....and...you know...if they reported you....you'd be done...you'd be done.....it can happen.....you know...if you're.....if you're a shit to your nurses...you'd be....you know what I mean...I'll get the bastard Dr 3b back...that's right....yeah....you know...but if you're nice to them they're usually lovely to you.....yeah.....*

The need for consensus in terms of reinforcing that the team are doing 'what is best' is clearly articulated here. In essence, fear of complaints or litigation can be a major determinant in the clinicians views over what would 'be best' for the patient.

12.1.4. Views on Prognosis – data sources

The variety of data sources allowed a view from a range of perspectives. This was advantageous in establishing a pattern in the themes according to their levels of direct or indirect influence on the decision process. It was evident that there were some differences between the views on clinical prognosis and social components of prognosis according to the forums or sources of information. Through analysis, it was clear that there was discussion or acknowledgment of clinical prognostic factors in all data types. One forum in which *clinical prognosis* discussions were dominant however, was in the ward round setting, where the majority of focus during the ward round was to review the current patient condition, trends in recovery, and the immediate clinical plan.

In contrast, it was seen that *social prognosis* issues were rarely discussed during the ward rounds, but more likely to be discussed after the ward round or in 1:1 discussions. The forum where social prognosis dominated discussion was in the MDT meeting, as previously identified. The data also revealed that there was more open discussion about social prognosis (and in particular, the 'angst' associated with assessing this) in the interviews and vignettes. These issues will be discussed in more detail in Chapter 12.4.

12.1.5. Summary

In summary, there were a number of factors that were considered by clinicians in order to arrive at a view on the patient's clinical and social prognosis. These were developed and regularly modified through unpredictable events in each individual patient's situation. In this way, the relative weight or influence given to any one factor was seen to vary for patients at any given time, and also between patients and teams. It is clear, however, that a series of events contributed to gathering clinical and social information about the patient that together, formed a view on their prognosis. Through a process of gathering information and ascertaining levels of consensus about the future prognosis, the clinicians identified views about prognosis that were then placed in context with other factors to consider the harms/benefits of feeding.

12.2. Beliefs about Nutrition and Hydration Interventions

This chapter will address the second key influence on nutritional decisions. That is, the clinician's beliefs or views about the nutrition and hydration interventions they can offer and the anticipated outcomes of these interventions at different times. Clinicians considered the impact of these interventions in terms of clinical harms and benefits directly for the patient. In addition, social issues relating to the impact of the intervention were viewed in terms of the harms (or burdens) and benefits perceived to be experienced by the patient, the family and the wider context of 'onlookers'. For the purposes of clarity, nutrition and hydration interventions are discussed as though they were independent of each other. In reality, the clinical and social aspects of each of these interventions were integrated during the process of decision making. This chapter will examine the clinical and social aspects of each intervention in the context of acute stroke care.

Figure 7 illustrates the focus of this chapter which will be considered under the following headings.

- Clinical Impact of the nutrition and hydration interventions
- Social Impact of the nutrition and hydration interventions

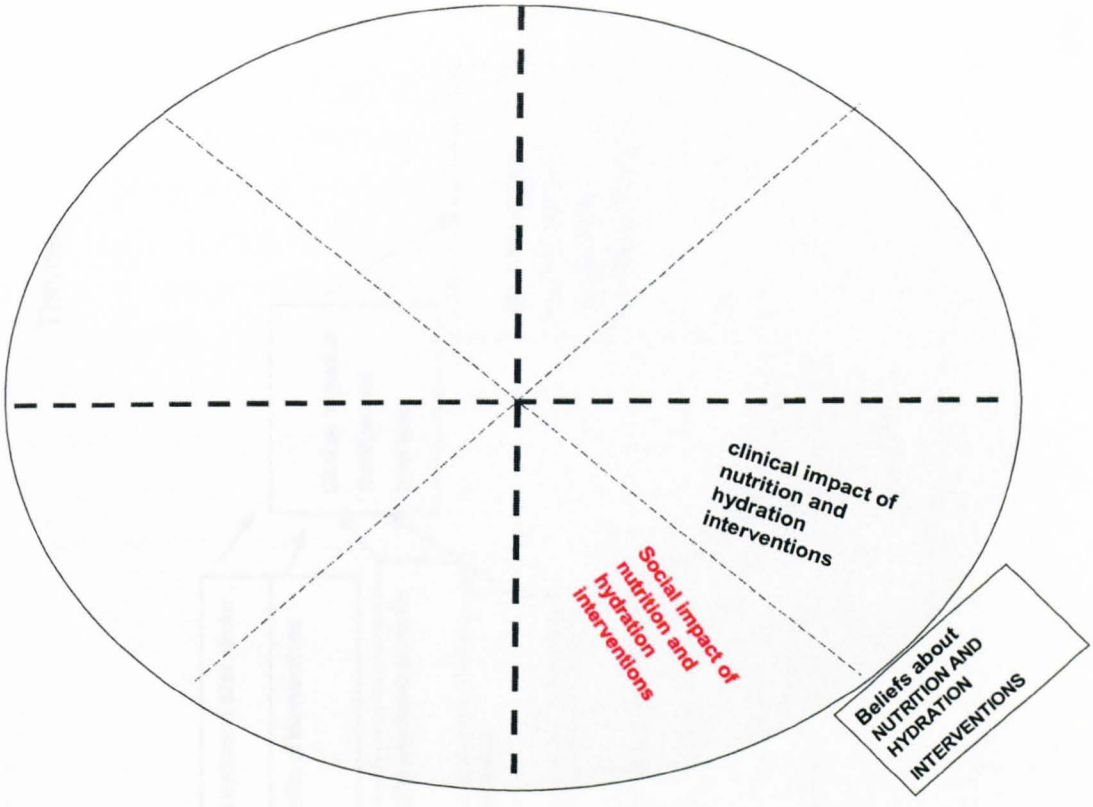
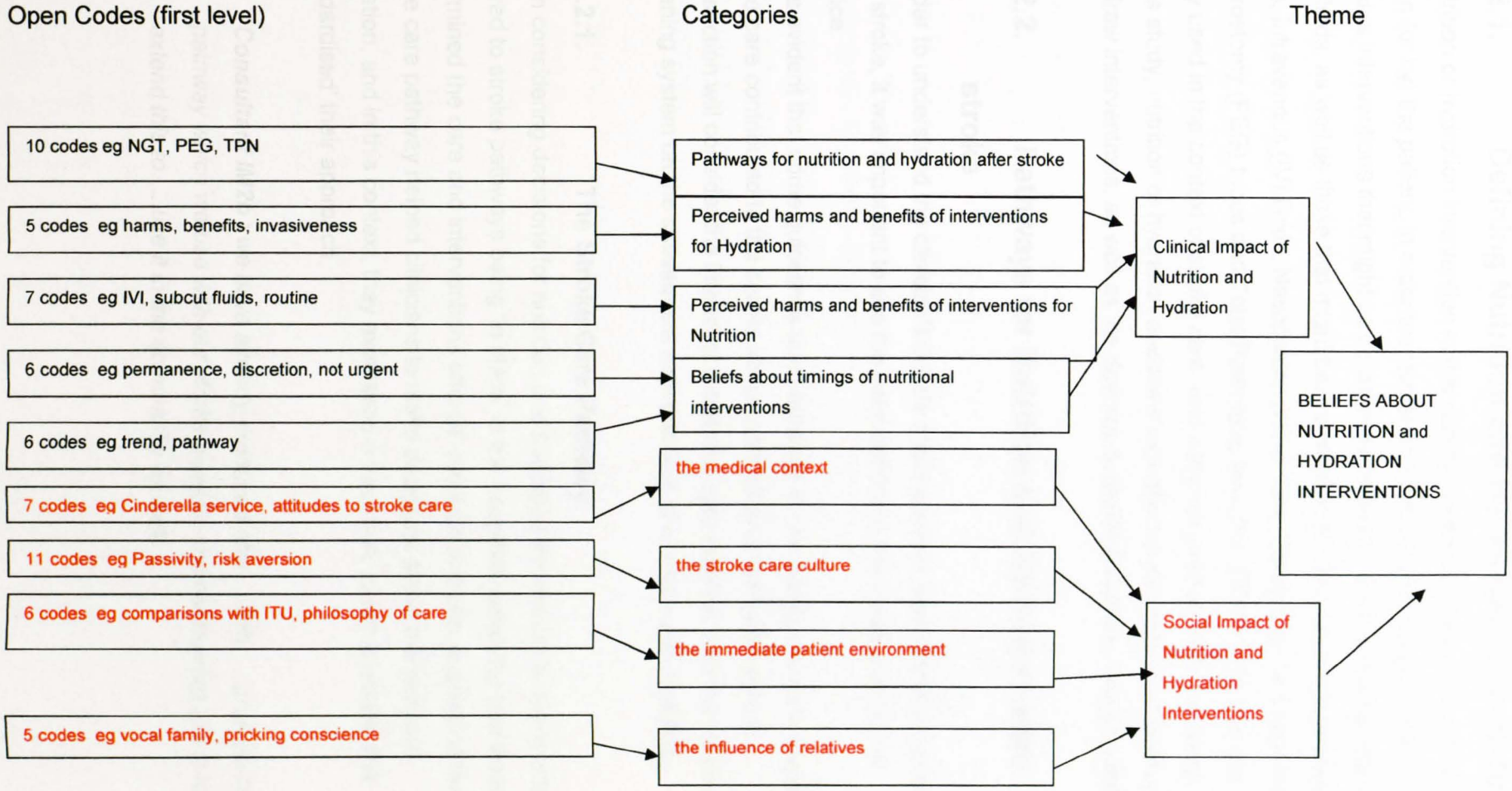


Figure 7 – Beliefs about nutrition and hydration interventions as an influencing factor in nutrition decisions after stroke

Figure 8 shows the analytical stages moving from open coding of data, through to developing 'Beliefs about nutrition and hydration interventions' as a major theme in the decision process.

Figure 8 - Theme Development : Beliefs about Nutrition and Hydration Interventions



12.2.1. Defining Nutrition and Hydration Interventions

A nutrition or hydration intervention in this context refers to actions that are carried out on (or by) the patient, in order to maintain nutrition and hydration levels. This includes interventions that might be considered 'ordinary', such as taking oral diet and fluids, as well as those that might be 'extraordinary', such as subcutaneous fluids, Intravenous (IV) fluids, Nasogastric (NG) tubes, Percutaneous Endoscopic Gastrostomy (PEG) tubes and Total Parenteral Nutrition (TPN). TPN methods are rarely used in the context of stroke care, and were not used at all in this study.
In this study, nutrition or hydration decisions included the decision to withhold or withdraw interventions, as well as the decision to institute nutrition following NBM.

12.2.2. Pathways for Nutrition and Hydration after stroke

In order to understand the clinician's beliefs about nutrition and hydration options after stroke, it was important to see the interventions in the context of clinical practice.
It was evident that some guidelines and pathways in use during the early stages of stroke care contributed to the beliefs about nutrition and hydration options.
This section will consider the impact of the stroke care pathway and the swallow screening system on the subsequent management of nutrition and hydration.

12.2.2.1. The Stroke Care Pathway

When considering decisions for nutrition and hydration interventions, many clinicians referred to stroke pathways being 'in place' in the hospitals, believing that these determined the care and interventions offered. Most participants stated that the stroke care pathway helped clinicians to make decisions about nutrition and hydration, and in this context, they expressed a view that, to some extent, this 'standardised' their approach.

> ***Consultant IM2b*** *: we have already produced erm.....erh.....a stroke care pathway which we use with our stroke patients and our current aim is to extend this to.....use it in the community as well.....*

The perception that the stroke care pathway was in operation with all stroke patients was echoed by other clinicians. In reality, however, documentary analysis revealed that only 8 of the 20 patient participants had stroke pathways in their notes. Further, none of these pathways were completed past day 3 of admission.

The stroke care pathways in both hospitals advised assessing the patient with a swallow screen on day 1 of admission, with advice to instigate 'intravenous fluids if swallowing impaired'. 'Consider naso-gastric feeding' is listed as a consideration on days 2-4 of admission on the stroke care pathway. Compliance with this 'target' for IV fluids was seen to be 100% in all patient participants who were NBM on day 1 of admission. There were some instances where IV fluids were commenced on day 2 if the patient was initially thought to be able to swallow.

As none of the stroke care pathways were completed after day 3, it was impossible to assess whether the pathway influenced the decision to start enteral feeding. Across the data set, no patients had NGT considered before day 3. Only one patient had a query for NGT on day 4, with the vast majority being after 5 days. The time range for commencing NGT feeding was 4 – 16 days, with only 1 patient receiving NGT feeding on day 4.

The events affecting these decisions will be further discussed in chapter 13. While largely absent from the participants notes, there were 'vague' references to the content of the stroke pathway by many of the participants. A few clinicians referred to the stroke pathway when asked in the interviews about the timing of enteral feeding options.

> ***Nurse IN2b*** *: so in our pathway it actually says...I don't know what day it's on unfortunately I can't remember...is it day 3?.....but it's very early on in the pathway isn't it ....where it says consider PEG feeding.....*

Interestingly, Nurse IN2b states that she thinks that 3 days might be the point at which they should consider PEG feeding. In fact, the pathway advises consideration for referral for PEG two weeks after admission.

12.2.2.2. The Swallow Screening Assessment

The stroke care pathway advises that a 'swallow screening procedure' should be carried out on day 1 of admission. Each hospital site has a system for swallow screening that involves nurses conducting a simple screen where they give teaspoons of water to the patient. Site a operated a system where nurses are

trained to give recommendations about modified texture diets for patients in some situations. Site **b** had a system in place where a patient 'failing' the swallow screening procedure would be placed NBM and referred to SLT for further assessment.
Most clinicians referred to the 'procedures' for swallow screening in terms of a routine intervention.

> ***Speech and Language Therapist IS1b*** *: The screen is done by the nurses....I think the policy is that everybody who is suspected of having a stroke should be put nil by mouth and screened....and the screening should be done almost immediately....*

Although clinicians described routine 'procedures' for swallow screening, many identified problems. SLT delays were the most commonly mentioned. This may be due to the SLT's five day working week leading to delays at the weekend, or simply waiting lists affecting the SLT department's response time.

> ***Consultant IM2b*** *: Well....the screening assessment is done by nursing staff.....and if there is a problem we hope that will be followed up by speech and language therapy staff.....and as you know unfortunately that may not be straight away for all sorts of unavoidable reasons.....*

> ***Consultant IM6a*** *: so a standard thing is to get them assessed for swallowing and feeding and again we like that done within 48 hours but we don't have the relevant therapists around all of the time.....and it's pretty easy with some patients... but if there is one where there is doubt about.....then we want the relevant speech therapist there....and....usually it's within 48 hours is our standard.....*

This variability in the timing of screening had implications for nutritional management of patients in the early stages of stroke. Doubts about a patient's swallowing resulted in them being maintained as NBM until SLT assessment.

> ***Nurse IN6a*** *: but if you can't assess it or it's not a good swallow then obviously we need speech therapy involvement and until that time they are nil by mouth.....and I am very happy with waiting for that....*

Most participants stated that SLT will not attempt to assess swallowing if the patient is unconscious. As a result, the patient stays NBM until they are alert enough for a swallowing assessment to take place.

> ***Speech and Language Therapist IS2b :*** *so if they are not appropriate to be screened because they are unconscious..... I am not sure what happens and I think from experience....of the people who we have seen some point down the line once they* ***have*** *been referred to us, I don't necessarily think there has been major action taken in terms of nutrition....they are unconscious, so nil by mouth....until they wake up....*

Responsibility for nutrition was suspended, pending SLT assessment, which was also suspended until a patient's consciousness level had changed. This created a void in the pathway, where some patients are 'trapped' in a NBM cycle by virtue of the screening pathway. This situation is neatly captured in the words of the dietitian ID2b below.

> ***Dietitian ID2b*** *: it's normally once speech and language therapy have assessed their swallow, then we get involved depending upon what outcome they come up with.....that's normally when they are referred to the dietitian.....now I know I have 2 patients just now on a ward here, and they have been in for about 3 weeks and they have been nil by mouth...because they are unconscious and the speech therapist can't assess them.....*

In the interviews it became clear that each professional group felt that, when a patient was NBM, the patient's nutritional intake was somebody else's responsibility. The nurses overwhelmingly felt that the dietitians monitored nutrition during this stage, with the dietitians being similarly clear that the nurses managed the patient's nutrition over this period. This apparent lack of attributed responsibility has implications over the management of nutrition of patients with reduced consciousness in the first weeks after stroke.

12.2.2.3. Monitoring Nutrition and Hydration Intake

In this study, it was evident that nutrition and hydration were managed and monitored differently. When IV fluids were insitu, the Fluid Balance chart was routinely completed. This recorded the amount and type of fluid given intravenously,

and the urine output from the patient (generally when catheterised). On occasions, IV fluids were omitted due to organisational issues on the ward, but generally, the fluid balance chart was updated regularly when IV fluids were insitu for those patients recruited.

This contrasted with the monitoring and recording of oral fluid intake. Food Record Charts (FRC) had columns which referred to oral fluid intake .These were not routinely completed, making the actual fluid intake difficult to determine. This situation was acknowledged by many participants, but particularly the dietitians, an example being dietitian ID2b below.

> ***Dietitian ID2b*** *: No, because a Dr can write that they are eating fair amounts and then you can go and speak to a patient and they will say something completely different, or a food chart will say completely different...that's if they fill them in.....eventually you might need to guess what they are having....or use other ways to find out if they are getting dehydrated....*

The lack of compliance with maintaining FRC's was noted to be a regular theme in the observational data. In the following discussion during a ward round, the discrepancy between the nurse's confidence about the amount of IV fluid taken, compared with her uncertainty about oral fluid intake is evident. Patient participant 16a was seen to be having both oral and IV fluids, but the total combined fluid intake would be impossible to ascertain in view of the omissions in records.

> ***Ward Round – Patient Participant 16a***
> ***Consultant Dr M7a*** *: how much...IV fluid are we giving her....she's not taking enough orally.....that's a....a question...not a.....*
> ***Nurse N5a*** *: er....eight hourly.....a litre over eight hourly....*
> ***Consultant Dr M7a*** *: right...again.....if she's taking anything orally...we don't need that amount.....do we.....erm....I mean how much is she drinking?.....*
> ***Nurse N5a*** *: we're going to do U's & E's in the morning.....*
> ***Consultant Dr M7a*** *: are we keeping a chart of how much she has?.....*
> *(Dr M7a and Nurse N5a look at Food record chart at the base of the bed)*
> ***Nurse N5a*** *: well....that to me doesn't look as if it's complete.....unfortunately.....she asks for a drink quite regularly though...and drinks it.....*

For patient participants who were receiving enteral feeding, the feed given was routinely recorded on an enteral feeding record chart. However, with oral diet intake, the FRC was often incomplete. This situation was acknowledged by participants, and once again, the dietitians raised the impact of this for patient's nutritional assessment and management.

> ***Dietitian ID2b*** *: Ideally what you want is if a patient....if the nurses thought their appetite was poor to fill in a food chart, to keep it for 3 days and if they felt that they needed more...to contact us.....but they don't fill the forms in very well....*

When reviewing the FRC's that were completed, it was apparent that the terminology used, and methods of recording oral intake created some difficulty in interpretation. Analysis of the records revealed that descriptive terms were used without direct quantification. Not surprisingly, when the clinicians were asked in interview to clarify and quantify 'small amounts', 'fair amounts', 'little' and 'good amounts', there was huge variation.

> ***Consultant IM6a*** *: 'small' means a bit but next to nothing I think....'fair' amounts...again getting a bit there but perhaps not enough...'little' not much difference there... 'good' amounts.. they are eating well.....I take all that with a pinch of salt....I mean it's very difficult that and that's why I like....you see when I go around and nurses....and I say are they eating? and they say they're taking stuff....I take whatever a nurse says with a pinch of salt...I look at the patients and their general demeanour....*

> ***Specialist Nurse IN6a****: I think it depends on the nurse who is looking after the patient, but they might talk about....but the meal is usually described so it might be porridge and.....and then they will say half a bowl of porridge taken and 3 bites of banana or something like that....so frequently they are written in terms you can understand.....but not always...*

All respondents acknowledged the limitations attached to the recording of nutritional intake.

12.2.3. Clinical Impact of Nutrition and Hydration Interventions

On occasions, the clinical and social dimensions of nutrition and hydration interventions were difficult to separate in the data. However, clinicians spoke of interventions in terms of the clinical impact on patients. It is for this reason that the clinical impact of nutrition and hydration interventions is defined as the perceived impact of the intervention on the patient themselves. This includes physical harm and benefit, as well as some aspects of emotional or psychological harms/benefits linked to the intervention. The issues seen to be representative of this theme will be described under the following headings

- Perceived harms and benefits of interventions for hydration
- Perceived harms and benefits of interventions for nutrition
- Beliefs about timings of nutritional interventions

12.2.3.1. Perceived Harms and Benefits of Interventions for Hydration

The clinical impact of the hydration intervention options were generally described by clinicians in terms of the harms or the benefits they provided for the patients. In this context, clinicians expressed general views over the available interventions, as well as their views about specific situations over whether the intervention would be in the patient's best interests. These issues will be explored in detail in this section.

12.2.3.1.1. General Beliefs about Hydration

The guidance documents[11] discussed in chapter 5, make no distinction between the interventions for artificial nutrition or artificial hydration. In reality however, the approach to, and views about artificial nutrition versus artificial hydration were very different.

As previously stated, hydration is generally commenced immediately on admission; Fluids are considered to be a routine intervention, given via IVI with no 'decision' to be made. This 'protocolisation' of approach was recognised by all of the clinicians.

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[11] Guidance documents on 'Withholding and withdrawing life prolonging medical treatments', published by the British Medical Association (2001) and the General Medical Council (2002).

Nurse IN5a *: so they come to us and they have not had anything to eat and they have got IV fluids in.....which is automatic.....*

Nurse IN2b *: They are always started on IV fluids to maintain their hydration.....and the swallow assessment is checked daily....*

Hydration is, therefore, considered to be essential for life and further supports clinicians beliefs and actions that IV fluids must be given routinely as soon as possible after admission. In the following, Dr IM5b describes the 'mantra' that is associated with the clinical importance of fluids.

Specialist Registrar IM5b *: because we're always drilled into us...you know you can survive without food for 7 days..no problems at all...it's water you can't do without....it's you know fluids you need...fluids....*

12.2.3.1.2. Beliefs about IV and Subcutaneous fluids

Given the essential nature of hydration, the clinicians had some options in terms of the mode of hydration intervention they could offer.

It is clear from the data that IV fluids are the 'first-line' default position, and are instigated in the majority of cases. In the study, all patient participants who were placed NBM routinely had a venflon[12] inserted to commence IV fluids.

There were some situations in which the IV fluids were believed to be too invasive when patients were seriously ill, hence clinicians offered an alternative option of subcutaneous fluids.

Specialist Registrar IM9a *: sometimes I put sub cut fluids up.....for a patient...to help....the family.....feel that they weren't dying of thirst....the difference is that IV is a more invasive procedure....you know talking about cannulating a dying patient...I don't think is humane...where as putting a*

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[12] Venflon = a small needle or cannula inserted into a vein, remaining for an indefinite period of time.

subcut needle[13] *in...isn't....isn't felt and it doesn't hurt....it's easier for a nurse to do.....*

However, the beliefs about the relative harms and benefits of subcutaneous fluids varied according to the clinical situation and the aims of the intervention. In some cases, there was a perception of minimal clinical harm which was felt to be acceptable given the presentational benefits of giving fluids. This was particularly the case when the patient was believed to be dying as above.
In some instances, however, clinicians themselves questioned their perceptions about the relatively insignificant harms of subcutaneous fluids. This is clearly expressed by Dr Im5b who demonstrates a clear sense of confusion over the harms and benefits of this intervention.

Specialist Registrar IM5b *: I tend to not use sub-cut fluids and if I do I tend to find that I am doing it more...to keep the nursing staff and the carers...family happy....rather than what I actually perceive to be the benefit of giving sub-cut fluids because.....there can be potential harm to them.....for example sometimes you end up with....sacs of fluid....the fluid just goes in under the skin and you have got basically a blister....now that's quite.... I wouldn't say it's common but I wouldn't say its uncommon...so it's....you know....you just think to yourself.....I just don't know what sub-cut fluids are all about...*

12.2.3.1.3. Beliefs about withholding or withdrawing hydration

Insights into the beliefs about hydration were most profound when considering the participant's views about withholding or withdrawing hydration options.
When considering withholding of fluids, there was general consensus that fluids should *always* be given and that it would be 'unethical' (Dr M1b) to omit to do so. The view that giving fluids is a 'duty' and that withholding fluids would be contributing directly to a patient's death was expressed by many.

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[13] Subcut = Subcutaneous needle, where the needle is inserted below the skin as opposed to into a vein.

Consultant IM1b *: I still think you have no right not to give IV fluids…I think IV fluids are absolutely essential because if you stop giving them fluids they will die…and I think that that is unreasonable….unreasonable not to give fluids……*

With regard to withdrawing fluids, some clinicians acknowledged that cessation of fluids may have a more social impact than a clinical impact, but in their descriptions, the issue of uncertainty over whether fluid withdrawal is physically harmful was prevalent.

All of the participants held the same view that withdrawal of fluids should only be considered if the patient was dying. Equally however, they acknowledged the unpredictable nature of the dying process.

Many clinicians cited the lack of evidence about whether IV or Subcutaneous fluids were generally beneficial or harmful for a dying patient.

Specialist Registrar Dr IM5b *: I am sure there is no evidence on this….I have spoken to a lot of people….there is nothing really to suggest that by giving intravenous or sub-cut fluids to the terminally ill patient we are doing nothing more than treating ourselves and not the patient….*

Consultant IM7a *: I…I think if we were….you know if we're consistent then……you probably……erh……..you could say if we were consistent then we shouldn't give fluids either really…..erh……..but I think….there is this big…ethical….and problem with relatives that…you know…..of…….of…is the patient in discomfort?…you could say with food….erm….again I don't think we've got a lot of evidence you know as to…….whether a patient is in discomfort because they've not got food….or whether they're in discomfort because they've not got fluids…….*

There was a recurring theme that withdrawal of nutrition can be viewed as 'beneficent' in terms of avoiding aggressive intervention, but withdrawing fluids would be harmful in terms of the symbolic impact of 'abandonment'.

Consultant IM6a *: there's a lot of psychology involved in this, there's a lot finality involved in it…it's as though….ok…we're not going to feed….we're not going to put them through the business of putting a PEG tube down and*

all the rest of it..... but not to give fluids as well...oh...you know....which if they are getting the fluids....you know.....it's a finality thing.....(tails off)

***Consultant IM6a** : we are irrational in our behaviour and I'm being honest about that....where you don't give them food...and you keep their fluids going and there's no rational.....rationality behind that.....what we should be doing is withdrawing everything and if need be giving them something....supportive and all the rest of it...otherwise are we prolonging their death?*

In conclusion, the issue of withholding or withdrawing hydration was seen as profoundly emotive as it opposed the universal belief that fluids are essential to life. Withholding or withdrawal of fluids may be seen to contribute to death.

***Consultant IM1b**: not give fluids is...I think it's an unethical...it's something I do feel uneasy about.. particularly if it went on for long...if it was for a few hours...that would be utterly reasonable...but to go on for a long time....erm...you know.....then where you may be playing a factor in their death...I don't think you have a right....where as I don't think doctors need to try hard....you know to keep people alive in terms of.....striving...to keep them alive you know....I think to actually not provide the basic care that a human being needs is unethical...*

Having considered the perceived essential nature of hydration, the contrasting beliefs about nutrition interventions will now be discussed.

12.2.3.2. Perceived Harms and Benefits of Interventions for Nutrition

The views about nutrition and nutritional options were more complex, and in many ways more contradictory than the views about hydration. This was partly attributable to the fact that there are more intervention options for nutrition, and less certainty over the harms and benefits of each. Specifically however, in contrast to hydration, the issue of nutrition was seen to be more complex because there was no universal belief or expectation to provide nutrition after stroke.

12.2.3.2.1. General beliefs about Nutrition

There was significant variation in views, and a marked degree of discretion regarding the use, withholding or withdrawal of the nutritional intervention options. This variability, and the relatively low evaluation of nutrition compared to hydration is evident in the following statement.

> ***Nurse IN2b*** *: I mean we are discussing feeding issues.....the hydration issue is always acknowledged and they do always have the IV fluids....but the feeding issue does tend to be low priority.....*

The issue of the human body's ability to 'survive' without nutrition appears to underpin some of the beliefs about its relative lack of priority. Clinicians gave broader examples of the ability to recover from 'starvation', such as the evidence taken from prisoners who have been on hunger strike, or people who have been held hostage. Interestingly the example of an 'illusionist', David Blaine, who carried out a 40 day 'fast' (taking fluids only) was given by one clinician (Dr IM5b) to highlight the perceived insignificance of nutrition within the public arena. This sets the scene regarding the backdrop of wider beliefs about the importance of nutrition.

> ***Specialist Registrar IM5b*** *: the majority of us if we stopped eating now....you know....David Blaine did it for 40 odd days.....you know....(laughs) I don't know what he has done for the cause....*

12.2.3.2.2. Beliefs about Oral diet Intake

Views on oral intake of food post stroke were heavily influenced by the risk of aspiration or choking. However, there was also some recognition that changes in the roles and responsibilities of nurses and the development of outside catering contracts for NHS food had changed the classification of food provision.

> ***Nurse IN1b*** *: At one time....I think in most hospitals nurses gave out the meals to patients.... and then it was seen like an auxiliary task and then it went over to catering and that's when the problem started.....food is not nursing any more....*

Whilst stating that they recognised the importance of eating and drinking for patient recovery, many participants acknowledged the limited attention given to monitoring or assisting with patient's oral diet intake. In the following by Nurse IN3b, a number

of issues are raised in terms of their contribution to the relative low priority given to supporting oral diet intake for patients.

> ***Nurse IN3b*** *: I think the biggest problem is if you have got someone who is not able to feed themselves...it's finding a member of staff to sit down long enough to feed the patient because sometimes it can be.....there are staff shortages all the time and also having things put appropriately in front of patients who need assistance....like making sure food is cut up if someone can't cut and so on.....those are the things that need to be looked at on the wards and sometimes...most of our staff are good but...you know if you have got 4 patients all needing feeding and you have one nursing auxiliary and are short of nurses....or you have a cardiac arrest coming in or you have got two patients who self presented with chest pains....you know....where are your priorities?.....*

Feeding was carried out by the auxiliary nursing staff on both of the study sites. However, auxiliary staff did not receive training or support on how this should be done.

> ***Nurse IN4b*** *: I have seen a great deal of people who need assistance to be spoon fed, I have seen some terrible practices, there is no training given in that....I have seen people come from a shop and maybe they have been a domestic cleaner on the ward and then gone on to be an auxiliary and they have been asked....anybody is asked to feed people....*

Feeding patients and meeting the nutritional needs of patients in hospital was therefore identified as a low priority in this study.

12.2.3.2.3. Beliefs about NGT's and PEG's

If the patient experiences a problem taking oral diet 'safely', the options for non-oral feeding broadly includes NGT feeding or PEG feeding. It was clear from the data that the clinicians held views about each of these options, and that these beliefs influenced their decisions about nutritional interventions.

As previously stated, there is little published clinical evidence to outline the risks and benefits of interventions such as NGT or PEG feeding. This degree of uncertainty about the evidence for and the clinical impact of each intervention was a recurrent theme.

There was broad agreement that NGT and PEG feeding are comparable in terms of the nutritional provision as shown in the following.

> ***Consultant IM4b*** *: Again I think it's very similar (nutritional intake).....it's very similar.....so for....what was said for PEG we can read for NG feeding*

> ***Consultant IM3b*** *: and then the big....the big decision is whether....you know...how you feed...enteral feeding...you know....which way are you going to...is it NG tube...is it...is it a PEG.....whatever....*
> *...there's nothing in the calorific thing that's different...it's just really for the ease of giving it...*

It was evident that clinicians held personally developed beliefs about the two main interventions that significantly influenced their views on their associated harms and benefits. These included beliefs about how invasive the procedure was, the risks associated with each procedure or intervention, and the potential for clinical review with each. Each of these aspects will now be discussed in detail.

12.2.3.2.3.1. Issue of Invasiveness

There was no consensus on which nutritional intervention was the most or least invasive in any given situation. PEG insertion was heralded as an invasive procedure through the protocols of consent, protocols which were not, at the time of the study applied to NG tube placement.

> ***Nurse IN5a*** *: the PEG is definitely.....you have consent....it's a big issue...it's an invasive surgical procedure, NG's just go up nostrils from the Drs point of view.... oh just put one of those up,...yeah...*

When forced to compare the two interventions, some clinicians questioned whether, from the patient's perspective, this view could be sustained.

> ***Speech and Language Therapist IS3a*** *: I think they are slightly different issues really....because obviously they are, there are risks with passing NG's obviously but I think...I see the PEG as a much more....I was going to say invasive....but then the NG....passing an NG tube is very invasive as well.....but there are more risks definitely with a PEG....*

Examination of the observational data supported the notion that invasiveness was not consistently applied to one intervention over another. In the following examples, the same medical clinician Dr M9a was observed talking to two different families about modes of feeding. In the first example, where M9a feels an NGT *should* be placed, she describes the NGT in very positive terms, suggesting minimal impact for the patient. In the second example, Dr M9a uses a subtle change of language to propose that the NGT would be less positive than a PEG tube due to the level of irritation that the patient experiences.

Observation – wife of 68a

Specialist Registrar M9a *: I think we should try him with some food…..*

Wife of 68a *: yeah….mmmmm*

Specialist Registrar M9a *: now….there are different ways of doing that….*

Wife of 68a *: mmmmm*

Specialist Registrar M9a *: mmm…..his swallow isn't going to be strong enough…..to swallow safely….so…what we….suggest that we do is…pop…..erm….a flexible….very thin tube…..up his nose…..which then goes….down the back (traces with her finger along her throat)…..and into the stomach….and it supplies liquid food straight into the stomach……*

Observation – nephew of 58a

Specialist Registrar M9a *: (about the PEG) you've just got the tube….that's right….yeah…..and then you put fluid food……into there……..and that goes in …over…over hours……*

Nephew of 58a *: right….*

Specialist Registrar M9a *: you know…it can be up to….sort of twenty hours…..while….while people are….getting on with their lives…..*

Nephew of 58a *: right……yeah…. but the…the same thing could happen…couldn't it….I mean she could …….the level of irritation might be less…..*

Specialist Registrar M9a *: it's* ***much*** *less….erm…..people can….rarely….pull PEG tubes out……it tends to be in those patients who are in a very agitated state……but……PEG tubes themselves are not painful….while they're in….and they're not irritating in the same was as having…a plastic tube stuck down your throat…….(as with an NGT)*

For non-medical clinicians, the patient's DNAR (Do Not Attempt Resuscitation) status often signalled the degree of acceptable invasiveness. In particular, there was a view that where decisions were made against resuscitation, other 'invasive' interventions (such as PEG feeding) would similarly be withheld. Conversely, where resuscitation was to be considered, there was an assumption that ANH would also be offered.

> ***Nurse IN1b*** *: Well……I think if you are feeding them…..they would usually be for resus wouldn't they….usually yes…..because you act as if you are treating them…..*

Medical clinicians recognised that a DNAR decision set the tone for the nature of intervention offered. Generally, the link between ANH and DNAR was created through the timing of the discussion rather than as a result of a direct association between these two interventions.

> ***Specialist Registrar IM9a*** *: It tends to be the two subjects that I discuss at the same time…..because you're talking about prognosis……and….you're talking about whether or not that patient….you feel in your professional opinion that patient is going to die in the immediate week…or whatever….so they go along…hand in hand……in terms of what you aim to do…..*

The potential dangers associated with seeing DNAR and nutritional intervention decisions as linked, was highlighted by some of the medical clinicians. This is clearly expressed by Dr M2b, although he later acknowledged that this distinct 'separation' and objectivity was difficult to maintain in practice.

> ***Consultant IM2b*** *: the person who is not to be resuscitated may well be….erm….. alert and enjoying….you know relating to their surroundings and appreciating their families visits….. and…erm……not wanting to be deprived of nutrition so I think these decisions have got to be made…..on their individual merits….but I suppose they are linked…..*

12.2.3.2.3.2. Risks associated with tube feeding

A further issue raised regarding the differences between the modes of feeding was based on the practical aspects of maintaining the tubes insitu. A widely cited reason to choose a PEG in preference to an NGT was if the NGT was being repeatedly

pulled out or dislodged. There was an accepted view that NGT's would be commenced before proceeding to PEG tubes as will be later discussed, and this is interesting in the context of the PEG seeming to create fewer practical challenges when insitu. Thus, the intervention with the greatest perceived risk of aspiration and problems with maintenance (ie the NGT), was the first line of intervention. This suggested that the decision about the mode of feeding was heavily influenced by 'social' issues (for example, issues of permanence) rather than the clinical issues per se.

> ***Nurse IN3b*** *: and if we had difficulty or if the patient is so restless they keep pulling it (the NGT) out.....that's another issue.....not being able to maintain it in position.....you can struggle to get one down and then it's out 2 minutes after the x-ray.....or even before the patient has gone up to x-ray because they are restless and don't want to keep it in.....that doesn't happen with PEG's in the same way.....*

The perceived risks associated with the NGT and PEG interventions related predominantly to the risks of aspiration, and the risks attached to the procedure itself. Throughout the data, clinicians highlighted the uncertainty over the clinical harms and benefits of the interventions. Whilst agreeing that NBM was the 'safest way to avoid aspiration' (as stated by IM4b), clinicians were uncertain about the relative risks between NGT's and PEG's. The 'evidence' to support either intervention was acknowledged to be sparse, but there was a general perception that there was less aspiration risk with PEG's compared to NGT feeding.

> ***Consultant IM4b****: Erm.....with NG tube....erm.....I think probably with NG there is a danger of aspiration probably is.....greater in that the tube may dislodge.....erh..... more easily than a.....a PEG tube that feeds.....but.....the danger of aspiration with a PEG tube is not completely...sort of.....unavoided....there is still that danger....*

The evidence that is available about the efficacy of enteral feeding, and in particular PEG's, created other uncertainties. Clinician's reported that patients often did not have long lives after PEG insertion, and this challenged the clinician's views about whether PEG's were beneficial for patients. In this case, the risks associated with the procedure itself were influential over the clinician's view of what would be 'best' for the patient.

Specialist Registrar IM5b *: I think a lot of the statistics about PEG's and alternative forms of feeding don't help us trying to convince relatives...patients.....that this is the best thing to do.....you know they look and say...oh...well you know.....50% are dead within 1 year of PEG insertion....and it's even higher than that I think....you know....you are up against it...*

With specific reference to enteral feeding and stroke care, most clinicians reported a vacuum of evidence to support them in making choices between NGT's and PEG feeding. In the following, this 'gap' in research evidence was explicitly acknowledged by Dr M7a, who hoped that the F.O.O.D trial would eradicate these uncertainties.

Consultant IM7a *: Well...I don't think the evidence is there...I mean that's why we need the FOOD trial*[14] *really...*

One issue that was recurrent when considering PEG feeding was the perception that there was a risk associated with the procedure itself. This introduced the clinical impact in its most significant sense, that of contributing to mortality. This was cited as a reason to delay the option of PEG feeding if another option was available.

Consultant IM10a *: : you know compared to NG which carries you know...negligible... procedure-related complications....PEG carries about 5% risk....of having potential life threatening complications be it leak or bleeding....you know.....peritonitis...and haemoperitoniomas..leakage...or things like that....so we don't rush into it....*

However, many clinicians were uncertain over whether the accepted practice to delay PEG feeding was in fact contributing to the mortality rate. Ironically, the result of waiting for the patient to have a PEG increased the risk that the patient would not benefit from the procedure.

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[14] The F.O.O.D (Food Or Ordinary Diet) trial, completed in 2004 – aimed to investigate the different modes and timing of oral and enteral feeding, alongside measures of mortality and morbidity.

Nurse IN2b *: I think in the past there has been....in situations where feeding has been withheld and patients deteriorate to such a state that the feeding has been an issue at a late stage in the admission and they have been PEG'd...the PEG tube has been inserted and they have not survived the PEG tube insertion....and sort of issues around if we had started feeding earlier would the patient have been able to withstand having the PEG tube inserted....*

Specialist Registrar IM5b *: Yes.....but I think if you.....I think the unfortunate thing is....is that people don't see the consequences of delayed decisions.....and I think that's you know....Oh...you know that patient who we didn't PEG...who sat here for 2 .. yes dead ....you know.....*

The issue of risk was also significant in terms of its impact on how the NGT or PEG was described to relatives. The associated risks were either highlighted or minimised, depending on the clinician's aims. In the following example below, the SHO discusses the risks associated with PEG surgery in terms of the anaesthetic procedure. There was no mention of the specific risks that might be related to PEG insertion, as listed by Consultant IM10a above.

Meeting with relatives of patient participant 82a – SHO and 82a's wife
SHO *: has somebody already spoken to you about this.....*
Mrs 82a *: well.....the nurse said something.....but.....*
SHO *: well.....because he can't feed properly through the mouth.....we want to put a tube in his tummy to feed him.....*
Mrs 82a *: yeah....well....he's not eating anything.....*
SHO *: mmmm.....the tube helps with that.....*
Mrs 82a *: I see....right.....*
SHO *: so....I just want to tell you a bit about the procedure....and what we do.....*
Mrs 82a *: yes.....*
SHO *: .....the procedure to put the tube in will be done with a general anaesthetic....and as with all general anaesthetics.....there's a risk of complications with that as well as those associated with the procedure itself.....it can cause pressure on the heart and lungs.....and obviously there's a risk of death with the procedure itself.....that's why we tell everyone*

about that.....about the risks.....and another thing with this operation is a risk of perforation.....but this will help to begin feeding.....and will bypass the difficulty with swallowing.....

In short, clinicians 'bias' their descriptions to support their preferred treatment mode in each individual case. This is because, on occasions, they were not encouraging choice, but instead, justifying a course of action.

12.2.3.2.3.3. Flexibility to review tube feeding

In general, there was consensus amongst all participants that an NGT was considered to be a 'short term' intervention whereas a PEG was a more permanent option. There were a number of reasons given for this. The first relates to the level of 'invasion', as identified in the first statement below, the NGT is perceived to be more invasive the longer it is insitu. In this case, there is a view that having an NGT for longer than 14 days passes a threshold for what is deemed to be acceptable for patients comfort levels.

***Dietitian ID2b** : 14 days...normally....I know the set kind of lines for PEG's is if they are going to be fed for over 14 days they are appropriate really for getting a PEG..because you don't want to be feeding a patient Nasogastrically....for a long time..... obviously having a tube in your nose is not ideal for the patient when it goes on and on....*

Another issue regarding the short term nature of NGT's was that the patient may quickly improve, hence 'surgery' for a PEG may be an unnecessary procedure. This echoed the previous views that a PEG should be delayed until a later stage

***Nurse IN6a** : PEG feeding's more long term....NG might just be short term...until they get better....*

The relative ease of siting an NGT and the equal ease with which they could be dislodged provided clinicians with opportunities to review their decision to feed via an NGT. In the following, this is clearly stated by Dr IM7a who differentiates between the two modes of feeding through descriptions about their relative permanence of use.

Consultant IM7a *:we tend to go for an NG tube...and also that gives you a bit longer.....it's not as permanent in my mind...whether it should be...you know....ethically is a different matter...but it isn't as permanent in my mind...because...NG tubes do come out....and if they come out then you make a decision do you put it back in again...PEG tubes generally don't come out.....erm.....of they're own accord or via....via whatever means and therefore...that to me is a permanent thing.....*

Clinicians admitted to generally preferring the option of an NGT over a PEG in order to allow some degree of control over whether the intervention would be continued. There was the view expressed by a number of clinicians that once a PEG is insitu, if the patient does not regain a 'good QoL', they are effectively 'trapped' in the outcome of their early decision. In short, the ability to review a decision to feed suits the fluctuations in clinical conditions associated with stroke. It was clear that this need for clinicians to review the tube is driven by their beliefs about the social implications of 'prolonging life' with tube feeding as much as by their views on the clinical efficacy of enteral feeding.

Consultant IM3b *: Well...we have to...we're not here to...erh.....prolong existence....we're here to prolong life...some meaningful life.....erh....I think that if someone's had repeated strokes for example.....and you're thinking of feeding them.....then are we doing the right thing....and then you might delay your decision about PEG in particular....and I hate being stuck with a tube and not being able to reconsider....*

Nurse IN3b *: Yes....because once you....once you put a PEG in then you have got to continue to feed...*

Consultant IM7a *: erm.....so...you go down that line...but you say to the. ...Ok.....if that's the decision we're making...you do realise this is permanent as far as I'm concerned...*

The main theme running through the issue of being able to review tube feeding, lay in the personal discomfort associated with making what is perceived to have been, with the benefit of hindsight, the wrong decision. These issues will be discussed in depth in chapter 12.4.

***Nurse IN7a** : if she remained drowsy after her PEG 4 weeks, 4 months after her PEG I think I would find that a difficult, not to live with but I would, I don't know I think a part of me would think oh my god I wish we hadn't have done it, we have done nothing to improve her life and all we have done is maintain her at that level……*

While the PEG tube was seen to be a successful feeding intervention when insitu, its relative permanence trapped clinicians into maintaining it. The practical problems associated with maintaining NGT's frequently forced a review of the decision by virtue of circumstance. Ironically, the fact that NGT's could 'fall out' or be dislodged was seen to be advantageous at times as this allowed a legitimate reconsideration of the benefits of enteral feeding.

***Nurse IN6a** : I imagine we have probably discussed it in a multi-disciplinary meeting….if we have made a mistake about feeding someone…..I know we have discussed in the multi-disciplinary meeting that if this tube comes out then we don't replace it…..we have made a mistake…*

Thus, in some cases, the decision for feeding (or withholding/withdrawal of feeding) was directly influenced by circumstance rather than pre-planning. This responsive (rather than proactive) approach to feeding, links to the clinician's uncertainty about what would be in the patient's best interests.

***Nurse IN7a** : No….I know we have had in the past where someone has had an NG in but the family have had second thoughts after a month because they are like well they have not improved…..it's like well we can't…we can't stop the feeding but the doctors might have wrote in the notes…if the NG becomes dislodged not to repass…because that is a common fault with NG's they are easy to dislodge or for a patient to pull out…*

***Consultant IM6a** : Because with the NG tube they often fall out anyway….so you're not pulling it (laughs) it's coming out…..do you see what I mean….so your problem is solved….and then….do you put it back down again…do you see what I mean….with….there is a fine difference between pulling something out and the patient pulling it out or whatever…..because you find with NG's quite often however you strap them in every now and again they come out again…..very occasionally it happens with a PEG but*

usually it's strapped in a bit more and it doesn't happen with the PEG...but there is a difference between doing that and something falling out....legally (laughs)

The clinician's beliefs about withholding or withdrawing nutrition had a significant effect on the decisions to feed with enteral feeding. The impact of these issues will now be discussed.

12.2.3.2.3.4. Beliefs about withholding or withdrawal of Nutrition

Issues and beliefs about interventions in terms of whether a clinician should commence, withhold or withdraw interventions were pervasive throughout the data. Withholding ANH is defined here as an active decision to not start feeding through an NGT or a PEG. Withdrawing ANH on the other hand, refers to the active decision to remove tube feeding once commenced.

Generally, clinicians expressed a view that a decision to withhold nutrition would only be taken in the belief that the patient was dying and it was felt that the treatment would be 'burdensome' or 'futile'. In these cases, *active withholding* of treatment (or omitting to treat) was viewed by clinicians to be acceptable. In some cases, there was also evidence of a 'wait and see' scenario, whereby clinicians adopted a *passive* approach to withholding of feeding.

With regard to withdrawing ANH, all participants agreed that they would only consider *active withdrawal* of feeding if death was imminent for a patient. Once a tube was insitu, clinicians believed that it would remain insitu for as long as it was practically possible. If the tube fell out, or was pulled out and not replaced, this was not seen as an active withdrawal of feeding, but instead as a decision not to re-insert the tube (therefore acceptable withholding of treatment).

Clinicians in this study found it relatively easy to withhold nutrition, but more difficult to withdraw feeding. Interestingly, the BMA and GMC guidance[15] recognises this, and cautions against withholding ANH to avoid a situation of possible future

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[15] Guidance documents on 'Withholding and withdrawing life prolonging medical treatments', published by the British Medical Association (2001) and the General Medical Council (2002).

withdrawal, emphasising that there is no ethical or legal difference between withholding and withdrawing.

> ***Consultant IM8a*** *: there has been some acknowledgement that the patient is dying.....and that the feeding is not...serving any humane purpose for the patient.....and...so we don't feed.....managing it that way probably does leave me open to litigation should there be a change of heart in the family in the future.....but...erm.....as I've said before....if you're trying to build up rapport and trust.....you can't constantly be going through legal channels to justify everything....*
>
> ***Specialist Registrar IM5a*** *: I mean some of these patients....we have been through the scenario where you think you're not going to get anywhere and you sit down with the relatives and you say look we're going to feed this patient for... x number of weeks....four to six weeks to give them every chance to come round....erm.....and you say well look if we are not getting anywhere....then it would be pointless going on and if everybody is in agreement on that then you pull the plug...that's what you do in theory anyway.....*

The 'fear' of being in a situation in the future where withdrawal may have to be considered was seen to be a significant factor influencing some of the clinician's beliefs. Many clinicians referred to a preference for withholding feeding after stroke in the early days so as to avoid potential problems later on associated with withdrawal.

> ***Consultant IM8a*** *: Have I withdrawn feeding?.....erm.....I don't know whether I can remember ever doing that.....because I.....I don't.....I would maybe hang on...I'd prefer not to go down that road....I think you either say we're going for it or not....*
> ***Interviewer :*** *So....you'd be choosing the sort of withholding route before you got to that point.....*
> ***Consultant IM8a*** *: I would tend to...yes...I might be wrong on that.....*
> ***Interviewer :*** *What do you feel the difference is...just so that I'm clear that I understand...from your perspective....*
> ***Consultant IM8a*** *: Erm...I think because.....I think once you start.....once you...if you've started.....then...I....I find it very difficult to stop.....I don't*

see how you...I think....in theory...withdrawing is easy...in practice.....I think it's very very difficult.....

The issues behind this practical difficulty are multifaceted and were raised by a number of participants. Nurse In3b and Dr IM2b raise the ethical and legal perspectives that contribute to this difficulty.

***Nurse IN3b** : : Yes.....once....if you omit something....or you don't do something that is ok....because.....and as long as you can back it up with the reasons why and its acceptable...then that is fine.....but once you do something you have to maintain it because to take away something that you have already started is unethical.....or some would argue it was.....*

***Consultant IM2b** : you are in difficult....legal territory withdrawing the treatment that someone is having.....whereas you are not in difficult legal territory failing to give a treatment that.....that wasn't being given to start with.....*

This was further compounded by the view that the legal perspective is not yet sufficiently clear or convincing enough to allow a clinician to comfortably proceed to withdrawal of nutrition.

***Consultant IM8a** : And.....ethically....we still have a problem with it...there's still a dichotomy...of what....the BMA are saying...yes...it's better to have tried .....and stop...and that's fine.....but law however does not support you in that.....in that...if you stop...then you have to be prepared....on the last analysis to stand up in court and say why you've stopped.....and I don't think many people are too comfortable about that....*

One final point relating to the clinician's discomfort about nutrition withdrawal echoed some of the issues that were raised when considering hydration withdrawal. There was a common perception that withdrawal directly leads to a patients death (more than is perceived to be the case with withholding). Many clinicians felt that this would 'cross a line' or become the 'slippery slope' towards euthanasia.

***Consultant IM10a** : then I find it difficult at some point to withdraw that....nutritional support...because by doing so...I am practising something*

which I do not...you know...believe in.....it becomes more like euthanasia...even though you know that the patients outlook now...at this stage doesn't look good....

Some of the concerns relating to the permanency of tube feeding and hence 'delaying' (or withholding) PEG feeding were grounded in the clinician's uncertainty about future prognosis and the fact that clinicians were concerned about 'condemning the patient to a miserable life' as previously discussed. The uncertainty expressed by clinicians partly related to their roles for providing both care and treatment and the distinction between these in the context of 'food'. Most clinicians in this study agreed that when they made decisions to *withhold* artificial nutrition, this was seen to be acceptable because it was felt to be a *treatment.*

***Consultant IM3b** : for a stroke....obviously you're not quite sure what's happening....erh...you don't know if this fellow's going to make a recovery or not....erm.....I don't....I don't starve people to death.....I don't do that....but if someone who's had a bad stroke is.....disabled after it...and say two or three down the line gets his pneumonia.....and it looks like...you know...it's a terrible stroke on the CT scan...and you call in the family and say look.....he's had a stroke...this is the natural history....defences are down.....we're not going to get him any better....I don't really think we should treat this.....quite honestly....are you with me or not.....*

Conversely, when considering the issue of *withdrawal* of artificial nutrition in stroke care, clinicians stated that they saw this as unacceptable because it was perceived to be *food.* In these cases, removal of food or 'basic care' would go against the rights of the patient and the moral/ethical views of a clinician. Dr IM3b uses emotive words such as 'slowly starve' to indicate his view that when considering withdrawal, the feeding was considered to be 'food'.

***Consultant IM3b** : I have seen one case...not of mine..... that was going on...and the nurses were very unhappy about that because they didn't feel that...you know.....it was...you're not supposed to withdraw feed....until you get the all clear from the courts.....that's our perception...you know.....erm.....in a sort of.....disabled.....in a fellow who's disabled...but going to live for a few...weeks.....so you stop the feeding and they slowly starve to death...you're not supposed to do that.....*

> ***Consultant IM10a*** *: there are quite a few colleagues who have the same view that...we can't you know....legally and ethically it's not acceptable to withdraw an intervention...especially when it comes to fluids and nutritional support....*

The issue of whether feeding is 'food' or 'treatment' is largely associated with the 'special nature' of feeding and the goals of intervention.
One final point relating to the issue of withholding ANH is the issue of connecting the action (or lack of action) to the outcome. All participants unanimously agreed that, despite concerns over starving patients, when they withhold nutrition, it did not lead to immediate death.

> ***Specialist Registrar IM9a*** *: I've had patients who I've felt are in a terminal phase....with different diseases.....and haven't fed them.....who you know are deeply unconscious....and I expected that they were going to die within days....and I've seen them last over two weeks....without food and water.....*

In addition, many clinicians identified that when a patient dies, they feel it is unlikely that their nutritional status would have 'made much difference'. In essence, they reported that the general medical condition leads to their death, not whether the patient was fed or not. The use of the word 'succumb' below highlights the expressed inevitability of death in some cases, such that a nutritional intervention is perceived to be irrelevant.

> ***Consultant IM4b*** *: It's variable....it's variable.....there are patients who are that stage for weeks and weeks on subcutaneous fluids...intravenous fluids.....erm for weeks.....but usually they succumb....not because of the fluid problems but because of the current illness that they sort of.....succumb to other illnesses such as pneumonia....hospital acquired infection.....that's what usually....sort of....terminates life....it's not the hydration or nutrition issue that terminates life..*

In the context of seriously ill patients, nutrition was rarely viewed as a critical component of treatment or of having a bearing on whether or not the patient survived. However, a few clinicians questioned whether the evidence was available to support this view.

Specialist Registrar IM5b *: We are not too big in the NHS at...you know getting to the bottom of what happened with every patient who died.....you know we think to the best of our knowledge....but you know....perhaps we should be looking at what if....especially when decisions like this are withheld or delayed...then perhaps we should be looking at.....would things have been different.....you know the fact that the patient was.....became septic because of a pressure sore....you know would they have had that pressure sore had...had we fed them as soon as they walked through the door?.....*

The combination of beliefs about nutritional interventions after stroke had a direct bearing on the clinician's interpretations of the patient's best interests. One key aspect over which this is influential is the timing of interventions as will now be discussed.

12.2.3.2.4. Beliefs about Timing of Nutritional Interventions

A recurrent theme throughout the data was a broad consensus that NGT feeding would be considered on or around day 5 (of a NBM period) with PEG feeding being considered on or around day 14 of NBM. One of the dietitians stated that they had guidelines to suggest optimal timing of interventions, but she was not certain of the source for this, and no references were made to guidelines by any other clinicians during the study.

Dietitian ID2b *: NG feeding is not suitable long term for patients, so then to put in a PEG....So from kind of stroke patients....that is probably the way it tends to go from what I have seen, they will start on NG...know they are going to need feeding for over 14 days so they get them on the PEG list to do that...14 days...normally....I know the set kind of lines for PEG's is if they are going to be fed for over 14 days they are appropriate really for getting a PEG.....erm.....I think that is set by the PENG...it's in our PENG books guidelines....that's the....Parenteral and Enteral Nutrition Group....yeah.....they are set from them....I think.....*

In the absence of clinical guidelines, a number of different perceptions about the appropriate timing of nutritional interventions were apparent. These related to perceptions about aspiration risk, the clinicians 'comfort zone' about the length of

NBM, organisational procedures and the impact of re-feeding syndrome. Each of these issues will now be discussed.

12.2.3.2.4.1. The Influence of Aspiration Risk

One of the key drivers in the early stages after stroke was the desire to minimise harm and the perception that aspiration could create the most immediate harm. As previously identified, a risk of aspiration often resulted in quite rigid adherence to a NBM protocol with IVI fluids. This was either with or without alternative nutrition. There was a prevailing belief that in order to prevent aspiration, the patient should be kept NBM. In fact, this belief was so pervasive that the clinicians stated that NBM status was the 'safest' position for a patient

> ***Consultant IM10a*** *: Nil by Mouth…I mean that is the safest approach against aspiration….*

This consultant went on to suggest that early feeding with an NGT can create greater harm than not intervening due to the risks of aspiration. The impact of this baseline belief was that nutrition 'can wait' in favour of managing the aspiration risk. This view was supported by observed practice, where the decision to place a patient in a NBM position was delegated to any clinical professional who had concerns about aspiration.

> ***Consultant IM7a*** *: Well I think….I think nurses will stop them swallowing at the drop of a hat (laughs)….you know….they do……erh….you know….if there's any doubt…they stop them swallowing…*

All of the clinicians participating in this study reported that feeding was less of a priority than reducing the risk of aspiration.

> ***Consultant IM4b*** *: one thing I believe is that nutrition is not an emergency situation……it can always wait….we can always wait several weeks and keep the patient's….you know well with adequate hydration…..*

12.2.3.2.4.2. Comfort zones to NBM status

There was clear consensus across all professional groups (including the dietitians) that nutrition was not an urgent intervention in acute stroke. However, the views relating to the length of time for which NBM could be safely maintained were hugely

variable. It was interesting to note that the clinicians' 'comfort zone' for maintaining NBM after stroke ranged from 24 hours to 2 weeks, with the discretionary element being widely acknowledged. There was no consensus within or across the professional groups, but characteristic of all responses was the uncertainty, and inability to state a specific time beyond which NBM becomes harmful. The series of statements that follow are presented as a 'list' in order to illustrate the contrasting and variable responses that were observed. Each participant was asked 'how long a patient should be kept NBM before enteral feeding should be commenced?' The responses included the following.

> ***Nurse IN5a*** *: I wouldn't be happy like I said before about a patient of mine having gone a week maybe without at least starting to rumble about feeding…*
>
> ***Speech and Language Therapist IS4a*** *: I would certainly be alarmed if it got to 7 days and it hadn't been considered….I think by day 2 we need to start to think about it, this is very general (laughs) but I think anyone who up to 7 days is nil orally is going to really start to suffer and I would like to see that considered before then…..but that's in an ideal world….it doesn't always happen.*
>
> ***Dietitian ID1b*** *: I feel that I am more than happy with up to 5 days….I think that is fine because it is enabling us to get all the initial assessments completed and to try and get a general picture of what is happening and to ensure that patients are assessed, anything longer than that, some kind of active decision needs to be made.'*
>
> ***Dietitian ID2b*** *: I can't come up with a definite point because it's hard to individualise for each different patient….but I think if they were getting fluids, obviously they are still going to be getting fluids even if they are nil by mouth, they are going to be getting IV, I think once you look towards coming up for a week….it matters for any patient.*
>
> ***Consultant IM6a*** *: which and if you want to do that we're talking about Nasogastric feeding and…..or PEG feeding….in the main we give patients a few days to see how things go….perhaps a week or so….OK…..there is no*

fixed time on this and it's a matter of judgment some people are left for two weeks others perhaps less than a week.....

What is clear, and is represented in the sample of responses above is the individual nature of these beliefs. The lack of clinical 'fact' to support their interventions in this area resulted in subjective and discretionary opinions. This variability was supported by the observational data in this study.

Some clinicians raised the point that the timing of feeding was not influenced by a set 'pathway' for intervention, but would be based on the needs of the individual patient. Once more, their 'comfort zone' to a NBM period was variable for each patient according to their history and clinical presentation. The majority of clinicians identified that the average length of time between the onset of NBM and feeding for patients would be 5-7 days. However, beliefs about the patient's 'frailty' or 'weight baseline' were brought into play to alter this average, such that a nutritional intervention would be more urgent in patients who were already perceived to be undernourished, where as obese patients were considered to be at lower risk of malnutrition than those who were underweight.

***Consultant IM4b** : With an NG tube....I would be thinking about....say....after say 48 to 72 hours.....again depending on their nutritional status...if the patient is obviously very malnourished and very frail then that will influence our decision....if they are very obese and need to lose weight then there isn't any sort of hurry to start....erh.....nutritional status*

This view was supported by one of the dietitian's who stated that the nutrition score on admission directly influenced her clinical recommendations about nutritional requirements.

***Dietitian ID1b** : I think though as well that it does depend on the patient because if you get someone who is admitted who is exceptionally frail, you wouldn't want to leave them more than a day / two days. Whereas someone possibly who has got a larger body weight, that period may be a little safer for them to be like that*

***Nurse IN5b** : If you have got some frail little person who has absolutely no body fat....and looks malnourished from the minute they come in you might find that you have got to move a bit faster there than you might on someone*

like me who has very obviously eaten chocolate right up to the minute of impact you know (laughs)....and then suddenly finds themselves just on fluid....although I think I might get hungry quicker!....

The issue of hunger is interesting in that it was rarely raised by clinicians. Where patients were NBM for long periods, there appeared to be no direct consideration of the patient's experience or discomfort that might be associated with a lack of nutrition. The issue of hunger was notable when it was raised (owing to its general omission), and in this context, a patient stating they were hungry might force consideration of nutrition.

***Nurse IN2b** : It's a bit difficult to put any time on it.....erm...it would depend on the patient.....they're sometimes quite alert and they have got good speech and they can tell you that they are hungry.....and it sorts of prompts you doesn't it (laughs) a little bit....to think about those issues....*

12.2.3.2.4.3. Organisational Factors and timing of interventions

In some instances, clinicians highlighted the impact of the hospital procedures on the timing of interventions. For example, the wards under study were reliant on other hospital departments to carry out assessments or conduct interventions for nutrition. In particular, the 'waiting list' for PEG placement was a recurrent issue affecting the timing of nutritional interventions.

Where the patient was waiting for a PEG, the consultants on the wards admitted to feeling 'concerned' about delays, but reported being generally helpless to change the situation. This was attributed to differences in working practice across medical or surgical teams, or different pressures that each department might experience. It was clear that the pervasive view that nutrition was not critical influenced the management of the patient, even when a decision had been taken to feed by artificial means.

***Consultant IM4b** : once we have arrived at that decision....the PEGging may take several days or weeks before it is actually done...*

Similarly the weekend posed problems for any clinician recommending anything but the most basic nutritional intervention.

Nurse IN5a *: It seems to vary……and rightly or wrongly it can depend on whether you can get hold of a doctor or not……if somebody comes to you on a Friday afternoon (laughs)…it can be Monday morning before you can get any poor little house officer with time to review quite frankly……but normally so long as they are getting the fluids and if you send bloods off and they come back and everything is not too deranged then waiting until Monday is not a problem*

Consultant IM7a *: Well…nobody's going to make a decision to put a PEG in and neither will it happen at a weekend….erm…..and sometimes and NG tube…..I think there aren't enough senior staff around who know the patients….to make a decision…*

The procedural aspects of MDT decision making did not always facilitate speedy decision making.

Specialist Registrar IM5b *: we established from day 1 what the patient's best interests was….and then weeks to months later we have actually carried it out and I just think what have we done there….we have just completely bounced ideas off each other…got a second opinion…you know……I have not got a problem with it…..I just think it's getting a little over elaborate now….*

Specialist Registrar IM5b *: I think it's having meetings for the sake of having meetings…..sometimes…..I am not saying always…but I certainly feel….I certainly feel that sometimes I have walked into one of those meetings….the MDT meetings and I have walked out and I have thought nothing has changed….nothing what-so-ever has changed…we are just going to leave things a little bit longer and then we will have another MDT meeting….*

As seen therefore, the organisational structures and process could be influential in 'making or breaking' the efficacy of the decision process. Timing of various forums, or seemingly incidental issues such as work rotas had a profound impact on the efficiency of the decisions about nutritional interventions.

12.2.3.2.4.4. The Impact of Refeeding Syndrome

The issue of refeeding syndrome[16] is a relatively recent consideration within the clinical setting and raises aspects of the decision process that appeared counterproductive to dealing with nutrition. In the quest to minimise the harm associated with aspiration risk, patients were often kept NBM for a prolonged period of time. When a decision was ultimately made for enteral feeding, another element of 'harm' is raised in the form of refeeding risk. Ironically, in some cases, the 'risk' of refeeding syndrome triggered the decision to *consider* nutrition, and then may further delay its implementation. This is evident in the example of patient 6b, as shown in the case notes below.

> ***Medical Notes (Dietitian statements) – Patient participant 6b***
> *Day 15 of admission*
> *Dietetic Review*
> *This patient has now been NBM for 12 days. If she is to be a candidate for enteral feeding, she will be at risk of refeeding syndrome. Please advise.*
> *Day 21 of admission*
> *Had PEG yesterday. Referral only received in department this afternoon, therefore 1 day of potential feeding already missed. I have come on to ward, no written referral on ward and no weight. Could have been weighed on hoist.*
> *This patient has been NBM for 18 days + and is at risk of re-feeding syndrome.*
> *Bloods show low Potassium and low Calcium.*
> *Check new bloods before feeding.*

Arguably, refeeding syndrome in this context is an iatrogenic condition occurring through prolonged NBM status after stroke. It was rarely referred to in this study, and where it was raised, it was usually done so by the dietetic staff when enteral feeding was due to commence. Not surprisingly, fear of refeeding syndrome did not, on the whole, promote early consideration of feeding.

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[16] Refeeding syndrome occurs when previously malnourished patients are fed high carbohydrate loads, resulting in a rapid decrease in phosphates, potassium and magnesium

Dietitian ID2b *: refeeding is an issue...7 days...yes I'd say about 7 days.....if not before depending upon the patient. Obviously any prolonged period of time between about 5 or 7 days after that they are going to start having problems....the weight lost in that time could be quite drastic because obviously you know from patients who don't eat, for other reasons, because they are ill, they are being sick, for 3 days they can lose a lot of weight, so it depends on the actual individual patient....So for someone who has been left over a longer period of time not being fed at all...it's going to lead to problems with that, and then its going to lead to problems when you start to feed them as well....*

Where refeeding syndrome was a risk, feeding needed to be reintroduced slowly.

Dietitian ID3a *: the decision then....would need to be made...well.....we're starting NG feeding...but instead of maybe taking two or three days to get to a final regime.....it might take up to five to seven days of slowly increasing the rate...and things like that....*

This situation appears counterproductive to a patient's recovery on a number of levels and was recognised by some clinicians to have potentially been avoided. This is clear in the words of SLT3a below.

Speech & Language Therapist IS3a : *Yes and sometimes PEG feeding's left too late when the patient has deteriorated at such an extent and then you get the refeeding syndromes as well....*

In summary, there were numerous complex issues underpinning the clinician's views about the timing and clinical impact of the available nutritional interventions. It was clear that nutrition was not perceived to be an urgent need after stroke, and this was illustrated in a variety of ways within the data.
This section has concentrated mainly on clinical issues notwithstanding the overlap this has with ethical, legal and social aspects. In the next section, the focus will be on the broader implications of nutritional interventions, referred to here as the 'social' impact.

12.2.4. Social Impact of Nutritional Interventions

The social impact of nutritional interventions is defined as the perceived impact on the patient and those 'around' the patient when providing, withholding or withdrawing interventions. This includes the views on caring and treatment, as well as wider resource or political issues. Whilst recognising that there were social impacts for the patient, these have been addressed within clinical impacts in order to accurately represent the beliefs and expressed views of the clinicians. The issues seen to be representative of this theme will be described under the following headings

- the medical context
- the stroke care culture
- the immediate patient environment
- the influence of relatives

12.2.4.1. The medical context

In expressing their views on ANH, clinicians were mindful of how their actions were perceived by those who could be in judgment. The influence of ethics committees, legal opinions and family views were clearly uppermost in the minds of many clinicians when making decisions about treatments for individual patients.

> ***Consultant IM8a*** *: I think Hippocrates said you shouldn't strive officiously to keep alive.....but we.....but we do tend to do that in modern medicine.....and I don't think its right....but that is not what I think, it's what ethics committees think and what the legal lawyers think....*

This view was expressed recurrently throughout the data, particularly in situations where clinicians felt uncertain over what would be 'best' for the patient. It was evident that the broad context had a marked effect on individual decision making.

> ***Specialist Registrar IM5b*** *: I think when you've got a conflict of interests and when you have family disagreeing with what your decision is or you are disagreeing with what the family say then I think it's always a good idea to get a legal....opinion on what's going on....at the end of the day the patient has to come first and that is where your duty lies....but you know the hospital.....that doesn't stop the hospital being sued...so I think you've got to get things straight before you...you know....plough ahead with what you*

think is right and then...you know.....before then you will probably have a second opinion before you went for legal.....

At times of uncertainty, clinicians were also mindful of expectations of them as public sector employees. In this way, the social impact of offering an intervention had a wider resonance, including resource allocation and NHS provision. Resource allocation was seen as a contentious issue and there was a feeling that clinical judgments were often interpreted as cost-saving measures.

***Specialist Registrar IM9a** : I think part of it is that you've got to impress upon them..... that....I.... I think....there's a view out there that the medical profession can be ageist, sexist, racist erm...in desperate need for beds....and that they...and.....and....er....you know provisions.....and that clinical decisions can be based on cost.....and I think that's a worry that a lot of you know...people have.....particularly if they've got an elderly parent who comes in.....so I think if you can approach it and make them appreciate that those aren't the factors that are influencing your decision making.....*

***Consultant IM6a** : you see some people who are very....who are more like the American situation where you can't let go of what is potentially a hopeless situation....you see some elements like that where....of course you do everything and you know....and then you come into....well....is it right to be spending all those resources on so and so when that money could go to someone to have a few hip replacements and in my own mind I think of those things too because resources are finite...resources are finite and you've got to think of the good of everybody not just the one person....the one family...the whole context comes into it as well...*

Some clinicians reported that audits, such as those reviewing surgical outcomes, had the effect of redirecting staff energy into 'self protection' rather than promoting care. Dr IM4b for example, suggested that the concerns over the reputation of the surgeons meant that they were reluctant to carry out the procedure.

***Consultant IM4b** : I think about a year ago the surgeons in this hospital refused to undertake any PEG insertions because the mortality rate was lumped together with their operative mortality so they perceived themselves*

as.....being shown to be poor surgeons so they refused to undertake PEG feeding in very frail elderly patients who probably....erh....would succumb to other....conditions after a period of say 3 months or 6 months because it's also pretty.....mortality goes as far back as 6 months its not just immediate figures...so they were reluctant and we had to.....write a very strong letter to the management and say this is not on that....erh.....and they must do that even though their figures may be shown to be.... wrongly to be on the high side because of that is not an excuse....that problem still persists....there are surgeons who have a very low threshold for PEGging so if....if they feel the patient..... is not strong enough they will not attempt even though you as the physician make a case on behalf of the patient they will find every excuse not to do so.....erm.....they will invoke technical difficulties in doing that....complication rate etc etc...

As identified, there were influences in the medical context that raised issues about the social impact of providing or withholding nutritional interventions. Some of these factors overlap with issues relating to stroke care 'culture', and these will now be discussed.

12.2.4.2. The stroke care culture

Beliefs about intervention options were seen to be influenced by the particular historical culture or 'philosophy' of care pertaining to the specialty. A large number of participants highlighted the 'legacy' of care in stroke services attributed to its origins in 'Care of the Elderly' as a discipline. This raised a number of issues in terms of the implications this had for attitudes and approaches to care. Clinicians from all professions described largely passive approaches to stroke care, with some consensus that stroke is generally associated with slow progress or poor outcomes.

***Specialist Nurse IN6a** : because I do think there is some ageism there, although there is not supposed to be....I think there probably is.....they don't want to look after people with strokes because it isn't dynamic.....it isn't their baby, I think a lot of people think that people who have had strokes, many of them are brought up at the time when there wasn't a lot you could do for them, or there didn't appear a lot you could do, and frequently they were described as the ones who sat in the corner and I suspect many consultants have seen them as taking up a bed that somebody else could take up....*

These underlying beliefs about stroke care were seen to directly impact on the nature of care offered.

> ***Consultant IM1b*** *: these people are not causing problems...they're lying still in bed...you have to actively look out for the problems of the patient with a stroke....and they have a low priority...they're treated very badly in the Health service.....it's a Cinderella speciality...it's not got high status.....(continued)...I think it's related to doctors feelings...of...erm...impotence...really to put it like that....I think you feel that you can't help these people so you want to walk away...it's very easy to just walk away....and for someone to see them from the end of the bed and say.... you know.....and to see them as something that you can't do anything about...*

This was recognised by other clinicians who expressed the view that their feelings of 'helplessness' when faced with patients after stroke created a single aim of transferring them as soon as possible to a different ward or consultant. Arguably, the impact of this view was, therefore, to passively monitor the patient whilst waiting for a bed elsewhere.

> ***Consultant IM3b*** *: it's a bloody stroke...send to her a stroke unit or whatever.....you know...I can't do anything for that.....OK.....and it needs...it needs erm.....possibly a similar mentality as someone who does palliative care medicine.....you know...or oncology.....most people are going to die...but you know....some of them you give a better few months for or something...*

This view was similarly echoed by the nurses, who reported periods of passive care while they waited for the patient to be well enough for active rehabilitation.

> ***Nurse IN3b*** *: well I feel stroke care is very passive really.....we are dealing with the symptoms rather than being proactive...do you know what I am saying....It's getting patients....observing them...keeping them hydrated....making them...giving them a safe environment until they are fit enough for OT and physio etc....*

Very often, clinicians accepted a 'slow stream' approach to stroke care, with delays in assessment and intervention being seen as 'normal'.

> ***Speech and Language Therapist IS1b** : the SLT assessment?.... I would probably say they are in a good couple of days before it's really thought of, it's probably thought about on their first day but it's not actually addressed until a couple of days in really, probably about 2 or 3 days in.....*

There was an overwhelming sense of allowing the clinical condition of the patient to dictate the intervention rather than a set of proactive interventions instigated to improve prognosis. This was largely due to the belief that recovery was dependent on internal bodily processes rather than active medical management.

> ***Consultant IM3b** : because when I was a houseman it was a stroke and a drip and hope for the best....*

Alongside the passivity highlighted above, there was general acknowledgement that stroke care was a 'risk averse' culture. Maintaining 'stability' for a patient was seen as a good outcome, while implementing new interventions was seen as risky. In addition, this risk aversion was echoed through acknowledging that placing limitations on interventions helped to minimise or avoid litigation. Avoiding litigation was highlighted as a key issue in clinician's minds in terms of the potential negative social impact of intervening.

> ***Specialist Registrar IM5b** : Erm.....yes I think so.....I think.....I think we perhaps....and this may sound terrible....I think we perhaps put too much emphasis on worrying about what can go wrong instead of just getting on with it and saying right....this is the best thing for this patient... (Continued) I think it's.....I personally think it's the fear of litigation.....you know....who's going to point the finger at who if something did go wrong.....erm.....and if that's the case should we not wait? ....you know wait another week and we will reassess in a weeks time....*

Some clinicians acknowledged that adopting the wait and see approach, while offering protection from being accused of unnecessary interventions, created the very circumstances which they had been trying to avoid.

Specialist Registrar IM5b *: My general....my whole.....my only point about alternative feeding is that we mess around too much before making a decision and usually the decision that you take in the end is exactly the same decision that your hunch told you as soon as you saw the patient.....and the patient stays in hospital for weeks....sometimes months waiting for us to decide what's the best way to go and the ethics of it all and in that time becomes weaker....becomes more at risk of complications from the procedure that you generally have to have.... and that is my only qualm about it is....is that because we are all living in a society where...you know we have got to double cross everything....*

In summary, the stroke care culture is seen to be a product of history, clinical context and the wider issues of law and societal expectations. In many aspects, it could be argued that the stroke care culture within which this study was conducted, was risk averse and characterised by a wait and see approach. The impact of this context on nutritional decision making is evident.

12.2.4.3. The immediate patient environment

The contrasting approach between stroke settings and other clinical environments was identified during interviews in this study. Clinicians working in related fields of ITU care, neurology and palliative care settings highlighted major differences in both attitude and expectations of staff. This revealed the impact of the clinical environment in terms of 'legitimising' clinical practice. For example, clinicians working on a neurology ward or an ITU setting described a very different 'attitude' and belief about ANH decisions after stroke. Clinicians working in these settings routinely adopted a more proactive approach to feeding. Nutritional interventions were perceived to be essential to recovery, and would be carried out on day 1 of admission.

Specialist Registrar IM5b *: they've picked up on this now in nutritional status in ITU departments.....they have realised that...you know....2 or 3 days without food does make a difference to the bodies healing and.....when the body....the weight deteriorates and you develop pressure sores and things like that....*

There was recognition that the ITU approach to nutritional interventions might generate the evidence for use in the field of stroke care.

> ***Specialist Registrar IM5b*** *: the acute wards....the ITU....the HDU and you know....small things on these wards make a big difference.....if you don't control the blood sugar on somebody they are 50% more likely to have an infection.....that is huge isn't it....just by doing something so simple as controlling blood sugar.....and I'm sure that...you know we are soon going to see evidence showing that if these patients don't receive....feeding within 12 hours of admission to ITU their mortality is 20% higher.....you know...there's going to be things coming through and all of a sudden we are going to think....god we have never thought nutrition....we've just thought fluids keep them hydrated....*

While the interview with the consultant Intensivist revealed a 'save life and think about the consequences later' approach, stroke clinicians were primarily concerned to avoid 'prolonging life unnecessarily'. The different approaches to treatment and care of patients in these different settings were frequently referred to in the interviews with all clinicians in this study.

> ***Consultant IM2b*** *: Yeah.....a lot depends on their background....erm.....for example in.....the psycho-geriatric ward where people are dying of Alzheimer's disease.....the family....the nursing staff get used to the patient taking less and less orally and they are happy to nurse that patient.....they don't feel that they are.....neglecting their nursing duties in a way that a general nurse does.....so it's....erm.....and education thing....*

With regard to stroke care, there was general consensus that a stroke unit was the best environment not only for each individual, but also for service development. The clinician's beliefs were largely expressed in anecdotal terms, rather than by reference to hospital audit or 'evidence'. Clinicians also attributed greater confidence to decisions in stroke care that were made in stroke unit settings compared with those arising from general medical settings.

> ***Nurse IN3b*** *: Yes.....But.....what was I going to say.....there is a general feeling now that these stroke units....that anybody with a stroke should go straight on to a proper stroke unit.....and....I have read that the....erh....you*

know.....the rate at which they recover and the quality of their life afterwards is far better if they go straight on the stroke unit.....which I can believe from my own experience...people know what sorts of things to do with stroke on there....

From a service development perspective, Dr M6a highlights the contribution made by stroke units to generating knowledge of the condition itself.

> ***Consultant IM6a** : Well that's the other thing.....when you get patients all in one place...you pick up things....you realise just how many of your strokes have got diabetes....you realise how many have atrial fibrillation[17]....you realise how many are young....God damn it there's so many....we've got so many under 60...whereas if they are dotted around on a medical ward....you know the odd one...you don't twig....but it drives home to you what a big problem it is and how much is in the younger group....yeah....yeah*

There was a generally expressed belief that a stroke unit environment would offer more proactive and coordinated decisions for ANH than would be seen on general medical wards or surgical wards. There was also an expressed belief that the nutritional needs of the stroke patient would be seen as a higher priority on a stroke unit compared to an ordinary ward.

> ***Dietitian ID3a** : if they're fortunate enough to be on the stroke side...the decision if they're nil by mouth to NG feed them will probably happen sooner than say if they were maybe on a surgical or orthopaedic ward....*

> ***Dietitian ID3a** : I'm surmising.....I'm....because....you'll often find ....that those wards (stroke wards) are perhaps...that staff are...in my opinion...more aware of the...malnutrition aspects.....erm.....if....and again there's guidelines...there's erm...the stroke admission guidelines..that xxxx (specialist nurse) helped devise....and I think....certainly they'll be on most*

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[17] Atrial Fibrillation – a heart condition affecting blood flow and blood pressure

wards now...that....that situation shouldn't be happening any more....that....you know...the....

These views were not supported by the observational data in this study. In reality, it was seen that although the initial period of NBM was longer on site **b** (general medical ward care) than site a (stroke unit) , interventions for feeding were generally made in a quicker time period on this site compared to the stroke unit. In essence, the perception that the stroke unit carried out nutritional interventions with greater priority or urgency was not supported by this observational data. The average times (in days) for NBM, NGT placement and PEG insertion are illustrated in table 3.

Table 3 – Comparison of feeding decisions and interventions across sites

	NBM (before decision made to feed, in days)	NGT inserted (days)	PEG inserted (days)
Site a (stroke unit)	1.46	11	36.8
Site b (general medical wards)	2.2	9.8	21

Another feature relating to philosophy of care and the immediate patient environment was expressed as leadership styles of the consultant staff. Clinicians acknowledged that the consultants who were responsible for the patient's care often had different approaches and different beliefs. This situation often generated views about how proactive care would be, based on the anticipated views of the lead clinician.

***Consultant IM6a** : you could go into one hospital and you could have one lot of patients that don't do quite so well....purely because the team are perhaps a bit laid back and another hospital and because you've got a dedicated.....and they do well....it's like anything in medicine....it's not just stroke....the care depends on who is looking after you.....not just the condition....and the dedication of the team....*

Medical clinicians were viewed by many of the non-medical participants as having the ability to facilitate or obstruct their care goals.

Nurse IN2b *: On the wards the patients are admitted under the consultant who is on call that day and their main area of interest...should we say...might be a completely different area to the stroke area....if you get the consultants that are interested in the elderly and stroke....they can sort of be advocates....*

Some clinicians cited instances where they had to use subtle means to manipulate the views of the consultants on occasions.

Speech and Language Therapist S2b *: Dr X is particularly difficult....but if you want something doing.....the way to get around him is to make him think it was his idea in the first place....*

In this way, the impact of the individual personalities and their personal views were seen to be profound when making intervention decisions.
One final aspect relating to the immediate environment, was the impact of the aims of the ward. For example, if a patient was on the admissions ward, consideration of enteral feeding would be deferred, as expressed by Nurse N2b below.

Nurse IN2b *: I think it's because of the nature of the ward....and basically patients come into us and they will be transferred off at some stage....depends if there is no bed availability...you keep them longer.....and I think sometimes we are quite poor in our area....erm....because they are not....they are there and they are getting the basic care....but unfortunately nutrition is not a priority when you've got a rapid turnover....and you have got acutely ill patients...*

After having stated this, Nurse N2b became 'flustered' and asked for the tape recorder to be turned off. She admitted to feeling shocked at having stated that nutrition was not a priority for her to consider with patients. Having previously worked in stroke care, she reported that she had 'taken her eye off the ball' with nutrition due to being in a different ward with different aims. This example is a tangible illustration of the impact of the 'environment' and the philosophy of patient care on the decision making for nutrition.
It is evident that the context plays a major role in determining participants views over which interventions would be clinically and socially 'in keeping' with the environment.

12.2.4.4. The influence of relatives

In general, one of the most influential factors affecting nutritional intervention decisions was noted to be the views of the carers or the next of kin. Although these views were rarely directly sought by the clinicians for any of the patient participants observed, it was clear that some of the more 'vocal' families influenced the consideration of nutritional interventions.

> ***Specialist Registrar IM5b*** *: I think it's a good idea to have the opinions of other people around you including family members...including carers.... I think it's good...erm..and it's always good to have people on your side with the way of thinking that you have got or if your thinking is wrong then to try and point you in the right direction...*

The following example is another powerful insight into the potential influence exerted by relatives, as observed with patient participant 65a. The observation is taken from a meeting held between the specialist registrar (Dr M9a) and 65a's wife, during which the wife directly asks about the 'lack' of feeding. In this case, 65a's grave prognosis had generated a DNAR plan, with interventions such as feeding being withheld. The significance of Mrs 65a pointing out the length of time without food and her own discomfort about this reveals a radical, albeit subtly handled shift in the clinicians view.

> ***Meeting between Dr M9a & Mrs 65a***
>
> ***Mrs 65a*** *: I keep on thinking.....erm.....it's been a....a while now.....six weeks.....is it six*
>
> ***Dr M9a*** *: Hmmm....is it?.....yeah...this week.....*
>
> ***Mrs 65a*** *: ....six weeks ....yeah.....*
>
> ***Dr M9a*** *: that's right...yeah....*
>
> ***Mrs 65a*** *: and I wonder.....er.....I'm sure the drip will not be sufficient enough.....you know...to feed him...because I could tell...he's lost so much weight.....*
>
> ***Dr M9a*** *: he has.....*
>
> ***Mrs 65a*** *: you know....*
>
> ***Dr M9a*** *: he has.....and that can be deceptive....when somebody's large ....when they come in.....and then....sort of six weeks later....you*

know....they still look healthy....but....he has lost a lot of weight....and....hmmmm....the drip's not enough.....

***Mrs 65a** : it's not enough....yeah.....*

***Dr M9a** : and I wonder....I think...that perhaps now....we need to.... give him a chance.....*

***Mrs 65a** : yeah....*

***Dr M9a** : to see if nutrition....you know...some food.....*

***Mrs 65a** : yeah*

***Dr M9a** : will change the situation.....*

***Mrs 65a** : yeah.....*

***Dr M9a** : it's not a promise....it might be that **this**....is as good as 68a gets.....*

***Mrs 65a** : mmmmm*

***Dr M9a :** and that.....what ever time remains for him....he'll need twenty four hour nursing care....*

***Mrs 65a** : mmmmmm*

***Dr M9a** : but I think that....if we don't give him some food now.....he's going to pass away.....because of malnutrition.....*

***Mrs 65a** : mmmmm....OK....*

***Dr M9a** : so we need to think about a tube.....*

Interestingly, following this interview, 65a had an NGT inserted. However, he died a few hours later. As seen, therefore, the clinician's views about interventions (or at least their plan about the intervention) could be influenced by the issue being raised by others.

Perceptions of care and the nutritional interventions offered were, therefore, affected by the clinical context and environment in which the patient was being seen.

12.2.5. Beliefs about nutritional interventions – data sources

As shown, the clinician's beliefs about nutritional interventions were expressed in interview and compared with events in the observational data.

Discussion about the relative harms and benefits of the nutritional interventions were rarely discussed overtly in the team. These discussions were largely omitted from ward rounds or MDT meeting forums, with the emphasis instead placed on the

future planning for interventions. For example, the ward round or MDT meeting discussion was seen to include plans for the next 24 hours or the next week, but rarely gave an overt rationale or justification for the proposed plan. This was also reflected in the medical notes.

The direct expressions about interventions in terms of their purpose, harm, benefit and use was more readily accessible through the interview and vignette data. As has been shown however, the expressed views did not directly concur with the observed actions, as each individual situation generated unique events.

12.2.6. Summary

In summary, there are strongly held personal beliefs about the clinical and social impact attributed to nutrition and hydration interventions. Many of these beliefs were 'covert' but included firm views about hydration as an intervention that markedly differs to nutrition. The analysis revealed beliefs about the 'value' of nutrition in stroke care, the perceived relative urgency of nutrition, and the harms or benefits associated with the possible options for feeding. As shown, for each individual patient admitted with a stroke, the clinicians form (and reform) views about whether or not each of the nutritional interventions available are considered to be in the patient's best interests.

12.3. Perceived Responsibilities

The clinician's perceptions about their own responsibilities and the responsibilities of others, played a major role in determining nutritional interventions.

It was apparent from the data that clinician's were mindful of both clinical and social responsibilities when making decisions for nutritional interventions after stroke. The clinical responsibilities often related to their 'given' professional role and the associated accountabilities. The social responsibilities included broader roles, whereby the clinicians felt some duty to consider the patients future or social circumstances and the implications for the patient, carer and society. This was largely based on their *experience* and duty as a public sector employee rather than their specific clinical role.

Figure 9 illustrates the focus of this chapter, that being the clinical and social components of perceived responsibilities.

As previously, figure 10 shows the analytical stages moving from open coding of data, through to developing 'Perceived Responsibilities' as a major theme in the decision process.

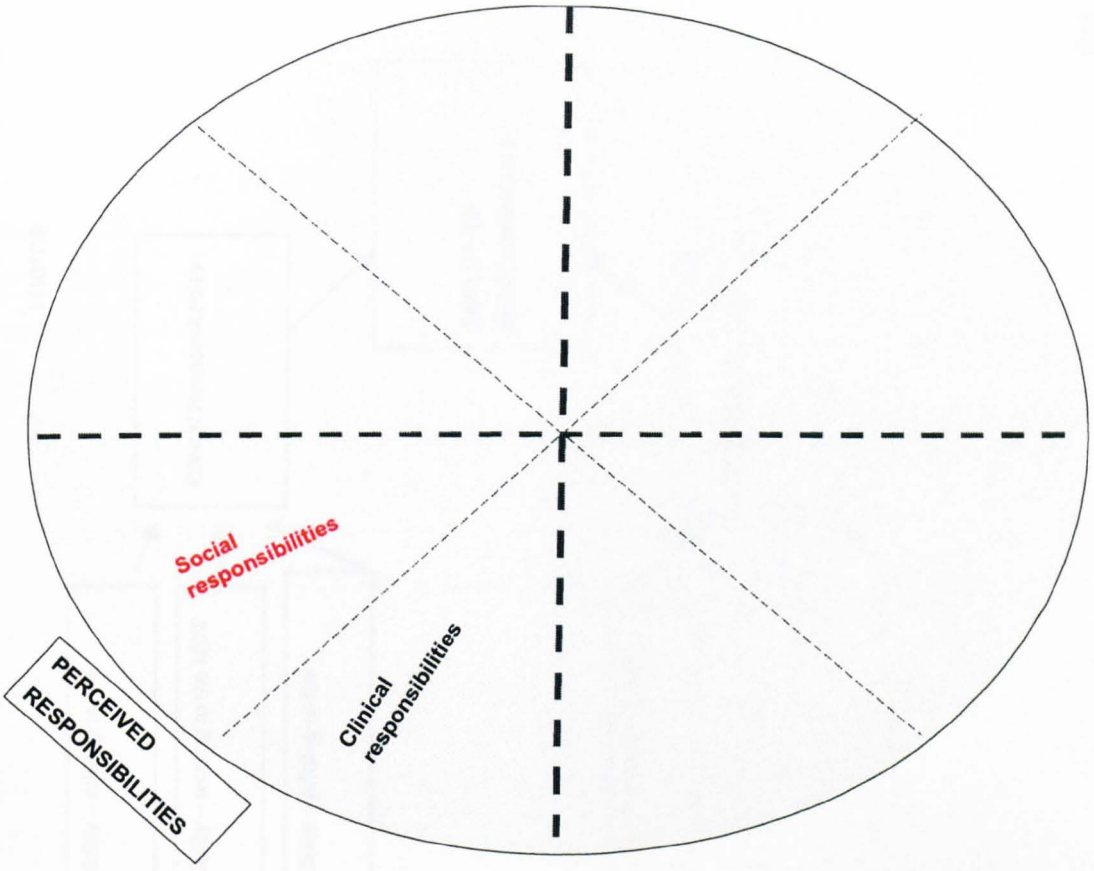
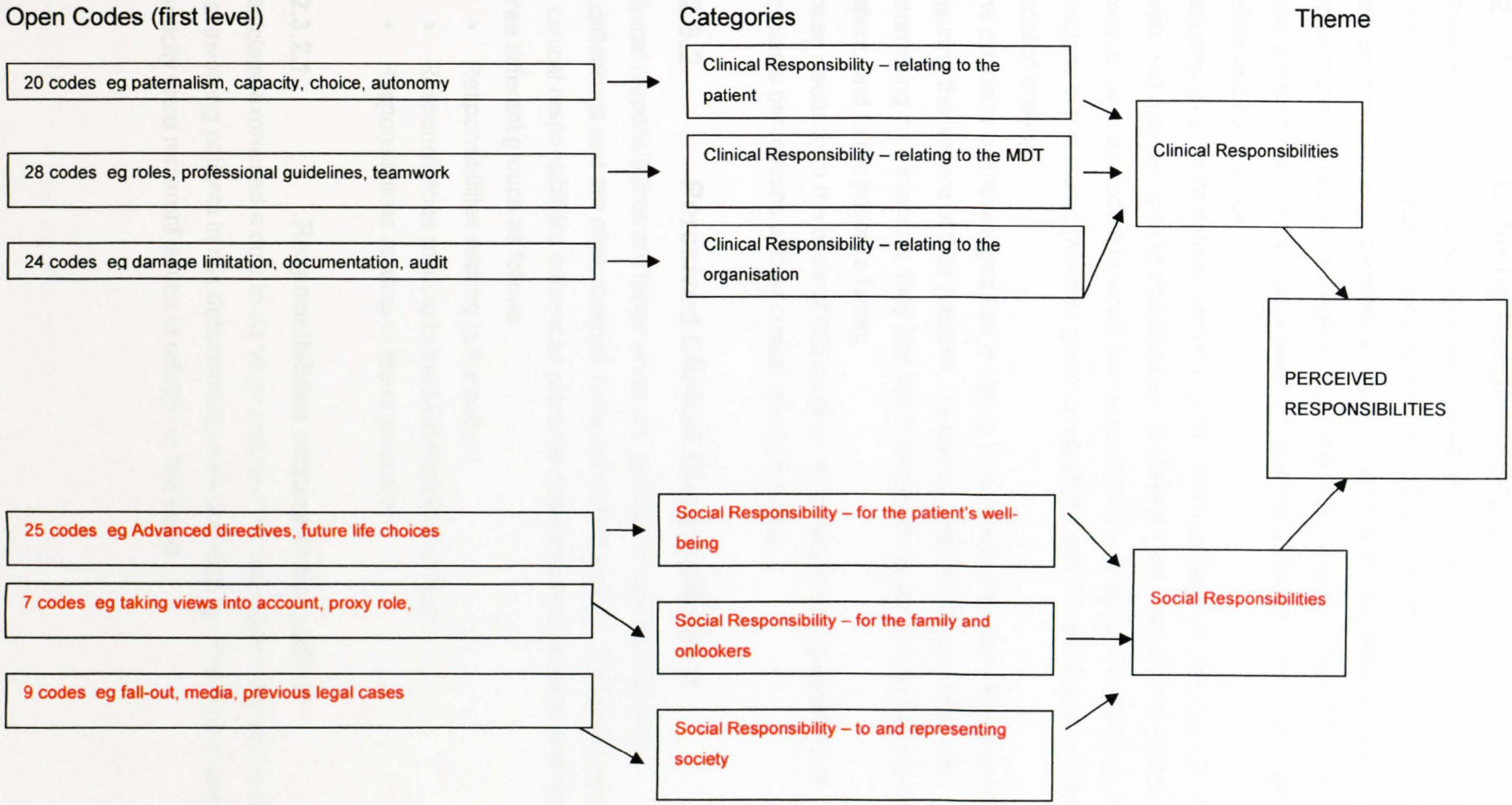


Figure 9 – Perceived responsibilities as an influencing factor on nutritional decisions after stroke.

Figure 10 – Theme Development : Perceived Responsibilities



12.3.1. Defining Responsibilities

Within this study, responsibilities are defined as the duties or obligations that are either 'given' to or 'adopted' by clinicians in relation to nutrition or hydration interventions. Some responsibilities were 'given' in that they were perceived expectations of the clinician working in a healthcare setting. Other responsibilities were 'adopted' by clinicians as a result of individual situation dynamics or personal beliefs and conscience.

Responsibility, by its nature, carries a sense of accountability. This can be on many levels and may be open to interpretation by different individuals. Of significance however, was the extent to which the responsibility was felt or perceived by the clinicians in this study, (whether given or adopted), and its subsequent influence on decision making.

The clinicians acknowledged that in caring for patients, they had responsibility for ensuring the welfare of their patients. Clinicians generally agreed that when determining best interests, they had both clinical and social responsibilities to the patient, and to the patient's family.

These issues form the basis of this chapter, which begins by discussing the clinician's perceptions of their clinical responsibilities.

12.3.2. Perceived Clinical Responsibilities

Clinical responsibilities are those which are gained through training and qualifications and are often steeped in the scientific tradition. Clinicians' perceptions of clinical responsibilities influenced plans for nutritional interventions and related to three different groups as follows

- Responsibilities relating to the patient
- Responsibilities relating to the Multidisciplinary Team
- Responsibilities relating to the organisation

12.3.2.1. Responsibilities relating to the patient

Clinicians expressed a duty to do 'what was best' for the patient, but acknowledged that involving patients in this determination was challenging. Paternalism and patient capacity were recurrent issues in relation to this issue.

12.3.2.1.1. Paternalism and responsibilities

Paternalism was one of many issues in the 'modern NHS' (as stated by Dr M1b) that contributed to clinicians' 'confusion' over the nature and extent of their clinical responsibility.

> ***Consultant IM1b*** *: you would ask the patient....I mean this is something that I would never have done 10 years ago...I would never have asked a patient what would you like to be done if you....you know if you died....erh...if your heart stopped...would you like to be resuscitated...it's something I would never have done 10 years ago...because I thought that that was unreasonable to put to a person who's near death...but now....people...a lot of people say you should ask these people....*

While recognising the problems created by old style NHS paternalism, clinicians were clearly worried about their ability to judge how far they should go in involving patients and their carers in decision making. Bridging the gap between making a decision in the patients best interests and a straightforward act of paternalism was particularly pertinent in cases of acute stroke where a patient may lack capacity to state their own views. Guidelines[18] suggest that the 'responsible clinician' (usually the medical consultant) makes and takes the decision about nutritional interventions. This position was acknowledged by some of the clinicians involved.

> ***Consultant IM10a*** *: the role of the physician is....in a medically led stroke service...is to ...you know...sort of make the....make that balanced judgment and...I feel that the final say...has to be for the in-charge physician....whether any intervention.....should happen.....*

Although, by virtue of their training, the doctors in this study felt equipped to take responsibility for their decisions, it was not always straightforward in practice. A

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[18] Guidelines such as the Draft Mental Capacity Bill (2003, with revisions over consultation 2005), Making Decisions (1999) and the British Medical Association Guidelines for Withholding and Withdrawing Life Prolonging Medical Treatments (2004)

simple question from a relative or a different medical viewpoint left some clinicians feeling isolated and on guard.

> ***Consultant IM7a*** *: you know...when you've got the husband breathing down your neck saying...are you sure this is right....it does...(laughs) yeah....erm...it is a bit solitary at times.....*

Attempts to incorporate the views from family and/or very close friends often further complicated an already complex medical situation. Having received the views of family members, clinicians stated that they sometimes had to override them.

> ***Consultant IM1b*** *: it's only when you feel that the family do not represent the best interests of that patient and I think in that situation...you have to go by what you think is right....and not by what the family thinks is right....*

> ***Specialist Registrar IM9a*** *: ...people who I don't think should be PEG fed who are in a terminal phase....and the families would be pressing for a PEG.....in my personal experience...I don't want sound...wish to sound paternalistic about this....I have managed to....talk it through with them.....and....bring them round to my feelings about it.....*

Interestingly, the clinicians emphasised that when the clinical facts were less certain, the views of the family were rarely 'ignored'. Clinicians sought additional professional advice when views did not concur.

> ***Consultant IM2b*** *: And.....there are times when I have consulted my medical defence organisation....not a few..... it's really when there is a difference of opinion between me and the family.....where...you know everybody is acting in good faith....everybody thinks they are acting in the patients interests.... everybody wants to act for the best..... but....erm..... we all have different opinions about what is for the best.....so you are never on your own.....I think you should never really be in an isolated position on these matters.....*

In summary, clinicians have not been well equipped to deal with the radical change in views about medical paternalism and the involvement of patients. In the case of

stroke, clinicians felt that this had left them struggling with determining best interests, as will now be discussed.

12.3.2.1.2. Responsibilities and patient capacity

The issue of clinical responsibility to act on behalf of a patient is largely determined by the extent to which a patient can contribute to the discussion over what would be in their best interests. In short, a clinician can legitimately take the responsibility to make decisions based on best interests when the patient does not have the capacity to do so.

When considering this issue, there were marked contradictions in the approaches to assessment of capacity as observed and expressed by clinicians.

When asked about assessment of capacity in interviews, there was a wide divergence of views about how capacity is assessed and how it should be assessed.

> ***Consultant IM2b*** *: We usually get one of our psychiatric staff along.....although.....strictly speaking...erm.....the physician can.....assess capacity and make a definite decision that they have it or they haven't got it.....it's if there is a middle ground and.....and it's not clear whether they have or not.....but....erm....you know.....I mean.....we all know patient's where it's perfectly obvious that they are not able to discuss.....their treatment and with nearly everybody.....who is not actually unconscious I make some kind of effort to discuss nutritional issues with them and I make a judgement of my own.....that they were or they weren't able to.....to join in....but.....if the family don't believe.....my opinion that you know.....they did or they didn't have capacity then.....erm....you need to get....you need to get....erm..... all the specialists on board I think for these difficult issues.....*

This view was echoed by others, whereby additional specialists are involved in contentious decisions regarding capacity. It was evident that formal assessment of capacity is not routinely carried out in stroke care, and where it was considered, this was usually after a period of time where it was clear that agreement (or compliance) was not achieved. Clinicians were in agreement that it would be rare to assess

capacity before making decisions about nutritional interventions such as NGT or PEG feeding.

> ***Specialist Registrar IM9a*** *: I've never personally got them*[19] *in to discuss capacity regarding PEG feeding.....erm...they tend to be called upon more about decisions of 24 hour care....they are not routinely called in to assess capacity for PEG feeding....because....I think it just tends to be that the people who are going to be PEG fed to be honest.....you know...the majority of them are going to be.....unconscious....so then...the whole area of capacity isn't complex.... (laughs)*

The issue of reserving capacity assessments for 24 hour care or financial situations was directly observed in one of the patient participants recruited to the study. In this case, 58a had a formal psychiatric assessment of capacity when the team were considering her discharge and guardianship status of her next-of-kin. She had previously had a PEG insertion with her relatives having been asked to consent on her behalf. Assessment of 58a's capacity was not raised in relation to consent for PEG placement.

The following text taken from observation field notes outlined the initial discussions on assessing the patient's capacity.

> ***Day 76 after admission – Patient 58a – observation field notes***
> *10.15am - I am sitting on the ward with 58a's medical notes after having explained to the staff nurse (SN) why I was there. The staff nurse approached me and asked 'do you know this woman?' I explained that I'd recruited her and so knew her as part of the research, but that I did not know her well. She then asked 'do you know if she understands what you say to her?' I explained that I did not know and told her to speak to S3a, the Speech and Language Therapist (SLT) who was also on the ward at the same time. The SN reported that 58a's nephew will be coming in tonight with a solicitor and that he wants nurses to witness the discussion to sign power of attorney over to 58a's nephew.*

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[19] 'them' – referring to colleagues in psychiatry

SN wants someone to tell her whether 58a could understand/consent.
S3a (SLT) suggested that she speak to another ward[20] because 'they do this there all of the time...I think the psychologist does it'. The SN responded – 'but that will take ages and he's coming in tonight'
The SN approaches 58a and discusses something with her. She then returns and says to S3a : 'I asked her about whether she understood about her money and she just laughed and said no.....I don't think she understands anything...'
At 11.00am – the SN 'phones a nurse specialist. The nurse specialist has worked recently with the community team for adults with learning disabilities.
' I need to ask you something. We've got a lady here with learning difficulties.....she's been institutionalised all of her life....she's had a stroke.....and her nephew came in yesterday and said he wants us to sign over power of attorney. I think we can witness it if we're happy that she understands...but where do we stand if we can't?'
The person on the phone is not sure and says she will phone back.
I left ward at 12.00 midday for MDT mtg – still no contact over this time.

The view about a patient's level of capacity had direct implications for decisions made about nutrition after stroke. Determining a patient's capacity automatically gave further information regarding the nature of the clinician's responsibility to make ultimate decisions. However, within stroke care, the approach varied. Attempts were observed to engage patients in some of their healthcare decisions, although this was variable and discretionary.

Studying the observational data, it was seen that in general, the patient's level of capacity was intimated through subjective information. Clinicians documented factors such as 'following commands' or 'responsive to questioning' if they felt that the patient was able to understand discussions. Phrases such as 'confused' or disorientated' implied a lack of understanding or capacity.

In the absence of formal capacity assessments, it was clear that on occasions, clinicians made judgments about capacity based on the patient's communication.

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[20] The ward being referred to is the Mental Health Unit in the hospital.

In the case of patient 16a for example, the patient's insistence to have ice cubes convinced the staff that she had capacity to be involved in her care decisions.

> ***Patient 16a - Medical notes - day 3***
> *07.30am Staff Nurse*
> *'requesting drinks. Remains NBM; Explained the reason for this, but she wants to drink. Has hydratory fluids insitu. Ice –cubes sucked as she has requested them. Tolerated without any coughing. Awaiting SALT assessment.*

Conversely, patient 23b was more passive in her communication, hence clinicians discussed her care with her family. The extent to which they assumed her lack of capacity (despite the SLT report suggesting otherwise) culminated in the family signing the consent form for her PEG placement.

> ***Patient 23b – Medical notes***
> *Speech Therapist - 'On assessment = oral & facial movements reduced in range on right with reduced speed. Vocal quality –appeared slightly hyponasal.*
> *Speech – very slightly reduced in clarity – but easily intelligible. No language problems observed. 23b reports no change pre/post admission speech & voice'*
> *Medical notes - Day 23 –*
> *SHO – 5pm - Family member not available to discuss regarding PEG procedure. Will come & discuss with family later today*
> *SHO – 8pm - PEG consent obtained*
> *The completed consent form detailed :*
> *Proposed Course of Treatment - 'PEG insertion'*
> *Statement of Health Professional – (NB – the word 'Patient' was crossed out & replaced with 'son')*
> *'To have PEG insertion – In view of feeding thro' PEG tube since swallowing was poor'*
> *Signed by SHO Medicine:. 23b's son signed in the section for witness*

This situation was recognised by some clinicians, as shown in the following statement by a Speech and Language Therapist. When asked in the interview about their involvement in the process to establish a patient's capacity, she was clearly

aware and concerned about 'gaps' in the teams approach to assessment of capacity, with patients communication being the main contributor to judgments of capacity.

> ***Speech and Language Therapist IS2b*** *: No we typically don't (get involved in capacity assessment).....and it's of the exception if we do....and I don't think I have been asked to contribute to consent but I can just think of one occasion where I have asked a question in a decision made about consent, with someone who had communication problems....and somebody had suggested that she didn't have the ability to make decisions and this lady had actually pulled her PEG out and had severe speech problems but not necessarily severe language problems and did have cognitive involvement but didn't appear that cognitively impaired.....and I questioned how they had made the decision that she didn't have the ability to make a decision.....and the feedback was definitely that they felt she wasn't cognitively able to take it on board....although* ***we*** *felt that she could.....*

This example clearly demonstrates that some clinicians were aware of the possible divergence of views about assessment, levels of capacity and the potential limitations in the current assessment process.

It was interesting to note that patients were often assumed not to have capacity (in contradiction of the Mental Capacity assessment guidelines[21]). However, once a patient's capacity had been demonstrated, the clinicians vociferously respected this, even when the patient's cognitive or consciousness status changed. One clear example of this in the data was linked to the clinician's views of patient participant 22a. Having previously expressed her wish to be fed, the consultant maintained the patient's view as uppermost in the decision process for nutrition even when the patient's health later deteriorated to the extent where her capacity was questionable. In this case, her wishes (or verbal advanced directive) were seen as overriding the clinicians own views. In this way, whilst still maintaining a responsibility to make the decision, the clinician was strengthened in his view that he had the primary

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[21] Draft Mental Capacity Bill (2003, with revisions over consultation 2005)

responsibility to respect her expressed wishes. This was supported through alluding to her capacity for involvement.

> ***MDT Meeting – Patient participant 22a. Medical consultant Dr M7a***
> ***Nurse*** *: The next patient is 22a.....*
> ***Dr M7a*** *: right...erm....spoke to her.....niece and nephew today.....erm.....and they felt that she'd expressed.....erm.....she's not been in this nursing home that she's in (Nursing Home name)...erh.....for very long....she thinks she was in another home before that....(unintelligible).....but up until....a few months ago....she'd been quite active.....and they thought that.....she wouldn't want a PEG tube.....however.....when I spoke to her....when she was alert....enough to have a conversation about it.....on Monday.....she was certainly indicating to me that...she did want to live...and erm.....if the way that that was going to have to happen was via a PEG then she would have one.....so I had quite a long conversation with her....niece and nephew....quite amicably.....erm.....about that.....and they agree that.....if that's what she's saying...then.....we'll have to go along with that.....but....obviously.....just lying there with a PEG in is not what they would think is what she would want.....and I've got every sympathy for that...but....now she's said to me 'I want it'...and..I think we've not got any choice.....so..all being well...she'll have a PEG on Friday.....*
> ***Nurse*** *: Ok.....*

Where clinicians felt a responsibility for the patient, there was a sense of protecting them from harm. 'Do no harm' is a fundamental ethic for all clinical professional roles, and this was influential throughout the nutritional decisions. Despite clinicians stating that they would respect a patient's autonomous choice, it was noted that they could only do this (and accept some level of responsibility for this) if they *agreed* with the patient's choice. One patient recruited to the study (p2a) generated considerable angst for the clinical team due to his desire to take oral diet rather than continue with PEG feeding despite a suspected aspiration risk. Whilst p2a had a dysarthric speech difficulty, he used an electronic communication aid, and appeared to demonstrate capacity to understand the implications of his choice. The following is taken from a meeting that was organised between the Speech and Language Therapist, patient p2a, and the patient's wife.

Meeting between SLT (OS5a) and patient participant p2a. P2a communicating via some speech and use of a Lightwriter communication aid.

Patient p2a *: and I don't want this (pulling at PEG tube)*

Speech and Language Therapist OS5a *: and you don't want the PEG?....*

Patient p2a *: no.....*

Speech and Language Therapist OS5a *: you just want to eat and drink normally....*

Patient p2a *: normal.....(starts typing on electronic aid)*

Speech and Language Therapist OS5a *: mmmm....and....you....feel that you're not having any difficulties with your swallowing...do I understand that....right.....*

Patient p2a *: no.....(types) ....if I choke so what?.....*

Speech and Language Therapist OS5a *: Ok....I choke...so what....so you're prepared to take that risk?.....*

Patient p2a *: yes....*

Speech and Language Therapist OS5a *: Right.....OK....I've listened to all of that.....and I.....I understand that that's the way that you feel....OK?.....alright?.....*

Patient p2a *: right....*

Speech and Language Therapist OS5a *: now will you just....listen to.....to our assessment....*

This discussion with the Speech and Language Therapist was replicated with nursing staff and the consultant in charge on a number of different occasions. Many of the clinicians perceived p2a's choice for oral diet to be so harmful to him, that they questioned his capacity to make a rational choice. The result was that the weight of responsibility felt by the nurses in particular, resulted in 'over-ruling' his choice as the nurses felt that it wasn't in his (and consequently in their) best interests. The issue of clinical responsibility here was so profound as to outweigh any patient choice or perceived social responsibilities. That is to say, the nurses felt unable to support the patient's wishes even when it was his 'informed' choice.

Medical notes – day 128 after admission – Ward sister

p2a is insisting that he has the meal he ordered and not a pureed meal as advised by the speech therapist. Phoned S5 (SLT) to ask her advice re : her treatment plan. She advised that Mr p2a did not agree with any part of the

treatment plan and is aware of the consequences. She advised to discuss with the consultant. Contacted Dr M7a (consultant), advised him of Mr p2a's demands. Dr M7a said to give him whatever he wanted. Spoke with X, senior nurse manager re: above. She advised nursing staff are accountable for our actions and that we should not give him normal diet, but give him pureed diet as directed by his swallow assessment. As ward manager, I advised all of my staff that they should NOT give him anything but a pureed meal. Went to advise Mr p2a that the only type of meal the staff on the ward would be giving him is a pureed meal. Advised Mr p2a of our situation and that I was not prepared for my staff to be put at risk and that we could not give him a normal diet knowing that he should have a pureed diet. Mr p2a not very happy with this, stating that he signed a form, and is aware of the consequences that he could die. I advised I was aware of his thoughts and feelings, but I wanted to discuss this further with my manager, and until then the staff would not give him any normal diet. Student Nurse went to see Mr p2a after me, and he stated that he wanted to go home and would self discharge. Wife and SHO contacted for them to come in and talk to Mr p2a'

The conclusion to this conflict was that patient participant p2a did indeed take his own discharge, and continued to eat and drink orally (with no reported adverse consequences) at home.

As can be seen therefore, the implications of patient capacity for determining the clinician's perceived levels of responsibility were significant. The issues of capacity assessment, beliefs about capacity and extent to which the clinicians interpret their own responsibilities all had a profound impact on the decisions for nutrition after stroke.

12.3.2.2. Responsibilities relating to the Multidisciplinary Team

The observational data revealed that the involvement of professionals and the perceptions of their roles and responsibilities varied in each individual patient's case.

12.3.2.2.1. MDT – 'given' roles and responsibilities

There is limited guidance available specifying the roles and responsibilities of each of the professional groups who contribute to this clinical decision. Most guidelines where they exist, are produced by the professional bodies themselves, and define

core roles for each professional in broad terms. This includes clinical competence issues, but also the guidance given by professional bodies on the scope for clinical recommendations. There are no available national guidelines for specifying MDT roles and responsibilities for the clinical decision process under study. Instead, apart from the core professional roles, most MDT's establish local systems according to the range and nature of the professional team configuration.
There were some circumstances in which the clinicians were clear about their responsibilities in decision making. In particular, the medical clinicians were aware of their central role in the process.

> ***Consultant IM2b*** *: Well as the consultant I am responsible for clinical decision making....so I take the staff and the patient's and relative's views on board whenever I can....but ultimately I have to take the decision and I have to be responsible for the consequences....*

This clear responsibility was echoed by other members of the MDT, who cited that the medical clinician has a key role.

> ***Nurse IN6a*** *: someone needs to make a decision about what is the right thing to do.....frequently they have an opinion one way or the other....but also in the end I am afraid I also pass the buck and say.....the consultant has to look at this as well....our poor consultants I think would rather talk it over in the multidisciplinary meeting and have a consensus view of how people feel as well as the families view.....I think they feel the responsibility as well.....I am glad I haven't got the responsibility.....I think it's frightening.....*

Where roles were clearly defined, clinicians used this as a mechanism to formally transfer responsibility to another colleague. In the following example, Nurse N2b describes the prioritisation of tasks for which she has no obvious responsibility, over tasks where responsibility is perceived to be negotiable. In this case, the passing of the NGT was cited as a legitimate task that could be transferred to another member of the team if necessary.

> ***Nurse IN2b*** *: (Passing the NG tube) It is a low priority...yes..... I think if anything was going to be left passing to the next shift it would be an NG tube.....our priority as nurses is to give medication and care....*

The changing picture of clinical roles within the NHS was seen to affect clinical decision making. It was acknowledged that professional roles are developing, and with this came a change in advice or guidelines issued by professional bodies. This was seen to influence the clinician's perceptions of responsibility and their subsequent behaviour.

> ***Consultant IM1b*** *: I think the nurses are now being encouraged not to do clinical care...and....you know....going more and more into administration.....and run the...you know...because it's not seen as important...I really would like to reverse that process and give people...the ward sisters the highest salary...*

Similarly, clinicians alluded to the influence of the professional guidelines over their work, but also to the differing perceptions between professional groups about their roles. The dietitians expressed a view about what they were 'allowed to do' professionally. Technically, they reported that their professional body would not allow them to *recommend* nutritional interventions, but that they could *suggest* that this might be appropriate.

> ***Dietitian ID1b*** *: I know with myself, I can be quite pro-active and I will suggest whether we need to be considering alternative methods of nutrition. Unfortunately with my profession...I can't actually recommend that someone is given alternative nutrition...because I am not allowed to do that, but I can suggest.....I can highlight my concerns and then it is just trying to get the appropriate liaison back through the nursing staff and through the doctors to actually address the problem. At times, as well, you do document things in the notes, can this please be reviewed on the ward round?.... and quite often it is ignored.....*

This position was similarly expressed by the Speech and Language Therapists where they feel they are not 'supposed' to recommend NBM, but instead suggest that they are 'not safe to eat and drink orally' (as stated by Speech and Language Therapist (S4a) during a session observation). This may in part contribute to the criticism of ambiguity in clinical recommendations as indicated by the Specialist Registrar (IM4b) below.

Specialist Registrar IM4b *: Erm.....from recent experience....erm.....I would say that speech and language therapists can....when they want to....not give you a straight answer.....you know....yes or.....yeay or nay.....erm.....but.....I think that was just purely the complexity of the patient that we had.....in fact I think it added to the complexity.....I didn't want the person (SLT) to make a decision as to whether this patient needed to be PEGged... I wanted an answer as to whether this patient was safe to eat or not.....and if not....could they foresee into the future and if not...right.....and I just wanted decisions and.....and if.....this is what the whole point is.....is that....if you are not competent to give your decisions say why....but if you are....you give it but you say look....I think if you....I think the patient can't swallow and I don't think the patient is going to be able to swallow for another.....10 years.....and this is forever....and get a second opinion if you want.....but at least there is a decision made....read in the notes....this patient is nil by mouth indefinitely.....and I don't think that happens.....we're too bothered about committing ourselves....*

The influence of risk as a factor in decision making was evident once again here. The reluctance of individual members of the MDT to commit to a particular decision, frequently made it more difficult for other members of the MDT to make their decisions.

This position was observed with SLT (IS1b) following an incident where patient 3b was thought to have aspirated as a result of drinking water directly from the tap at the sink. In this case, her response highlighted the perceived boundary of her role and responsibilities.

Speech and Language Therapist OS1b *: we had him supposed to be NBM...if he has aspirated it was nothing to do with me...*

In summary, there appeared to be little shared understanding amongst MDT members about the roles and responsibilities of each individual professional. This resulted in a problem with expectations, when professionals failed to live up to how others thought they should perform.

12.3.2.2.2. MDT – 'unassigned' roles and responsibilities

The result of changing and emerging roles for professionals was seen in some situations to create uncertainty over levels of responsibility or accountability. In

some cases, it was seen that no-one picked up an 'unassigned' responsibility, and in other situations too many people in the team had a view or sought involvement. Additionally, the lack of 'whole systems' approaches resulted in 'compartmentalised' care, with each professional in a MDT actually working in a unidisciplinary way. The practical consequence of this 'systems uncertainty' is shown below. There was a sense that individual responsibilities were more important than MDT responsibilities, as each clinician was driven by accountability for their part in the MDT plan, rather than considering the overall plan.

> ***Specialist Registrar IM5b*** *: Yes.....because I don't think...you know the dietitians come round and how much do we listen to the dietitians.....I will be honest with you I.....(sighs)....I read notes.....and would be more likely to read a speech and language assessment than a dietitian's opinion .....I don't know.....I don't know.....maybe it's because I take it as read that dietitians sort it out....whereas you know....I am interested in can they feed or can't they feed and if they can't feed then we will scratch our head....*

> ***Consultant IM10a*** *: I mean if I just say Speech and Language Therapist.....to deal with this...they might make decisions about you know....being too active in a patient who has no chance of recovery....and it might...the interventions might be inappropriate...on the other hand...they might underestimate...the....because they look from...erh.....you know.....a narrow angle....*

Some clinicians reported that MDT working created problems with communication and ownership of responsibility. It was clear that professionals needed to respect their boundaries, but this sometimes created tensions in team working.

> ***Consultant IM7a*** *: at the end of the day...you know...it's usually the consultant that's speaking to the relatives.....erm.....sometimes they have to iron out some of the things that have been said to them....by nurses...and you have to correct that and get that out sometimes....sometimes that produces a.....a difficulty...sometimes when.....you know...I think...sometimes nurses hide behind....oh you'd better make an appointment with Dr 7a.....and don't give any information out...you know.....you don't want them giving wrong information...I suppose this is*

the problem...and...erh.....I suppose....we...well I shouldn't expect.....a nurse...to....look at a CT scan...and understand what that might mean

When looking at the impact of the MDT on decision making, clinicians raised the issue of time delays whilst seeking information and agreement. Ensuring that the process was comprehensive was seen to make decision making less efficient.

***Specialist Registrar IM5b** : decisions that would have been made much sooner are now taking longer and longer.....and it's because we are bouncing questions off each other....bounce it back to me and then you're tied up in a meeting so you can't be in touch until next week and then the MDT takes place and we all sit there again and bounce questions off each other.....and you walk out of the MDT and you think well....we are actually no further forward than when we went into that room but everyone is happy....and nobody is apportioning blame and no one is taking responsibility*

The issue of giving information was noted to be particularly 'problematic' in decision making for nutritional interventions, in that clinicians were often unclear whose responsibility it was to inform patients or relatives about the possible options. For example in relation to PEG feeding, there were a variety of views expressed over who *would* and *should* give information to the patient and relatives. It was clear from the data that the procedure for achieving this remained inconsistent, as illustrated in the variety of views expressed below.

***Speech and Language Therapist IS1b** : as far as the information giving and the decision making the medic would be the one who is responsible for explaining the procedure, the risks involved, the advantages and the disadvantages and the dietitian and ourselves involved in the sort of information giving as well.*

***Dietitian ID3a** : Nursing staff would.....not always give them information....but just sit down and have a chat with them....as well as the doctors....that do the consent...*

***Consultant Physician IM8a**: because they weren't really getting the information.....the dietitians....who tend to be the people who did it... were*

pretty good but it was a bit patchy so some people got the proper information and some people didn't.....

***Dietitian ID1b** : they get referred and they have a PEG and they don't understand properly what the procedure involves or what that actually means for them at the end of the day.*

Although there was some consensus over the broad roles for each of the professionals, the responsibility for some aspects of the patient's clinical *status* was less well defined.

For example, if aspiration or dysphagia was suspected after stroke, the patient was often placed NBM and referred to SLT for a swallowing assessment. Generally, the referral to the dietitian did not take place until a decision was made to commence enteral feeding. As a consequence, patients were seen to be NBM for a period of time without the dietitian being involved. Given the length of time between placing NBM and initiation of enteral feeding (as seen in chapter 12.2), there was a major gap in 'ownership' for the NBM status in the early stages after stroke.

***Speech and Language Therapist IS4a** : Yes.....yes.....and very often if we haven't mentioned nutrition....it isn't mentioned so we have to be quite, even if we have discussed it with them they often don't make the referral to dietitians so that is something I am dealing with at the moment.....we really need to chase that up.....*

Interestingly, the doctors and nurses reported their perception that the dietitians would be involved with all patients who were NBM. Their view was that the dietitian played a major role in decision making for patients who were NBM.

***Nurse IN1b** : Oh yes.....yes they still get referred to the dietitian.....actually they are far more involved now in decision for feeding than they ever used to be.....*

This perception was not supported by the dietitians, who reported that their responsibility was to recommend clinical nutrition regimes rather than being involved in decision making for nutrition.

Dietitian ID3a *: so...as I say....erm.....we're not often involved in the decision making.....until....the NG tube's either been pulled out or in other cases has been established.....so certainly NG.....we might not get involved until the referral comes requesting a regime....well....sometimes they will get involved....but I think it's numbers again*

It was clear from the data that placing a patient NBM was seen to be a solution to a problem of potential aspiration. As a result, the NBM stage generated an impression that an active management plan was underway. In reality, the NBM status was a holding position without clear guidance over who should monitor or change the recommendation.

Dietitian ID1b *: We have had experiences in the past....I know with some stroke patients who have been left a considerable period of time before they have been given any alternative form of nutrition, possibly being assessed by a speech and language therapist, nil by mouth unfortunately the team hasn't made an active decision with regards nutrition and in some cases it has been a month...I have seen somebody without any form of nutrition.....*

In addition to perceptions about ownership of NBM status, the nurses were clear that they did not routinely see NGT decisions to be their responsibility, although there were occasions when they 'took it upon themselves to act'. Nurse N5a recognised this position, but also identified the problems associated with adopting a responsibility that is not strictly 'within role'.

Nurse IN5a *: Yes.....having said that....occasionally you will get a nurse who will say he should be on an NG and they just shove one up.....but It's not technically for us to do that.....you know....legally it's not for us to do that because of the ethical dilemma.....*

This view was generally contradicted by the doctors, who clearly believed that NGT decisions were commonly part of the nurse's 'adopted' roles and responsibilities, as seen in the words of Dr M9a below.

Specialist Registrar IM9a : *you know the time frame is that they're not going to see me for 4 days and the nurse feels that NG feeding would be*

appropriate the nurse will get....verbal consent then.....they would get on and do it without just because....I...I'm not there.....

The ambiguous position regarding NGT decisions contributed on occasions to a position where the clinicians were noted to 'distance' themselves from decision making by nature of it being outside of their role. In the following, the statement 'it's nothing to do with me' gives insight into the potential dangers of working according to strict role boundaries, when the responsibility is not picked up by others. The lack of an NGT, hence prolongation of NBM period can seemingly occur through the combined effect of unclear, unassigned, or unassumed clinical roles.

***Nurse IN5a** : and occasionally I have had consultants come on the ward on a Monday morning and say why hasn't this man got an NG in....(laughs)...and you think.....I don't know.....it's nothing to do with me....*

This degree of ambiguity, 'confusion' or detachment over roles and responsibilities created further uncertainties over nutritional decisions for patients after stroke. In essence, the organisational and professional issues could be seen at times to contribute to delays in decisions for nutritional interventions.

12.3.2.3. Responsibilities relating to the organisation

12.3.2.3.1. Maintaining a reputation

Clinicians expressed a view that they could not make decisions with regard to nutritional interventions without considering their responsibilities to their employing organisation as well as their professional body. This included a number of issues within their wider remit, such as considering the economic and resource constraints through to ensuring good 'public relations' for the NHS organisation.
In the following examples, the clinicians were acutely aware of their responsibilities for any 'ripple effect' as a result of their decisions, particularly in relation to overt withholding or withdrawing of nutrition.

***Consultant IM7a** : it can actually screw up their lives.....for a long time...if not for the rest of their life...you know...it's...that hospital killed my mum and that doctor in particular...you know...let her die.....and shouldn't have done....*

In the following example, the clinician articulated a very strong awareness of the implications of his clinical care.

> ***Consultant IM6a*** *: .you withdraw fluids they are dead within a week or whatever it is....ten days at the most...keep fluids going they might last three weeks or four weeks.....if we were really blunt about it we can use those beds for somebody else do you see what I mean (laughs) and those are real issues which we ought to discuss...*

The tension between maintaining a good reputation for the organisation, alongside rationing care was apparent. In the observations, the reputation issue was seen to carry greater weight in terms of clinicians concerns to ensure that relatives were 'in agreement' with plans before proceeding. Although clinicians raised resource issues in interviews, these factors were not observed in clinical practice.

12.3.2.3.2. Documentation – the paper trail

Another aspect that demonstrated the clinician's high level of awareness about their perceived responsibilities, was the degree to which documentation was used to demonstrate the management of care. Medical case notes, for example, were seen to be the central source of information and communication regarding patients and maintaining good records was seen to be paramount in clinician's views of their responsibilities. Interestingly, the records were seen as a powerful method of communication as they served as a 'hard copy' of recommendations. In a sense, the fact that a clinician had documented their views gave them some peace of mind that they had upheld their responsibilities.

> ***Dietitian ID1b*** *: Possibly with documentation....when you are writing things it tends to get to the capital letter scenario underlined with a couple of stars next to it to try and see if you can highlight them to read it....(laughs).....I don't care what they do...just do something....then by documenting it, at least I've done what I am responsible for....*

An interesting feature of written documentation that was acknowledged by many participants was the role that medical records played in assigning or attributing responsibility to individuals. Although being written contemporaneously, it was evident that writing about the *current* presentation often required some consideration

of how records would be perceived in *the future*. If viewed in this way, medical records are a tangible 'paper trail' for a clinician practising defensively. There were 'techniques' adopted in medical notes (with or without conscious recognition) that would allow the 'benefit of the doubt' if records were studied in the future. These included a failure to record some facts or interpretations, ambiguities about who had responsibility to carry out next steps, and often lack of clear direction or planning. In the following, dietitian ID1b highlights the importance of the documentation as a form of communication between professionals. She particularly indicates that communication can be affected *at the time*, and that this can have an impact on assigning accountability *in the future*.

> ***Dietitian ID1b*** *: the Dr has put for NG tube, and at the end of the day if it's not documented if anything goes wrong with that patient, who is responsible for it?.....because the documentation was incomplete.....but again we can't act psychic at the end of the day and interpret that through our reading.....*

All respondents recognised that the medical notes were predominantly used as the primary source of information for legal 'evidence' or litigation. This viewpoint indicated some cynicism about the current use of medical notes across a MDT. There was often an inherent sense of 'mistrust' between professional groups that they might 'blame' each other if things did not go well for the patient.

> ***Dietitian ID1b*** *: I think they (the notes) have gone worse quality to be honest.....I think a lot less things are being documented now and my concern is as well with some of the nursing handover sheets....what happens to those printed records that are done on the computer, are they kept?... if anything was to go wrong legally would we be able to cover ourselves from that?....*

In some cases, clinicians acknowledged that they practiced defensively and that the medical notes served as legal protection. Dr M5b acknowledged that some medical colleagues deliberately omitted information in notes so as to allow for flexible interpretations in the future. The contrast with the practice of other professionals was interesting. The visiting professionals (SLT and Physio) placed greater emphasis on recording their views, clearly stating the limits of their responsibilities.

Specialist Registrar IM5b *: we don't write enough down.....but then again we don't have enough time to write things down.....erm...and that just.....you can look at everybody else.....you know you look at the physio.....what the physio writes down.....you look at the SALT...erh....the speech and language therapist...and they're.....it's almost like a little essay....it's lovely.....and then you look at the doctor and it's just like a line....and you just think.....and I don't know whether that's...are we covering.....I remember working for a guy.....who would never write the diagnosis down.....Yes.....if don't write the diagnosis down how can you be sued....I mean....he knew what the diagnosis was but he just.....well he just left it kind of open....*

Another interesting 'device' regularly used by most of the clinicians in the medical notes was the use of the question mark (?). Analysis of the medical notes data revealed that on numerous occasions, clinicians had written '? for NGT' or '? for PEG' without being clear over whether this was a question directed at any particular individual or linking to any particular plan. For the majority of instances where this was recorded, subsequent resulting action was neither immediate nor consistent. In the majority of cases, it appeared as if the clinicians were using it to demonstrate that a possible clinical intervention had been considered. In this way, the 'query' device could legitimise *inaction*. This 'staged' approach to nutritional decisions was explicitly acknowledged by some clinicians, as indicated in the following.

Specialist Nurse IN6a *: I think at 5 days it's got to start going through your head.....so you can start having decisions for a week later....*

This aspect was reflected in the medical notes, although in such a way that could be considered to be vague terminology or ambiguity.

Dietitian ID1b *: Like query for the NG tube.....what do you want for it because quite often I document in the notes, I note that no consent has been documented down for this procedure, the nursing staff have contacted me and asked to provide an enteral feeding regime and there is no mention of enteral feeding within the notes, can this be clarified...*

The implications of ambiguous record keeping in terms of legal protection, but also the impact on the *process* of decision making was evident in this study.

12.3.2.3.3. Legal responsibilities for the organisation

Legal responsibilities were reported to be a factor influencing clinicians in decision making. Most clinicians were acutely aware that when there were 'difficult' cases involving enteral feeding, they sought legal advice over what they should do.

> ***Specialist Registrar IM5b :*** *at the end of the day the patient has to come first and that is where your duty lies....but you know the hospital.....that doesn't stop the hospital being sued...so I think you've got to get things straight before you...you know....plough ahead with what you think is right and then...you know.....before then you will probably have a second opinion before you go ahead.....*

Once more, the documents were heralded as retrospective 'evidence' for defending their practice. In the following, the dietitian highlighted the impact of poor documentation. She implied that this can be problematic for clinical planning, but also that the legal implications of omissions can be significant.

> ***Dietitian ID1b****: It can be...but at the end of the day it's patient's word of mouth. I know we have a particular patient on one of our wards at the moment an exceptionally complex patient where nutrition is just fundamental to this whole patient's care...very anxious family and then you go and they tell you he has had no NG tube in all weekend, you go and look at the notes and there is nothing documented. Why hasn't an NG tube been put in and even for the staff to cover themselves, attempted to pass NG couldn't do it, I have contacted such and such to have a go.....it's not documented....If it goes to court legally you've have not got a leg to stand on.*

Interestingly, the frequent reference to legal issues being influential in decision making was not supported by the observational data. In the interviews, clinicians reported that the legal implications had a major impact on the way they worked. In practice, there were no references to legal guidance for nutritional decisions.

As shown, there were views on clinical responsibilities that were influential when making decisions about nutritional interventions. In addition, the clinicians were aware of broader responsibilities relating to the life experiences of the patients and others. This will now be discussed in terms of 'social' responsibilities.

12.3.3. Perceived Social Responsibilities

In addition to their responsibilities for clinical issues, clinicians perceived themselves to have 'social' responsibilities that stretched beyond the immediate clinical information into looking at the possible future consequences. For nutritional decisions, the issue of whether ANH was considered to be food (therefore socially driven) or treatment (hence clinically driven) was central to many of the clinician's uncertainties over their professional responsibilities. It was clear, however, that there were additional social factors for the patient, over which clinicians felt a sense of duty. Furthermore, when considering social responsibilities, the consideration of best interests broadened to include responsibilities to the family and society. The features of social responsibilities will now be discussed under the following headings

- Social Responsibility – for the patient's well-being
- Social Responsibility – for the family and onlookers
- Social Responsibility – for society

12.3.3.1. Social Responsibility – for the patient's well-being

Quality of Life as a social component of prognosis was discussed in chapter 12.1. In this chapter, the degree to which the clinicians felt that they had a responsibility for the patient's future QoL will be discussed.

One of the main components of this dimension was the priority given to acknowledging a patient's wishes about their future Quality of Life. Although clinicians reported that formal advance directives ('living wills') were rarely encountered within elderly and stroke care settings, it was clear that any previously expressed wishes were strongly respected. Advance directives were acknowledged to be problematic, but clinicians reported that having this information gave opportunities to consider the patient's broader wishes. Where this information was available, the clinicians assumed a responsibility for ensuring the patient's wishes were respected.

> ***Consultant IM3b*** *: another one said and we wrote in the notes...If I go off...for god's sake don't put me on a ventilator.....we have to respect that...*

On many occasions, the clinicians expressed a duty to advocate for the patient's future QoL. It was clear that in some instances they felt that their responsibilities moved beyond accountability for clinical outcomes towards projecting whether the future QoL would be acceptable for the patient.

Specialist Registrar IM9a *: Yes...they tend to...particularly with the older patients they talk about...what they would wish in certain scenarios.....you know.....I wouldn't want to be a vegetable in a nursing home.....you know.....don't let them do this...or that to me....*

The impact of this for feeding decisions was such that clinicians actively avoided enteral feeding if the patient had expressed that they did not want this. In these cases, clinicians felt a responsibility to support a strongly expressed patient refusal, even in the absence of a formal advance directive. The 'duty' to consider the broader patient's view was, therefore, clear.

Specialist Registrar IM9a *: Erm.....we do have issues where patients have expressed prior to their stroke that in the event of them having disabling neurological conditions they would NOT want to be fed...erm....and you've got to take that into account...*

The above scenarios more commonly occurred in situations where patients refused treatments. However, there were similar responses observed when a patient requested treatment or feeding.

Specialist Nurse N6a *: there are some easy decisions, people who can tell you that they are hungry.....but then they would probably be the ones with minor strokes and probably a lot of hope.....*

Through observational data, there were examples such as the case of 22a, (as previously described), where the patient requested enteral feeding when alert, and this was respected, even when her clinical prognosis deteriorated. In this example, the clinician's strong sense of duty to respect the patient's wishes meant that he assumed a social responsibility to advocate on her behalf.
It is clear, therefore, that the clinicians carry a sense of social responsibility to consider the well-being of the patient in the outcomes of the clinical decision. Contributing to this issue are the patients previously expressed views alongside a 'projection' into the future about the patients future lifestyle.

12.3.3.2. Social Responsibility - for the family and onlookers

As previously observed when looking at views on prognosis and beliefs about nutritional interventions, clinicians acknowledged the wider impact of caring for a patient's family after a stroke. This goes further than *a pastoral role, to feeling a* strong sense of responsibility to manage the emotional needs of the family as well as ensuring that nutritional decisions concur with a family's view wherever possible. This was considered necessary to help acceptance of the current situation and future outcome. At times, clinicians were explicit about the degree of 'emotional' manipulation required to 'absolve' the relatives from any personal guilt during the decision process. Ensuring the relatives had a voice, without making them feel responsible for the ultimate decision was a major feature in the decision process.

> ***Consultant IM7a*** *: we do need to be very careful.....that when we see relatives...that....and....and it is often put in this manner...that we are asking them to make a decision about...do you want feeding....do you want resuscitation....and that should not be what's happening...we should be....we're doing a selling job as far as I'm concerned....we should have made the....you know...they have no legal rights...you know...you've got to consider what they.....what their feelings are...*

Respecting the perceived responsibilities of the *family* was also raised as an influential issue. In some cases, clinicians reported that accepting the patient's condition required the family to actively 'fight' for interventions. Whatever the motive behind this, the clinicians reported sensitive management could prevent future negative 'fall-out'. The responsibility to manage the family's grief and acceptance is, therefore, clear.

> ***Consultant IM1b*** *: you have to involve the other members of the family...because many of them will come....be on a guilt trip...and so you know....they want everything done...*

Another feature of a clinician's responsibility to support families was that, in some cases, the needs of the family overtly and legitimately outweighed the needs of the patient. This view was expressed in situations where a patient was dying, or was very unwell, and clinicians felt that clinical intervention such as ANH would be of no benefit. In these cases, if the family requested ANH, most clinicians stated that if

they could not convince them otherwise, they would invariably 'go along' with a family's wishes. This decision would be driven by attempts to minimise the potential future legacy of 'harm' caused by conflicts in the *process* of deciding. In the following examples, the clinician's views about what might be clinically best for the patient were dismissed in preference for supporting the broader needs (and perceived responsibilities) of the relatives. In this way, the clinician's responsibilities for ensuring good social outcomes were evident.

> ***Consultant IM6a*** *: we had extreme distress here with the husband and all the rest of it.....I mean well Dr xxx was thinking...well....although I don't think we should do it...and I felt the same.....but it was oh let's put the PEG down and he's going to look after her at home and all the rest of it.....he wants to look after her at home.....he can do it.....why not go ahead with it....and I think we were on the verge of saying although we didn't agree.....but providing he was willing to look after her we would go along with him...*

> ***Consultant IM7a*** *: but I think....I mean...I've had...occasions when...I've had disagreements with relatives....sometimes you've....basically what they're saying is either...I'm not prepared for this death yet...or they're guilty about something...or often...you will not get to the bottom of that.....erm....but for those patients...for those relatives who are not yet prepared...and it's especially those people... who have looked after their spouse...or it might be a daughter that's looked after a mother....erh...for a long time....and they really...that's their world...and they just don't want to let go of that....*

Clinicians were in agreement that family involvement facilitated acceptance, but the process was noted to be complex. Many clinicians raised the issue of 'proxy' decision makers, and the problems of allowing families to influence decisions. Dr M6a made the distinction between family members in terms of their level of legitimate entitlement to contribute to decision making.

> ***Consultant IM6a*** *: Well again it depends....there's family and family isn't there....there are patients who've got very close family who've been very caring to the patient and very much involved but clearly you're going to listen a lot more to those sort of people....like we were just talking about this one that we were in disagreement with but he has been a caring husband and he*

has been very closely involved so you are going to take more notice of him than a nephew who's only seen the patient once every three months....do you see what I mean...

This view was echoed by others, including nurse N6a when she described the value placed on the views of certain family members. She indicated that if the family expressed their view with certainty and conviction, it was rarely disputed.

***Nurse IN6a** : I think there was the initial plan to feed this lady...and she (the daughter) was a strong...sort of no....this is **not** going to happen....and she was really against it.....and...so then there was a big discussion with the daughter and the consultant...and it wasn't erm....broached again....she just wasn't fed.....*

Formal Advanced Directives (or 'living wills') as already described, were a legitimate way of transferring the responsibility to the patient in situations where the patient could not contribute. However, the wisdom of taking an advanced directive as expressed through family members was again prone to individual interpretation. In both of the following examples, the negative outcome of negating the family's need to act as a proxy was clearly expressed.

***Consultant IM8a** : I think it was basically based on the fact that his father....who wasn't his Next of Kin.....that those were his wishes...and that there wasn't an advanced directive....and so that when one of the family members is saying...he must be fed...and you don't have proof of his premorbid ideas.....but going against the family is extremely difficult.....*

***Consultant IM6a** : it still doesn't always solve the problem.... but it helps you legally if somebody's done it....do you see what I mean.....so even if you say ok we're going to do....the patient has said this...there is the living Will and these close relatives and everything...it's not easy even then....legally it might be but practically it might not be....you've still got to be certain that this IS what the patient would have wanted.....*

Interestingly, the medical consultants felt responsibility for the emotional impact of decisions on other members of the clinical team. In some cases, they were explicit about providing interventions for a patient in order to support the nurse's needs to

be 'doing something', physically and emotionally. Dr M4b raised the sociological impact on the nurses, were their 'caring' role to be challenged by withholding or withdrawing food or fluids.

> ***Consultant IM4b*** *: Feeding.....yes....because again it's a sort of moral dilemma.....relatives and nursing staff feel that.....if you discontinue feeding you are abandoning the patient completely*

As seen, therefore, the perceived social responsibility to the family and onlookers was significant enough at times to overrule the perceived *clinical* responsibilities of harm/benefit. In addition, the perceived responsibilities of the family and other MDT members were considered to be influential. These social responsibilities were observed to be accepted as legitimate influences on the nutritional decision process.

12.3.3.3. Social Responsibility – to and representing society

Throughout the data, there were recurrent references to society's expectations of clinicians in the context of difficult decisions. Many clinicians reported that they tried to consider the 'ripple effect' of their decisions on society, and that this was increasingly difficult with the influence of litigation. There was a tangible fear of the risks associated with making the 'wrong' decision and being seen to be either trying too hard, or conversely, not trying hard enough for the patient.

Through the data it was seen that the influence of both the media and the perceived 'threats' of the law were powerful contributors to a clinician's sense of responsibility. Whilst understandably wanting to avoid personal litigation, the sense of duty to act in the best interests of society was also clear. Clinicians were observed to consider their personal role in furthering society's knowledge about clinical decisions, but also respecting their duty to minimise the potential for further damage to the public reputation of clinicians. That is to say, they felt a role to educate society about medical challenges, but recognised that society may judge them personally for some of the outcomes.

Dr M9a identified that clinicians were 'under fire' with general mistrust from the media about their role and their motives.

> ***Specialist Registrar IM9a*** *: I think that there's a perception again out there that erm.....we see it again on the front of tabloids.....you know...old people*

just left to die and you know...the implication is that there is something that could have been done to change that.....

Society's expectations and demands were raised by many clinicians as a factor that increasingly influenced their clinical decisions. Nurse N5a discussed the impact of increased access to medical information from the internet and other sources, alongside, the contribution of the patient's charter for making patient's rights more transparent. In this example, she indicates that when making decisions, clinicians have a duty to consider the broader societal impact in a way that would not have been necessary in the 'old NHS.'

***Nurse IN5a** : then patients are a lot more...a lot more misinformed basically and feel that they have rights that they don't and also feel that we are fair game.....so they are worried about their relatives.....patients relatives and families have always expressed concern in different ways.....some of them can be aggressive and some of them can be over the top....and you accept that....but that is on the increase...flack and pressure generally from families is on the increase...we must work harder to educate society about the issues here....*

Dr M5b suggested that despite the air of mistrust about clinicians, there had also been a shift in terms of the expectations of a clinician's abilities and duties. His view indicates that expectations rarely match the reality, and cites the Tony Bland case as indicative of 'unreasonable' expectations.

***Consultant IM5b** : I think the problem with society today is that we....can't accept nature anymore and that we can't accept that unfortunately we do.....we are born and we do die and that there is a time for each and every one of us....and I....my problem sometimes is that we can't say enough is enough....and that doesn't just mean to go with giving intravenous antibiotics that means feeding as well....and....you know....there was the famous case about the guy who had brain damage from Hillsborough....we do need to bear those cases in mind...*

In summary, therefore, clinicians felt unable to ignore the needs and expectations of wider society when making clinical decisions.

This section has indicated the responsibilities of both the clinicians and others that are influential in the decision process. This includes those relating to the patient's social needs, the immediate impact on 'onlookers' and the wider external resonance linked to decisions made.

12.3.4. Perceived Responsibilities – data sources

The issues defining perceived clinical and social responsibilities were pervasive throughout all of the data sources and were major influences over the decision process for nutritional interventions.

However, when studying the data to ascertain how responsibility was represented, it was clear that there were themes within each source of data collected.

When analysing the interview data, clinicians articulated a clear view over their responsibilities that was not present in the naturalistic data. For example, they discussed the nature of their roles, and gave clear boundaries for the limits of their responsibilities in terms of professional guidelines. When considering the observational data however, these 'limitations' were rarely acknowledged, and often, the discussions and documentation were ambiguous in terms of defining responsibilities. There were frequent occasions when a ward round ended with a 24 hour clinical plan, but without clear delegation of roles and responsibilities. This was similarly represented in the medical records, where detailed planning of who would do what was not recorded. On occasions, where clinicians were discharging their responsibility, this was clearly recorded without ambiguity. This may in part have been attributable to the clinicians need to overtly signal the end of any personal accountability.

The MDT meetings were the main forum for immediate requests or transfer of responsibilities rather than a thorough review of each case. This meeting was often characterised by referrals to other professionals for opinions, or requests for social services involvement for discharge planning. Although the responsibilities were not overtly expressed, it was evident that the forum was used to discharge responsibilities 'publicly' in some cases. For example, on occasions, MDT members stated limits to their involvement, such as dietitian D3b stating 'I can't do any more for this person until the SLT has been to assess'.

It was clear, therefore, that responsibility and accountability was communicated in differing ways across the data sources, often determined by the clinician's levels of certainty or uncertainty about the plan.

12.3.5. Summary

In summary, clinicians revealed a strong sense of personal responsibility for clinical and social issues in every patient scenario, alongside respecting the perceived responsibilities of others. Many of these views were overtly expressed, but within day to day decision making for patient, there was also ambiguity and uncertainty. This chapter has identified the key issues that underpin clinician's beliefs and perceptions about their own responsibilities in the decision processes and their views on the responsibilities of others.

When considering best interests, the issue of responsibility had multiple perspectives, taking a broader account of the clinician's own interests as well as those of the patient and their family. These are expressed and legitimised in terms of their accountability within clinical decision making.

As shown therefore, issues relating to perceived responsibilities have both clinical and social aspects that are major contributory factors in the decision making for nutritional interventions after stroke.

12.4. Personal Conscience

The issue of personal conscience echoes some of the previously discussed areas as it arises out of, and is inextricably woven through, the clinician's views on prognosis, beliefs about nutrition and hydration interventions and perceived responsibilities. Personal conscience issues were seen to represent an important contribution to decision making for nutrition after stroke.

A definition of personal conscience that is adopted for this study, is that it is the motivation governing a person's thoughts and actions. It is clear that issues relating to personal conscience are highly individual, often involving personal beliefs about religion, morality or humanity. As such, personal conscience dictates that any decisions have to 'feel right' for the clinicians involved.

Many of the issues categorised under personal conscience in the data were revealed during interviews. It was clear that the clinicians experienced underlying 'feelings' about the decisions that were not directly observed. These 'hidden' influences on behaviour reflected the clinicians' moral or ethical stance about the value and meaning of life in general.

The clinical and social dimensions of personal conscience will be discussed in this chapter.

The clinical aspect related to issues where the clinician held a fundamental view that the clinical plan (intervention or non-intervention) was right or wrong for the patient. This was based on their education, training and beliefs about their role as a clinical professional. The social aspect of personal conscience related to ensuring that the process or consequences of the plan felt right or wrong for those involved. This was subject to greater variability of opinion across the team as it is subject to a wider set of social influences.

Figure 11 illustrates the two aspects within this theme that will be discussed in this chapter. These will be presented under the following headings

- Clinical Conscience
- Social Conscience

Figure 12 shows the analytical stages moving from open coding of data, through to developing 'Personal Conscience' as a major theme in the decision process. As previously, the diagram serves to lead the reader through the headings and subheadings within this chapter, by working from right to left.

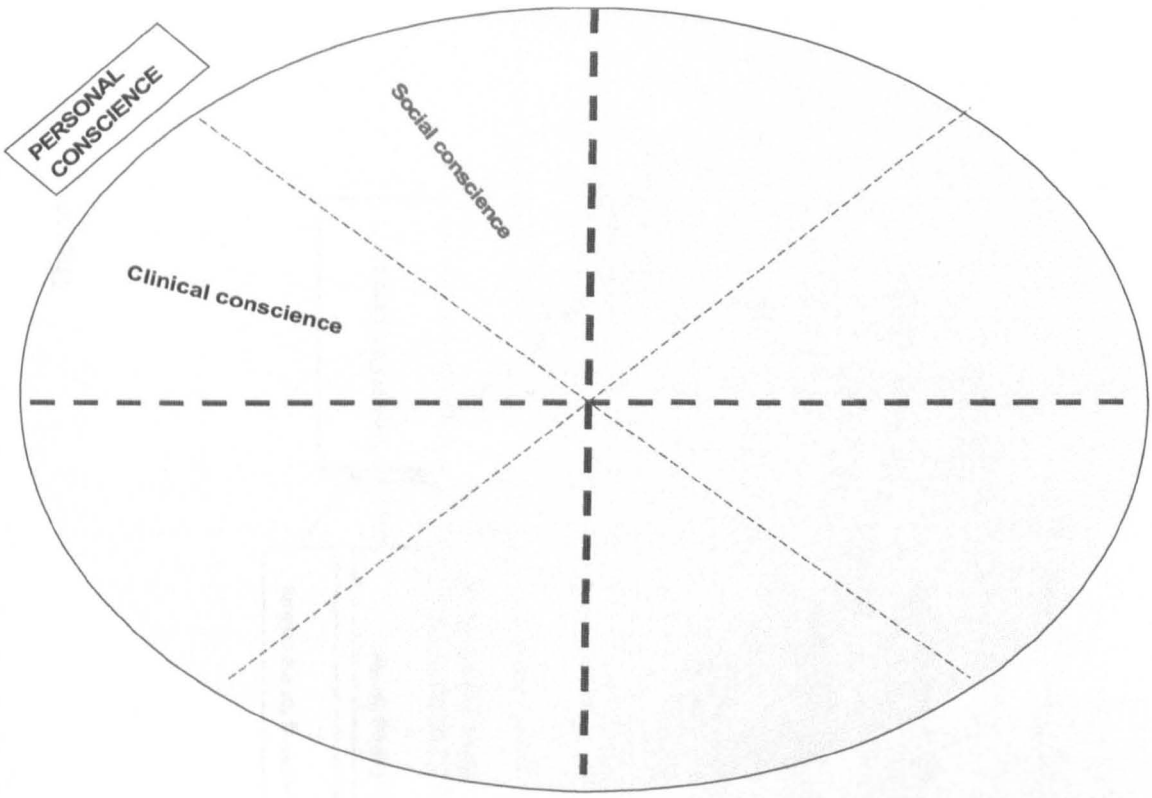
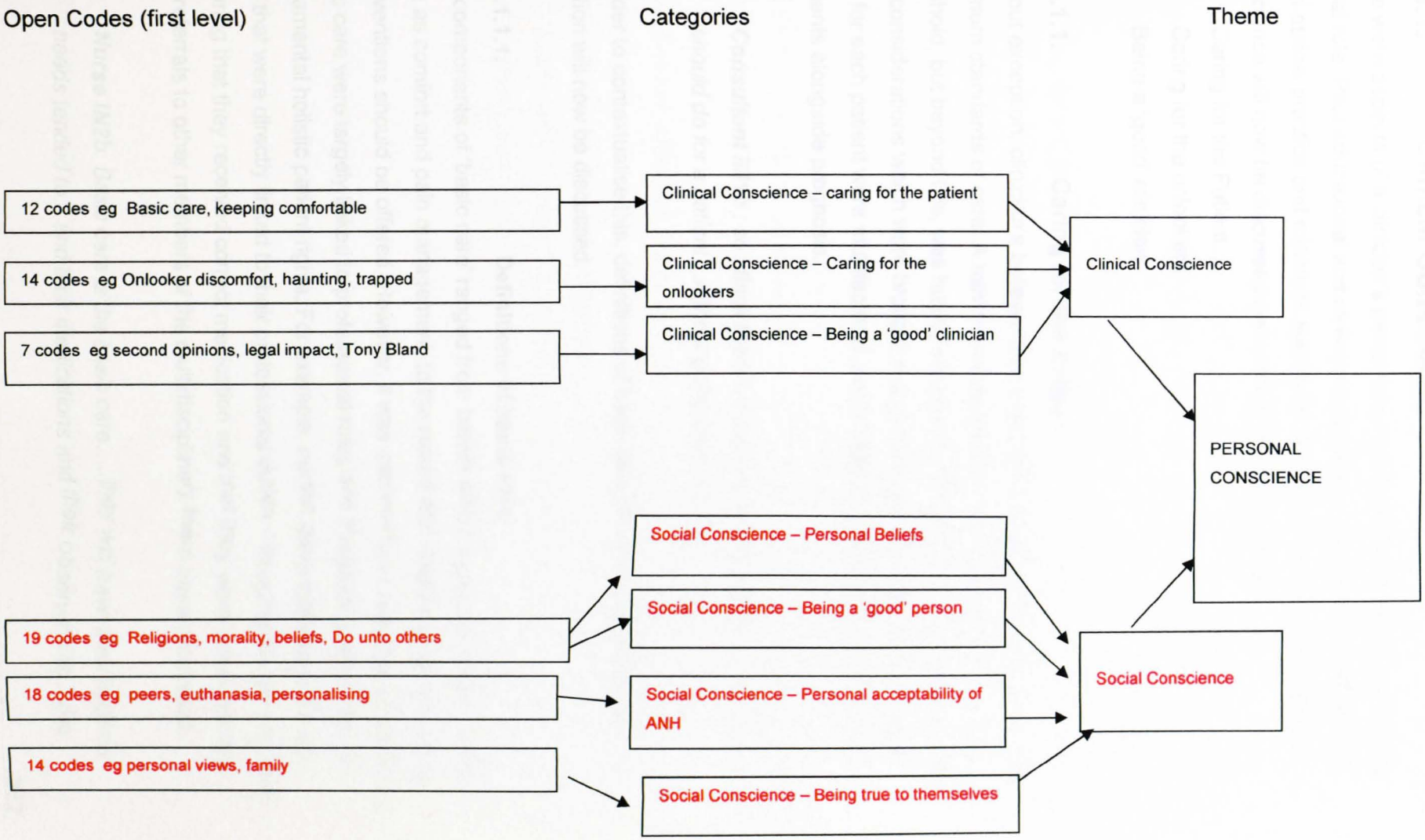


Figure 11 – Personal Conscience as an influencing factor on decision making for nutrition after stroke.

Figure 12 - Theme Development : Personal Conscience



12.4.1. Clinical Conscience

There were aspects of a clinician's personal conscience that related to their 'given' clinical role. Past educational and clinical experiences combined to create beliefs about ethical practice and minimum standards of care. These aspects of clinical conscience will now be discussed under the following headings

- Caring for the Patient
- Caring for the onlookers
- Being a 'good' clinician

12.4.1.1. Caring for the Patient

Without exception, clinician's believed that they had a professional duty to provide minimum standards of care. A minimum standard of care was fixed at its lowest threshold, but beyond this, was hugely variable in relation to each individual patient. The considerations which were brought in to play to determine the basic level of care for each patient were multifactorial, but broadly included ethical and social elements alongside prognosis.

> ***Consultant IM1b*** *: so I think there's a certain basic minimum which you should do for a patient...without going over the top...*

In order to contextualise this, definitions of basic care and the views held about nutrition will now be discussed.

12.4.1.1.1. Definitions of basic care

The components of 'basic care' ranged from beliefs about a person's basic needs such as comfort and pain management, to the nature and degree to which clinical interventions should be offered. However, it was interesting to note that definitions of basic care were largely linked to professional roles and obligations rather than to fundamental holistic patient rights. For example, nurses gave definitions of basic care that were directly linked to their professional duties – keeping the patient clean, ensuring that they received correct medication and that they were monitored and that referrals to other members of the multidisciplinary team were processed.

> ***Nurse IN2b****: Basic care is the basic care.....they will have their hygiene needs tended to... and their medications and their observations....the*

referrals will be sent to...any appropriate person that needs to be involved....such as speech therapy....dietitian... physio...occupational therapists....they are...they are all involved... it is difficult (when nurses are busy) but at the end of the day we are still nurses and we are still in a hospital environment and the patient should be getting the care that they deserve.....

For the doctors, basic care was viewed within the context of limited outcomes and predominantly related to the clinical expertise of keeping patients comfortable and free from pain.

***Consultant IM8a** : I think you should keep people comfortable and make sure they are hydrated but I don't think you should be forced to treat them if in your opinion and that of other responsible medical opinion the patient has no chance of recovery.....just keep them comfortable....*

This variation in what constituted basic care generated some difficulties for multidisciplinary teams. As professional groups held different definitions of basic care, there were often disagreements between doctors and nurses over acceptable levels of intervention for particular patients.

***Consultant IM2b** : I've been in situations where peoples' personal views create problems.....some where the nurse believes that this is the session to persuade the family to agree to.....an invasive treatment[22].....even.....even excellent nurses do that and it's a bit of a worrying area....I don't know why they do it.....I just don't know why they do it.....I think it's very difficult to be a nurse.....and to nurse somebody....erm.....who isn't receiving adequate nutrition.....*

Whatever their definition or baseline for 'basic care', all clinicians were in agreement that providing basic care was not negotiable. The extent to which basic care included nutrition will now be discussed.

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[22] In this case, the context for the 'invasive treatment' refers to PEG insertion

12.4.1.1.2. Nutrition and basic care

For some groups of clinicians, basic care included nutrition and feeding. For others, nutrition was excluded. Where patients were alert and had no signs of swallowing difficulty, there was a general belief that patients would be fed.

> ***Nurse IN1b*** *: Erm……I think usually…..they would come and they would feed……I think it….you know…..I think it goes against human nature for a medical……to deny anybody nutrition….. not the basic care……and I think nutrition is basic care….*

Similarly, it was clear that nutrition was perceived to be basic care if withholding it was directly linked to cause of death.

> ***Consultant IM1b*** *: I would not let people die because they're not being fed…you know….I think there's a basic minimum that you do for a human being…and you know…I think that is…euthanasia in a sense….if you don't…if you don't actually…provide the basic thing….and it may just be the fluid..in some cases*

As previously discussed, the act of feeding went beyond its clinical role. There was a strong symbolic role associated with feeding, signifying that the patient hadn't been abandoned. When patients were able to swallow, clinicians were in agreement that they would be given food as part of meeting their basic care needs. However, assisting the patient with this basic task was given a low priority. This was evident in the lack of training given to nurses on how to feed patients.

> ***Nurse INA4b*** *: None…oh you get no training on feeding….but at least I had had children so that helped….I have seen people come from a shop and maybe they have been a domestic cleaner on the ward and then gone on to be an auxiliary and they have been asked….anybody is asked to feed people….*

Despite the low value given to assisting feeding, it was clear that all clinicians were in agreement that oral diet intake was a basic care need, and would be offered to all patients who could swallow.

ANH moved feeding from being a low level nursing task to a higher order technical task. As a result, there was greater variability of opinion about whether this was basic care or treatment. This was evident in the terms that the clinicians used to describe ANH in particular situations. For example, the term nutrition was largely used in relation to ANH and in the context of treatment. However, there were occasions when the clinicians referred to ANH as proving 'basic food and drink needs', hence being viewed in these cases as basic care provision.
In the context of withholding or withdrawal of ANH, clinicians never talked about withdrawing food and drink, and only discussed hypothetical withdrawal of ANH in terms of cessation of a treatment regime.
It is clear therefore, that both the mode of feeding and the symbolic impact of the intervention were strong factors affecting views on whether nutrition was basic care or treatment.

12.4.1.1.3. The influence of ethics

Alongside the personal beliefs about basic care and the extent of clinical responsibility to provide this, there were other features of providing care for patients that appeared to differ between professional groups. For example, formal training of doctors on ethical issues was reflected in interviews with medical staff, who referred to formal ethical frameworks. In general, doctors shared a view that clinical and ethical issues were theoretically distinct, and that they would seek external support for ethical dilemmas.

> ***Consultant IM2b*** *: I mean if there are medical questions about what to do I would ask another doctor….. but if its perfectly obvious to me medically what is going on and you are asking the other physician to essentially give you an ethical opinion then I would probably get my…..ethical opinion from somewhere else…*

The lack of formal training on ethics was identified by some other clinicians as contributing to their difficulties with clinical dilemmas. It was clear from the data that many non medical clinicians interpreted the current legal guidance on withholding and withdrawing as being synonymous with ethical guidance.

> ***Dietitian ID1b*** *: I think you get all sorts of issues obviously once you have started nutritional feeding in both NG and PEG……you get the ethical questions…when you….you know about withdrawing it…..you also get a*

question sometimes if the patient doesn't want it but the family do....it's a minefield...I hate it....and we don't get training on it...

In cases of great clinical uncertainty, labelling the source of uncertainty as ethical led medical clinicians to seek a second opinion, and non-medical clinicians to 'step back' from their involvement. In the following for example, nurse IN1b expressed obvious relief at being able to 'avoid' the problematic ethical issues by 'opting out'.

***Nurse IN1b** : with feeding....it's the ethics of it all isn't it.....it's too difficult for me...I pass that to the doctors to deal with.....*

This situation was recounted and observed repeatedly throughout the study. Where cases were perceived to be ethically difficult, clinicians more readily expressed the limits of their clinical competence to deal with the case in the 'right' way. In these cases, their personal discomfort ensured that they actively pursued support in decision making.

***Dietitian ID2b** : I think there was one case that got a bit complicated to do with ethics, I made sure that got taken out of my hands and given to a senior dietitian because it was too complicated for me....*

In summary, the clinicians have a personal conscience about what their clinical responsibility is for a patient. When considering 'caring' for a patient, it was seen that this view is informed by educational training and defined roles, but that they are also subject to personal interpretation. These issues will now be discussed in terms of how they relate to the caring environment.

12.4.1.2. Caring for the onlookers

As previously discussed, the need to care for 'onlookers' was viewed by clinicians to be a legitimate clinical role. In this case, the onlookers referred to all of those involved, such as the family, the carers and the MDT.

In terms of the clinician's clinical conscience, an extremely strong and recurring theme throughout the data related to the clinicians past experiences of patients and the outcomes of care. Clinicians felt a need to support onlookers during the process of decision making not only to help the process itself, but also to avoid any negative perceptions about how patients were managed. It was clear that previous negative

experiences had left deep personal impressions on clinicians such that they wanted to avoid any repeat experiences.

There were various ramifications of how clinical conscience influenced clinicians approaches to onlookers which will now be discussed

12.4.1.2.1. The visual impact of care

The most dominant theme in this area was the clinician's need to avoid an 'unacceptable' image of care. In most cases, this was represented in visual terms, where the visual impact of care needed to engender trust in the professionals through presenting a competent and nurturing approach. The visual and symbolic impact of giving subcutaneous fluids to patients for example, was discussed in chapter 12.2. In addition, however, there were occasions where the visual impact of care 'crossed a line' for clinicians. Non medical clinicians in particular, cited the personal discomfort associated with 'watching' a patient losing weight when nutrition was withheld. Although this view was expressed in interviews, it was not evident in the observational data.

> ***Nurse IN7a*** *: They do....especially when you think the family come in every day and you can see like they are wasting away.....we have had times and I have been like fuming where they (the doctors) have waited so long to come up with a decision that they are like we will see how they go....and it's like.....we are in week 3 and they are not able to swallow, how long are we going to go.....*

In theory, the balance between creating a view that the clinicians were neither striving too aggressively to treat, nor abandoning a patient by not treating, was key to the process of being seen to do the right thing. However, this was an extremely difficult balance to achieve.

> ***Consultant IM6a*** *: that is a difficult area which I'm still....I have a bit of a nightmare about...it doesn't happen very often but if you've got the patient who you have.....you are feeding....i.e giving treatment to and have done for a certain length of time and....erm.....you're not seeing any improvement in their condition... where do you go?....it doesn't look good and doesn't feel good when you have no idea...*

With reference to hydration, the visual and emotional impact of this intervention was clearly expressed in personal conscience terms. The issue of whether IV fluids should be maintained up to death was discussed in chapter 12.2. IV therapy sent a strong visual message that the patient had not been abandoned and was receiving a clinical intervention. There was also a commonly held assumption among patient's relatives that IV fluids had a nutritional component. However, clinicians were not always equipped with sufficient information to determine how long a patient would survive. There was always a danger that withholding for a short period of time would extend into days and weeks making an ethical decision at one point in time being subsequently unethical.

> ***Consultant IM1b*** *: but to not give fluids is...I think it's an unethical...it's something I do feel uneasy about.. particularly if it went on for long...if it was for a few hours...that would be utterly reasonable...but to go on for a long time....*

Interestingly, the relative *lack* of visual impact associated with NBM was cited as a reason for why this state receives little attention. The fact that there was no immediate link between NBM and weight loss for example, 'hides' the possible consequences of withholding nutrition.

> ***Specialist Registrar IM5b*** *: Yes.....but I think if you.....I think the unfortunate thing is....is that people don't see the consequences of delayed decisions.....and I think that's you know....Oh...you know that patient who we didn't PEG...who sat here for 2 .. yes dead ....you know.....*

Dr IM5b further stated that lack of nutrition would not be recorded as a cause of death in cases where there had been prolonged withholding of nutrition. In this study, 10 out of the 11 patients who died, were given CVA and associated pneumonia as the causes of death.

12.4.1.2.2. Fear of negative consequences

In some instances, a clinician's experience of negative outcomes in previous cases had a direct impact on ANH decisions subsequently for other patients. For some, this resulted in a preference to 'wait and see' rather than actively feed. For others, this resulted in an attempt to be more proactive with feeding. Clinicians recognised that they modified their approaches based on their past experiences with patients.

***Nurse IN2b** : I think in the past there has been....in situations where feeding has been withheld and patients deteriorate to such a state that the feeding has been an issue at a late stage in the admission and they have been PEG'd...the PEG tube has been inserted and they have not survived the PEG tube insertion....and sort of issues around if we had started feeding earlier would the patient have been able to withstand having the PEG tube inserted....you have got to use everything as a learning curve....and so....you do sort of tend to think back and think that scenario we had like this and we did it that way so we will do it this way this time...and see what is the outcome....*

In the main, clinician's views were most strongly influenced by very recent cases, and those that had been considered to be particularly problematic. In these cases, a 'collective conscience' had been generated whereby there was a shared legacy of concern. In this study, this was evident on **site a**. A number of clinicians referred to one individual case whereby the perceived negative outcome for the patient and family had left a deep impression on team members. There was frequent reference by a range of clinicians to the same patient who had been a 'difficult case' eighteen months previously. There was a sense that the outcome of his situation had deeply affected the personal conscience of each team member, and although this was shared, their sense of having 'failed' to resolve the dilemma in a satisfactory manner left a communal feeling of having 'got it wrong'. The negative consequences for previous patients 'haunted' the clinicians. This was particularly evident when patients were alive and thriving clinically, but were deemed to have a questionable Quality of Life. In these instances, the 'visual' and continuing presence of the 'living' patient served as a constant reminder of the perceived 'wrong' decision made.

***Specialist Registrar IM9a** : so he was PEG fed....and everybody felt...well..he's not going to make it.....and he has.....and he's now in his early forties and he's living in a nursing home.....with profound personality problems.....erh....aggressive.....disinhibited to his two daughters....and....so that was.....a shocker...*

***Nurse IN6a** : he is alive, with a not very good quality of life, he is in a nursing home, can't be with his children, he swears near his children which he would never have done, erh.....maybe he will get home when the children have*

left home and they can bring their friends round, but at the moment they can't do that...

This issue of 'getting it wrong', and then living with the consequences was exacerbated by the feelings of helplessness after the event. In many clinical pathways, there are review points where clinical care can be reviewed if it is no longer perceived to be creating benefit. In the case of enteral feeding however, as previously expressed in chapter 12.2, the clinicians felt trapped once the tube is insitu. When clinicians were faced with the worst case scenario in terms of QoL, their aims of care in both clinical and social terms were seriously challenged. In the following, these issues were articulated in terms of the uncertainty over whether to address clinical or social prognosis issues.

***Nurse IN6a** : The fact that they haven't died and they are not deteriorating as you would expect them to.....and I think....maybe.....I know....some PEG's probably some do go in late but then.....what have we kept them alive for?... have we done the right thing?....and I do know there have been times when it was.....thought.....oh crikey should we start, because this person is still alive.....but then the decision is made...no we will just keep them comfortable.....but I think it's hard and it's quite distressing really when they carry on and they do stay alive a while.....*

A number of clinicians talked about the importance of 'getting things right' for the patient as expressed above. It was deemed to be similarly important to get it right for the family, and for other clinicians. One key aspect of doing the right thing was ensuring that the family were fully involved in the process. This aspect has been previously discussed in the context of responsibilities and influence on decisions. In this context however, the inclusion of the family is seen to serve a different, but equally important role, that of avoiding leaving the family with a negative legacy. There was a fear that any perception that a plan had been 'forced' onto a patient without the agreement of family might result in unpleasant recriminations.
The uncertainty regarding when it was acceptable to *support* a family's viewpoint and when it was acceptable to *overrule* them was expressed by a number of clinicians. In the end, many stated that they resolved these situations by doing what 'felt right at the time'. However, involving the family did not necessarily make the decision making process easier.

***Nurse IN7a** : Possibly.....but then I just feel are you using the patient, are we doing defensive nursing, defensive medicine.....are we doing it to treat the family and appease them or doing it for the patient...or indeed for ourselves....*

In summary, the fear of negative consequences and the need to manage the process in a way that reduced any negative perceptions was a strong contributor to a clinician's sense of doing the right thing. Inherent within this approach was the clinician's need to be supported by others. This will now be discussed.

12.4.1.2.3. The importance of rapport

A recurrent theme when considering clinical conscience was the importance of good relationships for supporting clinical decision making. Clinicians raised the huge range of emotions that may be experienced by people 'at the bedside', and the need to take this into account when deciding on the right thing to do. The emotions identified ranged from anger and fear through to hope, and clinicians talked of the need to manage these responses in a way that created trust and realism.

***Specialist Registrar IM9a** : Because I usually find that they're at their most anxious.....desperately frightened....and if you can get some type of rapport at that point.....you can move on.....and put things in perspective for them...it's important for me to do that...*

Observation on the ward – after meeting with the family of 68a
***Specialist Registrar M9a** : yeah.....I have the knack of doing this....if I give them positive news...then suddenly they're going to die.....and if I do the talk of doom.....they pick up (laughs)...*
***Nurse 1** : it must be an awful part of your job doing that sort of thing....*
***Specialist Registrar M9a** : you know what....it's not.....I think because.....I think it's one of the most important things that we do.....I think it's awful....I think it's awful if you've not spoken to them.....I'd hate that.....I think it's really important.....and at least you're doing something positive for something that's really very sad....I've got to say though normally.....Thursday mornings are....a rollercoaster....'cos I see a lot of the families...and everybody just walks out sobbing.....*
***Nurse 2** : they all love her though.....there's a Dr M9a fan-club here....*

Specialist Registrar M9a *: as long as they're doing fine...then they love you.....although I do think they respect you either way...and that's important to me...*

As is evident above, open communication was considered important, not only for the positive impact on the patient's family, but also for the clinician's reputation. The importance of rapport between members of the MDT was also seen to be significant in terms of affecting the decision process.

Consultant IM3b *:if you're a shit to your nurses...you'd be....you know what I mean...I'll get the bastard Dr 3b back...that's right....and they can get in the way with your plans....yeah....you know...but if you're nice to them they're usually lovely to you.....yeah.....*

As seen, therefore, clinicians expressed the need to ensure good rapport and open communication in order to get the process right. This was seen to improve the decision making process, but also left the clinicians with some personal satisfaction that they had done the 'right thing'.

The final aspect of clinical conscience to be explored relates to the clinician's need to have a view that would be consistent with their peers. The implications of this will now be discussed.

12.4.1.3. Being a 'good clinician'

A recurring theme within clinical conscience was the clinician's needs to be 'good' at their job and to be supported in their work by their peers. Where there was clinical, legal and ethical uncertainty, clinicians reported that they would be influenced by the views and actions of their clinical colleagues. This extended from giving professional and legal advice, to seeking advice from colleagues about their clinical work. In this case, clinical conscience was profound in affirming the clinician's identity as a 'caring professional'.

12.4.1.3.1. Seeking reassurance

One way in which clinicians gained personal feedback about their clinical work was through seeking second opinions. Whilst many clinicians talked about this option as a way to facilitate decision making, others raised the importance of second opinions for their personal support. Where clinicians were uncertain about how to proceed,

seeking another clinical viewpoint enabled a 'clear conscience' that their clinical actions would be supported.

> ***Consultant IM7a*** *: my approach to that if we've got a difficulty...is that I'd get somebody else in....I'd ask somebody else to look at the case and say...do you think...and I've been asked to do this...do you think....it's right?...*

As previously indicated, some doctors raised the potential for isolation when making decisions. There were occasions in the data where the clinicians actively sought reassurance that their opinions were in-keeping with their peers. It was evident that the process of discussing patients with colleagues enabled clinicians to be clearer about the pros and cons of a course of action. Whilst this did not share the responsibility of the decision making, there was a sense that clinicians felt more secure about the decisions that they subsequently made.

> ***Consultant IM7a :*** *you have to assess the patient medically to decide.....whether that's right or wrong.....and you have to live with that..so you check out what others think.....*

As seen therefore, general principles about being a 'good clinician' affected decision making. Clinicians required personal reassurance before proceeding with confidence in uncertain clinical plans.

12.4.1.3.2. Legal precedents – setting the baseline

A recurrent theme in the data related to the contributions of legal precedent towards developing the doctor's clinical conscience. With reference to this research study, the key legal precedent cited by the medical clinicians was the outcome of the Tony Bland case. Interestingly, however, there was no mention of this case by any of the other professional groups.

The Tony Bland case generated polarised views about the rights and wrongs of ANH withdrawal. Some clinicians responded to this case by stating that they felt the outcome was wrong, and not in keeping with their own view about what should happen in these cases. Dr IM2b strongly rejected the implications of the legal precedent in respect of her clinical practice, preferring instead to be guided by her own conscience.

Consultant IM2b *: I think……in the Hillsborough case I was not in favour of the withdrawing of nutrition to him…..once we had it……..because nobody can say……what somebody else's quality of life is…..or what life is worth……..I thought that was wrong…I have to say…I don't think about that when I am working…*

Others however, accepted the outcome of the Tony Bland case as setting the baseline for clinical care. Interestingly, Dr IM9a used the Bland case as the mechanism to distance herself from the difficulties of the decision process.

Specialist Registrar IM9a *: and the withdrawal of feeding when people have got a PEG …erm……you know….the precedent's been set where that goes to court…so that's quite straightforward …*

While the legal precedent might lead to a greater number of cases being decided in court, it was not generally considered to solve the many difficulties arising in decisions for stroke patients.

Consultant IM3b *: there…there is an awareness of the…the Bland case and the vegetative state cases…and the principle that you can't starve a patient to death…which I'm sure happened…..over a course of a century ago when I was a houseman….but you know…stroke care is different to these vegetative ones….*

Dr IM3b concluded this discussion with the view that 'whatever happens, you have to sleep at night' reflecting the pervasive theme that while legal precedents created a framework, they did not replace personal judgment in individual cases. Surprisingly, three clinicians directly raised the need for 'test cases' to help determine what 'should be done'. In the following, Dr IM7a expressed the view that the situation of uncertainty would persist in stroke care for some time until legal cases offered some direction. Once more, it was apparent that more weight is given to the legal contribution when the clinical evidence vacuum persists.

Consultant IM7a *: and until…erm…maybe…you know….a case or two goes though the courts….and…we know…what we've got…I mean…up to now all we've got is…the Bland type cases…that go through the courts…erh….and that you have to get permission…..so…you know…somebody….somewhere*

is going...you know.....will end up like that...I see...and then I suppose we'll get an adjudication (for stroke)....but if these all have to go...through the courts...we have a long wait for the answers...

In summary, this section has considered the impact of clinical conscience in determining views about clinical care. As seen, these issues relate to views and behaviour associated with being a clinical professional. There was a sense that clinicians felt that they would be judged for their actions and opinions in the clinical context.

Having considered the aspects of personal conscience that were directly linked to the professional role, this chapter will now go on to explore the other main dimension, that of social conscience.

12.4.2. Social Conscience

Social conscience refers to those aspects of the clinician's beliefs that have been generated from their wider roles within society. This might include their personal role as a family member, or linked to their interests and activities that are aside from their employment. Clinician's held different beliefs, values and experiences which made this component of decision making highly variable.

Social conscience will be explored in terms of the potential impact on nutritional decisions as seen in the data. These aspects will now be discussed under the following headings

- Personal Beliefs
- Being a 'good person'
- Personal acceptability of ANH
- Being 'true' to themselves

12.4.2.1. Personal Beliefs

Within the theme of personal beliefs, there were many issues that contributed to a clinician's social conscience. The personal beliefs expressed were sometimes directly attributed to their general moral or religious beliefs. However, at other times beliefs were described in terms of 'humanitarian' values.

The clinician's personal beliefs were most overtly expressed when talking about the ANH interventions, largely because these are associated with 'end-of-life' issues. The impact of these social conscience issues will now be discussed.

12.4.2.1.1. Religious Beliefs

For some clinicians, it was clear that ANH decisions were directly affected by their own personal religious background or viewpoint. In some cases, this gave clinicians a consistent baseline from which to operate. For others, their personal faith background generated a degree of uncertainty over what would be considered right or wrong when making decisions.

Themes coded to 'religion' within the data were isolated to those references to an 'institutionalised' or widely acknowledged faith. That is to say, only those situations in which a clinician directly stated that their religious views or upbringing influenced their decision processes were included within religion as a coding category. This was especially important to the process of analysis, in that this issue is one in which there could be highly subjective interpretations on the nature of faith. It was important in the data to isolate those aspects that the clinicians *themselves* attributed to their religious views. It is for this reason, that religion was coded independently from other related concepts of morality and general beliefs.

As stated, some clinicians were aware that their religious perspective directly influenced a particular view on ANH. For example, Dr IM10a expressed a 'rigid' stance over withdrawal of ANH, based on his religious beliefs.

> ***Consultant IM10a*** *: No...I mean....that's...I am a believer....erh...in.....addition to being a medical practitioner...I believe in God....I don't think it is in our hands to decide....that's....affects my decisions somehow.....so...I do not withdraw feeding....nutritional support.....but....I could live with not initiating nutritional support....*

Some clinicians cited cases where their religious backgrounds encouraged an opposing perspective. Dr IM9a, although still calling herself a 'practising Catholic', was clear that some aspects of her clinical thinking were markedly at odds with her religious beliefs. She expressed a view that the church can be 'out of touch' with the clinical reality, and that her faith was used at times to challenge critical thinking. In this way, she acknowledged that her faith gives her sufficient strength to oppose the teachings of the church if her conscience was strongly opposed to the objective guidance.

> ***Specialist Registrar IM9a*** *: Bizarrely.....a strong Catholic background.....and being a practising Catholic...one thing I cannot bear is...erm.....sentimentality and dogmatic thinking about...erm.....preserving*

life at all costs.....when you're not really talking about that...sometimes the average church-goer has no idea of the reality of these issues...

The 'life-prolonging' technologies within healthcare (including ANH) provided contemporary challenges for clinicians who had some religious basis for their views on end-of-life issues. The fact that natural death can be manipulated or delayed created difficulties for those who were conscious of not wanting to 'play God.' Preventing death appeared to benefit a patient where as prolonging life had the implication of potential harm. This tension was highlighted within ANH decisions after stroke in that the issue of artificial feeding appeared qualitatively different to other interventions (such as giving antibiotics) in terms of their personal conscience.

***Nurse IN6a** : I was brought up a Catholic, part of me thinks that...I am not sure where I am up to with God anymore, but I think he is there, I think he is good, overall I think that is where I am at with him, there is a part of me that feels maybe he gave some people with strokes...swallowing problems so that they didn't have to live with it.....but then we have all this technology that we can use, and has he given us that?*

In addition to the religious views held by some clinicians, it was clear that the religious beliefs of the patient and family were influential on nutrition and hydration decisions.

It was evident that whilst clinicians were respectful of the religious viewpoints expressed, there was potential for some conflict at times if the patient's belief did not match their views. This point is particularly interesting in that it is not necessarily the clinical views of the team that were relevant here, but the personal conscience of the clinicians in allowing them to support the patient or family's wishes. For example, the clinicians stated that they would have to support the views of a patient if they refused treatment on religious grounds. If, however, the family refused treatment on behalf of a patient lacking capacity, clinicians were unanimous in their view that they would seek further advice, irrespective of the patient's expected prognosis. This highlights the role of the clinician's own conscience to act as a patient's 'guardian'. This view is powerfully expressed by nurse IN2b as follows.

***Nurse IN2b** : Jehovah's Witnesses....what a nightmare.....I've only seen one case....the family wouldn't let us do what we thought was right, so we got the*

solicitors involved in the end....even if the patient was going to die...we couldn't just stand by...

This situation was echoed in a less explicit manner by Dr IM7a who suggested that there were 'covert' ways in which clinicians could carry out interventions that were more consistent with their own personal beliefs. Despite the importance placed on involving a patient's family, it was evident that the family view could only be supported if it fell broadly in line with the clinician's personal conscience.

***Consultant IM7a** : only a few percentage (of families) will say....no....life is life....you carry on.....you must not stop and...whatever... however, there are subtle ways....(laughs) which...we can still carry on...and yet....given that it's not making any difference....erh...then....Ok...we can still do it....*

Some clinicians raised the fact that it was increasingly problematic to accommodate religious perspectives in a pluralist society. Different interpretations within faith groups were acknowledged and there was a feeling that clinical plans were affected in cases where strong religious views were expressed.

***Consultant IM3b** : yes.....you have to look at...everyone is individual and unique....you know....well.....whether you say you're God's child or not....but everybody's circumstance is unique....and what's OK for one is not OK for another...it's so difficult...but you HAVE to make a decision sooner or later....*

There was an acknowledgement by some clinicians that religious views and cultural beliefs were inextricably linked to ANH decisions and other 'end-of-life' issues. The plurality of religious belief in the UK adds to the complexity for the clinician, with Dr IM10a suggesting that the increasingly diverse social 'mix' in the UK is resulting in increasing uncertainty over how to proceed in some healthcare decisions. This being the case, the view previously expressed that ANH decisions will become more complex as technologies and legal views develop was further supported by the impact of increasingly diverse religious and cultural views.

***Consultant IM10a** : it's maybe a religious thing....you know...in Saudi Arabia where I know a Professor who works.....you know he'll say someone's' very ill....and then he'll say...well....it's all in the hands of Allah*

now...he'll do what he can...it's all in the hands of Allah....and they accept that....and if he dies it's the will of Allah...and we don't have quite that same perception...because we're a secular society....it's getting more difficult...

In summary therefore, religious views were seen to play a significant role in the clinician's personal and social beliefs and in doing so, informed their views on nutritional interventions in certain circumstances. The impact of views on morality will now be discussed.

12.4.2.1.2. Beliefs about Morality

Issues of morality were pervasive throughout the data. They were usually expressed as universal truths which dictated the minimum standards of care. As such, there were parallels with the way in which views were expressed about basic care.

> ***Consultant IM1b** : I mean I don't feel...you can walk away and let people die without doing the minimum....amount for them....so I think your views do....do influence how you are...*

Within the context of morality, clinician's referred to judgment not just by their colleagues and professional peers, but also by the wider society. There was a requirement to act as a 'moral' person, ensuring that all patients were accorded respect and dignity. These essential components of care were applicable even after death.

> ***Consultant IM1b** : I think in terms of religion.....religion comes into it...because it's your humanity and how you feel about people and I don't think that's one religion...I think that's all religion...I think....but.....people without...who are atheists are often the most religious of all....I don't mean that in any nasty way....but it does temper how you feel....*

> ***Nurse IN4b** : if we know we have a lady or a man that is going to die today, we check that they are clean and that, but I wouldn't dream of going in and knocking them about, that's the wrong expression but to bed bath them..... you can do that for the poor soul when he has passed away....can't you...*

Morality emerged very strongly in the context of nutritional interventions and stroke care. In cases where clinicians believed that PEG insertion was not in the patient's best interests, this was often described in social terms of being an infringement of their dignity. Many clinicians believed that PEG tubes in particular prolonged an 'undignified life' to the extent where, on occasions, the PEG tube (rather than the Quality of Life) became synonymous with a 'lack of dignity'.

> ***Nurse IN4b*** *: and I don't know how many patients I have seen go for a PEG and then die.....I am not ageist or anything but I do think people should be left....or able to die with dignity rather than....people should be made comfortable, pain free, fear free but sometimes I think things are taken too far for too long.....sometimes I don't agree that a PEG is humane care....*

Particular challenges to maintaining patient dignity arose in relation to patients who had dislodged or removed the tube. Restraining a patient to re-insert the tube was considered to be highly undignified and potentially abusive. Even in situations where clinicians expressed a belief that the enteral feeding would be in the patient's best interests, there was an obvious reluctance to re-insert the tubes too often, or indeed to restrain the patient to prevent this from occurring. As previously indicated, clinicians were unable to ascertain whether the patient was in fact trying to 'refuse' tube feeding, hence they struggled with their conscience about how much to persist. It was clear that in many cases, frequent re-passing of an NGT that had been 'pulled out' by a patient was interpreted as the patient 'wanting to die' rather than related to physical agitation.

> ***Specialist Nurse IN6a*** *: I think....if you have patients pulling the tube out all the time, I know sometimes they can be confused but I think.....we also need to be just checking how confused they are, and what message are they telling us....*

Given this underlying perception, it was not surprising that clinicians questioned the morality of 'forcing' a patient to accept interventions. There was widespread consensus that clinicians should never physically restrain a patient in order to keep an NGT or a PEG feeding tube in place. However, the social acceptability of restraining patients was also believed to have changed, with clinicians referring to a time in which they were allowed to prevent a patient from pulling out a tube. There

was recognition that over time, what was possible had been diluted by what was currently socially acceptable

> ***Consultant IM8a*** *: Oh yes....we used to sort of.....put them in sort of bandages so that they were like a boxing glove....just to stop them pulling tubes and drains out....you know.....you are not allowed to do it now....you can't restrain patients anymore.....even though it's for their own good.....it makes it very difficult to keep things in sometimes.....*

Despite physical restraints being considered unacceptable, many clinicians were comfortable with using pharmaceutical sedation as a means to restrain a patient.

> ***Specialist Registrar IM9a*** *: I've never used physical restraints and I would feel that I was assaulting a patient who did that...even if...you know their agitation...that they weren't legally capable...I would not be happy with using something physical.....saying that....of course we can use the chemical..... kosh...(laughs) ....and sedate these patients.....*

Clinicians reported that they would sedate patients in extreme cases to keep nutritional interventions in place. However, this was not observed during this study. Morality based thinking was evident through much of the data when clinician's regularly tried to 'place' themselves in the patient's position. Clinician's frequently used the default view of 'do unto others' as a moral guide to what was acceptable practice. This was not expressed in terms of religion, but more in basic humanitarian terms of how they would expect others to treat them or their family.

> ***Consultant IM1b*** *: there's no right or wrong....but what is...you know....what would I like done to me....in this situation...or my family.....or my mother....suppose it was my mother in that bed....what would I want done....*

Clinician's recognised the complexity and impossibility of knowing exactly what each patient would want, so they drew on a fundamental precept of humanity – that being, what is good enough for *them* must be good enough for others. This highlights the fact that in the absence of universal guidance, there were some instances when personal views on morality were the most useful source of guidance available for clinicians.

Consultant IM3b *: While I know we are all different.....I treat my patients as if they were my father mother brother or sister...OK.....and I try and treat them...as you can see in the photos behind you....as...if it was one of those....Ok.....erm.....I don't think I can put it better than that .....*

In summary therefore, issues and beliefs about personal morality have a profound effect on clinicians' decision making. It is clear that doing what they 'feel to be right' has a powerful influence over their views about nutrition and hydration interventions.

12.4.2.2. Being a 'good person'

An additional component of their social conscience related to the clinician's notion of being a good person. This aspect was measured in relation to their role as a family member or personal friend.

One key theme within this area was the degree to which clinicians 'took their work home with them'. Some clinicians talked about having 'sleepless nights' (Dr M7a, Dr M6a) when they had 'difficult patients'. Others talked about feeling the need to 'offload' to their own family members at times. It was difficult to establish the degree to which discussions with their own family influenced their decisions, but it was clear that at times, they used this mechanism to get another perspective on difficult cases. The words of Nurse IN4b below highlights her personal need to check her view with those of a more objective social peer.

Nurse IN4b *: sometimes I go home and rant...you know....kick the dog (laughs)...but when I discuss things with my husband...I do get a sense of reality again...we can be in a warped world in the hospital....*

The particularly fine line between withholding or withdrawing nutritional interventions and the views of society on euthanasia was informed by elements falling within social conscience. Many clinicians expressed the view that whilst euthanasia was clearly illegal and something they would not do, they struggled at times to support a patient's prolonged death without feeling some 'guilt' over their role. This tension seemingly could never be resolved within their personal conscience, unless the clinician was able to attribute it to solid clinical foundations. That is to say, there was an overwhelming view that 'killing' would never be socially acceptable, where as 'letting die' could be socially acceptable if it was clinically supported.

This is shown in the words of Dr IM3b below.

> ***Consultant IM3b*** *: It's just not....it's just not the thing to do really is it.....(smiling) we're not into euthanasia...you know.....but we can let them die if that's the best thing....*

These issues were influential on nutritional decisions in that the social acceptability of the nutritional options was fundamental to the clinician's beliefs and decisions. Once more, the perceptions about the interventions themselves influenced the social conscience over what would be best for the patient. Dr IM10a stated this clearly in terms of his beliefs about ANH withdrawal. This was not attributable to his clinical beliefs, but instead to his social conscience about the potential negative impact of his actions on his beliefs about himself as a humane individual.

> ***Consultant IM10a*** *: but let us say the patient was more stable to the point that I feel that well...there is nothing to prevent me offering nutritional support....then I find it difficult at some point to withdraw that....nutritional support...because by doing so...I am practising something which I do not...you know...believe in.....it becomes more like euthanasia...even though you know that the patients outlook now...at this stage doesn't look good....I wouldn't be a good person if I did otherwise...*

When considering the impact of being a 'good person' it was clear that clinicians could not be objective in decision making. Although their clinical role was the default position in difficult cases, clinicians gave valuable insight into the emotional and personal legacy of having a personal conscience. Clinician's often expressed these feelings in relation to their own family role. This was highlighted by two consultants, as seen below.

> ***Consultant IM7a*** *: you know...it's...that hospital killed my mum and that doctor in particular...you know...let her die.....and shouldn't have done....and....and we are.....and....you know....that's not the position that I think...you know.....most doctors want to be in....we have mothers and fathers too...*

> ***Consultant IM8a*** *: I think Drs have to be brave sometimes and make a decision not to treat people.....and its very difficult not to treat people*

because everybody expects you to do something...but we are only human though....

The need to act in accordance within expected moral boundaries of broader society is, therefore, seen to be influential for clinicians when making decisions.

12.4.2.3. Personal acceptability of ANH

This theme echoes elements within chapter 12.1 where issues relating to the patient's Quality of Life and patient 'hauntings' were discussed.
Where this aspect provides further insight, however, is the extent to which clinicians personalised the impact of their decisions.
Having had experience of ANH decisions and outcomes in the past, many clinicians had developed a personal belief about what they would want for themselves or their family. This was not expressed in clinical terms, but instead was captured in their views about what they would consider to be morally acceptable for human beings. Whilst some participants stated that they would try to be objective in decision making, others stated with some honesty, that they knew their personal views affected the recommendations they made at times. This was clear in the words of Dr M8a below

> ***Consultant IM8a*** *: I am often distressed by...attempts at keeping alive in persistent...and near persistent vegetative states at all costs...and I find that....horrific.....erm.....and I think it's something that I perhaps think a bit more about because those concepts were brought up throughout my education and my...spiritual life.....erm....and so I've had to personally feel sure about those particularly as a practising doctor.....and so I think.....sometimes that does get in the way...*

There were clear personal views on whether clinicians themselves would want enteral feeding if they were ever in such a position. It was evident that there was little ambivalence about this, with nearly all of the participants stating strong views either to accept ANH or to reject it for themselves or their family. This was rarely expressed with qualification, but was more of a 'definitely would' or 'definitely wouldn't' response. Some of the influences over these positions will now be discussed.

Many of the clinicians expressed views on whether they would want artificial feeding in any circumstances. For some clinicians, this related to dignity and independence, for others, the issue of feeding was strongly linked to Quality of Life. In general, when linked to QoL, there was a view that enteral feeding was generally consistent with a poor QoL.

> ***Specialist Registrar IM5b*** *: I wouldn't want to be fed no.....we need to.....in my opinion differentiate between living and existing and I would rather have.....two good quality years of life than 5 of just merely existing...*

Some clinicians made a distinction in their personal choices about which mode of feeding they would consider, and which would be intolerable. Once more, this was linked to their views about the social impact and perceived QoL. In general, clinicians who felt they *would* consider ANH were more positive about NGT's as an option compared to PEG tubes. This was linked to their beliefs about being 'trapped' in the position of having poor QoL as discussed in chapter 12.1. In the following, the Speech and Language Therapist S4a states her non-negotiable personal view on the two feeding options.

> ***Speech and Language Therapist IS4a*** *: I would have an NG yes.....but I wouldn't have a PEG.....definitely not....it's there forever...*

In addition, it was seen that the clinician's social conscience about whether enteral feeding was 'right' was, in part, informed by the views of their own family. This was seen to be influential in that if the clinician's felt a sense of 'do unto others', these perspectives inevitably guided their views on what would be a humane position. One such view was expressed by the dietitian ID1b below

> ***Dietitian ID1b*** *: I know from my family, they wouldn't want enteral feeding for example if they had a severe stroke, and I know from my father specifically....if he couldn't do his activities of daily living, especially if he lost the use of his hands....because he does model trains that kind of thing, he wouldn't be interested, because he has always said I wouldn't want to continue on being like that.....*

A final point that could not apply to all participants but was seen to be extremely significant where it existed, was the impact of personal views linked to having had a

member of the family on enteral feeding. On interviewing nurse participant N7a in her role as a nurse within a stroke unit context, she revealed that her father had a stroke and was subsequently fed via a PEG tube. Her views about PEG feeding were clearly influenced by this experience.

> ***Nurse IN7a*** *: so I think maybe that is.....at the back of my mind.....when I see like families, and I always tell them, I say from personal experience a PEG isn't always the best thing, and maybe I shouldn't maybe the Drs would shoot me if they heard me say it but.....I just think I have been on the other side of the fence as a relative so.....and it has an impact on the family...because my brother was 12 and he thought the PEG would make dad better and it didn't.....so I think he was like waiting for my dad to get up and walk and talk and things and he never did.....how can I not let that influence me?.....*

In summary, the issues within personal conscience are seen to arise from and persist within the two dimensions of clinical and social conscience.

12.4.2.4. Being 'true' to themselves

This final point relating to personal conscience was extremely powerful in the data. The issue of being 'true' to themselves was an 'in-vivo' code, lifted directly from a participant quote. As seen in the following Dr IM7a's own integrity is a prevailing issue when making decisions in uncertainty.

> ***Consultant IM7a*** *: I still...might have got things wrong.....and you have to accept that....and I haven't got a problem with that....I haven't got a problem...you know...if we've not done the right thing for a patient.....admitting it...you know...that's not a problem to me that.....I think...you know...I don't think we can be right all of the time.....but we must be true to ourselves....*

This issue of personal integrity varied according to each situation, hence it is a factor that cannot be directly predicted or exactly replicated. It is clear, however, that certain situations reached a critical point whereby the clinician's gut instinct or tolerance of the situation was surpassed. At this point, the issue of being true to personal beliefs became fundamental. In the following ward observation, Dr M9a's

statement 'I can't see him like this for much longer' indicates that she has reached the threshold of her personal conscience, and this then overruled any other aspect of care for 68a.

> ***Ward Round – Patient participant 68a***
> ***Nurse*** *: Just the person.....can I have a word about Mr 68a?.....*
> ***Specialist Registrar Dr M9a*** *: yes...how's he doing?....*
> ***Nurse*** *: I think he's getting overloaded.....he has IV and NG up and he looks.....*
> ***Specialist Registrar Dr M9a*** *: is he still chesty?.....*
> ***Nurse*** *: he's still as chesty.....*
> ***Specialist Registrar Dr M9a*** *: He's poorly isn't he.....I haven't seen the family since last Thursday...do they realise he's gone down?....*
> ***Nurse*** *: they were in last night...and they were quite upset....*
> ***Specialist Registrar Dr M9a*** *: maybe I'll see them tomorrow.....*
> ***Nurse*** *: Ok....*
> ***Specialist Registrar Dr M9a*** *: when does he have his feed....'cos we need to sort out his sliding scale with that and his IV.....*
> ***Nurse*** *: er....it's on his bed.....*
> *(both the nurse and Dr M9a walk into side room to see 68a and return after two minutes)*
> ***Specialist Registrar Dr M9a*** *: ok...I'll write his notes up....can you ring his family then.....I really think we've reached the point where I need to have the nitty gritty discussion....I think we have to move to syringe driver now....I can't see him like this for much longer...*
> ***Nurse*** *: yeah.....Ok....I'll see them later....*

The issue of personal conscience was an aspect that clinicians acknowledged, whilst recognising the extent to which this influenced their clinical decisions. It was evident that they had a need to maintain an external *impression* of objectivity, and in doing so, would only consider their personal feelings when it came to a critical threshold. In the following, Dr M5b suggests that some delays in decision making were deliberately planned so as to give the impression of thorough management.

> ***Specialist Registrar IM5b*** *: I'm saying that.....I'm saying that if I were to....or I am sure if you were to audit this and ask the majority of people...or ask people who were involved in decision making.....right what was their*

hunch as soon as they saw the patient first time...and then carry on and find out what the actual decision was in the end.....I would be surprised if it was not far off 100% what the initial hunch was....now I think if that's the case and it really is approaching 95 100%.....which I would be surprised if it isn't....then we are really doing something wrong in-between the two points aren't we....

As can be seen, therefore, there are various events over the course of a patient's hospital admission in which the clinician had their own personal conscience challenged. The influence of these factors was profound. The data suggested that there were issues within personal conscience that appeared to have been developed though a social context, and were maintained by the clinician's role in the social world. These factors evolved and developed over the course of the patient's hospital admission.

12.5. Personal Conscience – data sources

As has been apparent throughout this chapter, issues of personal conscience were most overtly expressed during the interview data. There were few instances in the naturalistic data where clinicians directly (or openly) acknowledged their own feelings about a patient or their care. Where these instances occurred, it was seen that they had profound effects on the clinician in terms of certainty to either act or withhold an intervention.

12.6. Summary

In summary, this chapter has explored the Personal Conscience dimension as one of the influencing factors within decision making after stroke. It was clear that whilst this issue was not routinely acknowledged or discussed in a broad forum during decision making, it was profoundly influential in the clinician's perceptions of 'doing the right thing'. Each clinician had a clinical conscience, created and maintained by their professional role, and a social conscience which was based in their humanitarian values as a human being. When clinicians were uncertain regarding nutritional interventions, it was clear that these 'feelings' contributed to the level of uncertainty in some cases. However, although generally dormant, issues of personal conscience did move the clinician towards more certainty if their personal threshold was reached.

These issues will be discussed further in chapter 13.

13. The process of decision making

In the previous chapters, each factor influencing the nutritional decision has been presented as an isolated component of the process. In reality, the decision is affected by the way in which these components present themselves and interact. The purpose of this chapter is to discuss the evolutionary process by which clinicians weigh up the information that determines the patient's best interests. The chapter will provide examples of the relative influences rather than an exhaustive account of the possibilities. In doing so, it offers a brief description of decision making in practice.

13.1. Best Interests

Best Interests was the phrase most often used to describe how clinicians resolved competing courses of action when making nutritional decisions for patients. From the data, it was evident that the normative pathway of not to feed directly reflected the clinicians views on harms and benefits of nutritional interventions. As previously identified, commencing feeding after stroke had to fulfil the first criterion of 'not doing harm' before the benefits of feeding were considered.

> ***Consultant IM4b*** *: You would assume that you should do the best for the patient....erm....as long as you are not going to do any harm and that the treatment which you are going to give is going to be beneficial to the patient....I think those are the basic principles of determining what is in the best interests of the patient.....ie that the patient is likely to benefit from that treatment and two....that that treatment is unlikely to produce any harm that is greater than the treatment being given..*

The term best interests was the 'catch-all' phrase that captured the legal, clinical and sometimes philosophical issues behind a clinician's decision. As previously identified, the notion of best interests operated on various levels when making clinical decisions. Some of the most difficult clinical cases observed and described, were characterised by the fact that the patient could not state their own views. In these cases, clinician's were required to form a view of what would be best for the patient and others. The components of this evolutionary process were previously illustrated as figure 3 in chapter 10.

13.2. Decision Outcomes: To feed or not to feed?

When making decisions for nutrition after stroke, there were potential options to commence, withhold or withdraw feeding at a number of junctures. These 'decision points' could be regarded as a series of 'outcomes' in nutritional decision making. In the data, the decisions to commence or withhold feeding were revisited for each patient at different points. In each case, the relative impact of the four key influences varied. These issues will now be discussed under the following headings.

- Explicit decisions to withhold nutritional interventions
- Non-explicit withholding of nutritional interventions
- Decisions to commence nutritional interventions
- Withdrawal of nutritional interventions

13.2.1. Explicit decisions to withhold nutritional interventions

Analysis of the study data revealed that there were instances when the normative pathway of 'not to feed' was maintained through explicit decisions to withhold nutrition from a patient. In these cases, there was a clear and certain decision that feeding would generate more harm than benefit.

In some cases, where there was a decision not to feed, it was clear that the clinician's views about the *patient's prognosis* carried the greatest influence. For example, some patients had a very certain poor prognosis, and this provided grounds for limited intervention. In the case of patient 65a, the clinician's view was such that the patient was imminently going to die, hence nutrition was withheld, along with other 'active interventions'. This reinforced the view that feeding only occurred when clinicians were actively treating a patient. The anticipation of a grave clinical outlook was in itself sufficient to justify explicit withholding of nutrition, as seen below.

> ***Medical notes patient 65a (day 2 after admission)***
> *'poor prognosis, not for antibiotics – unnecessary. Not for resus. For TLC only. No active interventions' (SHO)*

> ***Medical notes – patient 68a (day 3 after admission)***
> *'Keep comfortable – discussed with family. Explained the diagnosis and likely prognosis. Agree not for resus.' (SHO)*

' family understands about patients condition. Keep NBM with IVI.' (Staff Nurse)

In other cases, an uncertain prognosis encouraged the clinician's to hold back from 'risky' interventions to avoid any potential harm. In the following example, withholding food was seen by clinicians to place patients in the best possible position for recovery by removing the risk of aspiration.

Medical notes – patient 1pa – (day 9 after admission)
Discussed with family; reinforced long term job - Outlook/prognosis uncertain/degree of recovery unknown/variable. Explained likely to take weeks/months in order to improve. At this stage, keep safe from chest infection with NBM and IVI only' (SHO)

Other examples from the data highlighted the potential influence of *beliefs about the nutrition interventions* themselves. Patient 22a was alert and was deemed to have capacity on day 9 after admission. At this stage, her prognosis for both surviving the stroke and her ultimate QoL were felt to be good. The clinician's strong beliefs about the risks of aspiration with oral diet resulted in a decision to withhold oral feeding at this stage.

Medical notes patient 22a (day 9 after admission)
'Mrs 22a asking for drinks. Reasons why they are being withheld from her given'

Personal Conscience was the most influential factor in the case of patient 7b, where the consultant had previous knowledge of the patient's views and wishes relating to artificial nutrition. Patient 7b had had a PEG following a stroke five years previously. She had insisted at that point that she wanted to eat and drink oral diet despite the possible risks of aspiration, and her PEG had subsequently been removed. On this admission, patient 7b was neither gravely ill, nor displaying signs that enteral feeding would be of particular risk. However, her previously expressed views were highly regarded. On this admission, patient 7b presented with cognitive difficulties that precluded her involvement in the decision. However, having had some previous knowledge of the patient, the consultant made a decision based on what he 'felt was right' in her case. In this case, the decision was to withhold feeding. After a period of time had elapsed, this decision was reviewed to allow 7b to take *oral* diet, despite

a likely aspiration risk. The 'usual' approach to maintain NBM when there was a risk of aspiration was therefore overruled by the personal conscience issues of supporting the perceived wishes of the patient.

> ***Medical Notes patient 7b***
> *'in view of past history, not for PEG or NGT. To take oral diet despite risks of aspiration' (SHO)*

As has been demonstrated, in cases where decisions were explicitly made to withhold feeding, there were often different reasons for the same outcome.

13.2.2. Non-explicit withholding of nutritional interventions

From the data, the normative pathway of NBM generated a 'non-explicit' withholding of nutritional interventions in some patients. These situations were characterised by the 'wait and see' response, where nutritional decisions were seen to be 'pending'. There were many examples of this in the data and where this occurred, it was the result of different influences.

The first examples given below were based on the clinician's *beliefs about the nutritional interventions.* In the case of patient 7a, the plan regarding feeding is left open and ambiguous, with the use of the (?) denoting uncertainty about how to proceed. The consequence was that there was no explicit plan for nutrition, other than to await the ward round. In the interim period of three days, there was no recorded attempt to feed the patient. At this point, 7a's prognosis was felt to be good, and it was still 'early days' in the admission. In the following, possible courses of action were identified but not pursued.

> ***Medical notes – patient 7a (day 3 after admission)***
> *'remains NBM with IVI. Has SLT seen yet?*
> *??for NGT until safe? Await Ward Round.' (HO)*

These examples differed from those seen under explicit withholding in that the decision to withhold feeding was never clearly stated. Characteristic of this response was the regular reference to something being 'considered' rather than something being 'actioned'. The plan to 'query' or 'consider' an action was, on occasions, seen to legitimise 'inaction' and this persisted over prolonged periods without resolution or

a sense of urgency. This was often observed when uncertainty over harms/benefits persisted, with no convincing evidence from the influential factors to challenge the 'do not feed' position. In the following example of patient 23b, the uncertainty about the nature of the swallowing problem is evident. The team were uncertain about whether a PEG tube would be beneficial, based on whether this was likely to be a short or long term swallowing problem, and whether surgical insertion of a tube would be too invasive. In this case, there was no overt decision to withhold PEG feeding, but equally, there was no decision to proceed with PEG feeding. The result was that of non-explicit withholding until evidence convinced them that feeding may be of benefit. In this case therefore, uncertainty in beliefs about the nutritional interventions created the greatest influence.

> ***Medical notes 23b (day 16 after admission)***
> *'swallowing mixed. ?? for PEG' (SHO)*
> *'note consideration for PEG by SHO today – alternative feeding issues do need further discussion' (SLT)*
> *Medical notes 23b (day 17 after admission)*
> *'Feeding needs to be considered' (SHO)*
> *Medical notes 23b (day 18 after admission)*
> *'Considering feeding'*

Other examples from the data revealed the combined influence of *views on prognosis* and *views on nutritional interventions* in leading to non-explicit withholding. In the case of patient 12b for example, the uncertainty about her prognosis led to an interim position of not providing nutrition. This was not in the belief that she was dying (hence nutrition may be 'futile') but instead due to uncertainty about whether feeding would be of harm or benefit at this stage. In this case 'Wait and see' refers to withholding most interventions (including nutrition), with the implication that decisions will be made at a later point.

> ***Medical notes – patient 12b (day 9 after admission)***
> *'ISQ[23] – no real change. Maintain IVI. Wait and see'*

---

[23] ISQ – In Status Quo

As can be seen from these examples, there were a variety of influences at different points that resulted in non-explicit withholding of nutrition. This practice was observed to be a regular 'holding position' at numerous points within each patient's recovery. This was typically observed when issues or factors emerged that returned clinicians to a state of uncertainty about the harm/benefit analysis.

13.2.3. Decisions to commence nutritional interventions

There were examples in the data when decisions were made to commence nutrition, either orally or enterally (via NGT or PEG). As with the decisions to withhold nutrition, the decisions to commence feeding were reached following consideration of a variety of factors but in all of these instances, the benefits of feeding outweighed the risks.

In the first example, the clinicians based their view on feeding patient 82a by considering both his *prognosis* and their *belief about the nutritional intervention* of a PEG. It is evident from the SHO's discussion with the family that the potential 'harm' associated with PEG placement or feeding was overshadowed by the anticipated benefit he would get from the nutritional input. The degree of 'certainty' that a PEG should be commenced was evident in the confident manner in which it was discussed with 82a's family. At this point, the decision had effectively been made, with the family being informed of the plan rather than being asked to contribute to it.

> ***Telephone call made by Staff Nurse to 82a's wife :***
>
> ***Nurse 1*** *: hello is that Mrs 82a?.....the doctor wants you to come in.....you know to talk about how we're going to feed him.....No....he's not eating much again today....and the doctor wants to talk about a tube..... you know.....about feeding him.....yeah...well....could you come in this afternoon?....say.....about two thirty threeish.....ok...see you later love.....*
>
> *Subsequent meeting with Mrs 82a later that day. The SHO on the ward discussing with relatives.*
>
> ***Medical SHO*** *: right.....you know that we wanted to talk to you about Mr 82a's nutrition.....*
>
> ***Mrs 82a*** *: yes...that's right.....*
>
> ***Medical SHO*** *: has somebody already spoken to you about this?.....*
>
> ***Mrs 82a*** *: well.....the nurse said something.....but.....*

***Medical SHO** : well.....because he can't feed properly through the mouth.....we want to put a tube in his tummy to feed him.....*

***Mrs 82a** : yeah....well....he's not eating anything.....*

***Medical SHO** : mmmm.....the tube helps with that.....*

***Mrs 82a** : I see....right.....*

***Medical SHO** : so....I just want to tell you a bit about the procedure....and what we do.....*

***Mrs 82a** : yes.....*

***Medical SHO** : .....the procedure to put the tube in will be done with a general anaesthetic....and as with all general anaesthetics.....there's a risk of complications with that as well as those associated with the procedure itself.....it can cause pressure on the heart and lungs.....and obviously there's a risk of death with the procedure itself.....that's why we tell everyone about that.....about the risks.....and another thing with this operation is a risk of perforation.....but this will help to begin feeding.....and will bypass the difficulty with swallowing.....*

In the following example, both *prognosis* and *personal conscience* played a role in influencing the medical staff that patient 58a should have a PEG. In this case, the recognition that there had been no nutrition for 12 days was cited in order to illustrate that for this clinician, the situation had reached a threshold in her 'comfort zone'. Not only did this influence the decision to actively feed 58a, but there was sufficient certainty that this needed to be carried out urgently as the clinician felt some personal responsibility to ensure that the patient was fed. This unquestioning approach illustrated the potential power of personal conscience in influencing decisions.

Medical notes patient 58a (day 13 after admission)

'needs PEG unable to tolerate NGT. No food for 12/7. Booked PEG urgently for Friday afternoon.' (Specialist Registrar)

Perceived responsibility was also seen to have a significant impact in some situations where feeding was commenced. Where this occurred, the strength of views of those involved often determined the outcome. For example, in the case of patient 4b, the clinicians were seen to be uncertain about whether a PEG should be pursued until they met with the family to discuss this. Once they had met with the

family and the family actively requested PEG feeding, the decision was made. This is clear in the following example from the medical notes.

> ***Medical notes patient 4b (day 19 after admission)***
> *Morning entry : 'has had NGT. Now needs PEG?'*
> *Afternoon entry : Met wife and daughter. Risks/benefits of PEG explained. Agreed to go ahead. Referred for PEG'*

13.2.4. Withdrawal of nutritional interventions

The withdrawal of nutritional interventions refers to those instances where feeding had been commenced, but an active decision was made to withdraw it on the basis that the intervention was generating more harm than benefit.

As indicated in chapter 12.2, there were no overt decisions by the clinicians in this study to withdraw feeding, and this was supported in interviews by the universal belief that withdrawing nutrition from a patient would be 'wrong'. However, avoiding re-commencing a nutritional intervention was observed in this study. That is to say, if a feeding tube 'fell out' or was displaced, a decision was made that the tube should not be replaced. There were two main scenarios in which this took place. The first was when a patient's condition deteriorated such that feeding was no longer considered to be beneficial. The second was observed in situations where patients had had prolonged feeding, without obvious improvement in their clinical condition. In these cases, there was a decision made in advance of the tube being displaced that it would not be re-inserted if the tube was displaced at a future date. The net effect was the withdrawal of nutrition.

There were many examples in the patient data where this occurred. These have been previously cited in chapter 12.2.

The one exception in the data whereby an *active* decision was made to withdraw tube feeding was in the case of patient p2a. The major difference in this example was that the patient himself made the decision to have his PEG tube feeding withdrawn.

The factors influencing decisions not to re-insert feeding tubes were seen to be complex and echoed those where explicit decisions were made to withhold feeding. In the first example below (65a), both the patient's *prognosis* and the clinician's *beliefs about nutritional interventions* combined to generate a view that the NGT itself was harmful. In this case, the definition of harm lay in the belief that nutritional interventions were 'burdensome' (hence harmful) to patients in certain clinical

situations. This was particularly related to the act of tube insertion as well as subsequent management. The result was that although not convinced that there was sufficient harm to actively remove the NGT, the clinician saw re-insertion of the tube as constituting greater harm than benefit. This echoed the previously stated view that 'too much' intervention could be seen as aggressive rather than compassionate.

> ***Medical Notes – Patient participant 65a***
> *He's deteriorating. If NGT comes out, do not re-insert. For TLC only. Diamorphine pump to be commenced.*

An example of the combined effect of *prognosis* and *personal conscience* was demonstrated by patient 68a, where the clinician expressed a view that 'enough was enough' with active interventions.

> ***Specialist Registrar M9a about Patient participant 68a***
> *...I have spoken to the family and we have agreed to leave the NGT in place....but to suspend feeding at the moment to give him a rest.....*

The view that 68a was dying resulted in a view that they should avoid an aggressive approach, and should work instead towards 'keeping comfortable'. It was evident in this example that there was some personal discomfort attached to 'striving' to feed, and that the 'social' impact of caring carried greater influence than the perceived harm of actively intervening. The result was non-explicit withdrawing, whereby the tube was left insitu so as to give the impression of continued intervention, without the perceived burden of continuing nutrition.
As seen, there were examples in the data in which nutrition was non-explicitly withdrawn based on the belief that providing continued nutrition generated greater harms than benefits.

13.3. Summary

In summary, this chapter has discussed the evolutionary process of decision making, showing how the four influential factors combine and interact to produce different outcomes in each case. It has been shown that the same outcome can be reached by taking different factors into account, and that the same factors in different patients can lead to different outcomes.

13.4. The Research Question - Revisited

This chapter concludes the 'Findings' section of the thesis.

In order to ascertain the relative success of the study, it was necessary to consider the findings in context of the original research question. The research aim was to investigate the key factors in decision making for nutritional intake for patients who have had an acute stroke.

Chapters 9-13 have given detailed accounts of the main 'drivers' in the decision process when considering a range of nutritional interventions. The key findings identify that the process is weighted towards a plan 'not to feed' in the immediate period after stroke. Nutritional decisions were influenced by the clinician's beliefs about four key aspects at any given point in time. Estimating harms and benefits was fundamental to this process, with a preference towards precaution and risk minimisation. The net result was a decision either to maintain 'not feeding' or to 'commence feeding' based on the clinicians feelings about what constituted best interests in each individual case.

Decision making for nutrition after stroke is therefore shown to be a variable process, with an unpredictable course and outcome. The conceptual models presented encourage insight into a process that has, to date, been largely elusive to description.

The chapter that follows will discuss the contributions to research made by this study and the implications for current clinical practice.

14. Discussion

The purpose of this final chapter is to place the findings of this study in the context of clinical practice and research evidence. The chapter will first acknowledge the limitations of the study and will then proceed to discuss the clinical implications of the findings. The chapter will conclude with recommendations for future research.

14.1. The Limitations of the Study

This study has highlighted and explored the complexity of decision making in relationship to feeding stroke patients. However, before going on to explore the implications of these findings, I will examine how my methodological approach impacts upon the interpretation of findings.

There were three main areas that proved challenging in this study. These related to the design of the study, the nature of the population, and the impact of the research ethics committee process.

The study design was ambitious in order to capture the inputs to decision making from a number of people over a lengthy timescale. Given that there was only one researcher, the number of sites and patients recruited made it difficult to be present at all times. This required a pragmatic approach whereby I attended meetings and ward rounds where possible, and in the interim I observed the patients in their 'day to day' business. In this way, I applied a consistent approach to data collection, if not an entirely comprehensive one. If replicating this study, it would be beneficial to consider carrying out data collection exclusively on different study sites in order to capture all sources of information where possible. Another main difficulty affecting the design of this study related to time constraints. The study was supported financially for a defined time period and covered the costs of one researcher only. This placed necessary limits on the depth and scale of the research undertaken. One clear compromise for example, was the extent to which data saturation, as defined by Strauss and Corbin (1998, op cit), could be achieved. Data saturation around the key themes was successfully achieved. However, given the wealth of data collected, it was impossible to pursue depth analysis on 'fringe' concepts during the time available. This does not compromise the quality of analysis or the integrity of the findings presented, but reflects a methodological compromise in practical constraints.

The study population raised particular challenges in both design and data collection techniques. The patient participants were recruited when acutely ill and often lacking

mental capacity owing to their reduced consciousness or cognitive changes. This required a sensitive approach to gaining consent and data collection. Once more, a pragmatic and flexible approach was required in order to respect the privacy of those involved.

A final point related to the impact of the research ethics committee process on the study design. As the committee required details of the study design in advance, this placed necessary limits on the ability to apply 'purist' grounded theory techniques, such as theoretical sampling. In order to seek research ethics committee assent, purposive sampling was required. Once more, although creating a methodological constraint, this issue did not affect the quality of the study design or findings.

This study has, out of necessity been a small scale piece of research. The methods and methodology have been consistent with the research aims and have been successful in generating rich data and findings. To achieve greater transferability of findings, repeating this study with an increased number of participants (both patients and clinicians) and study sites would be advantageous.

14.2. The significance of the key findings

This study has identified issues relating to nutritional interventions after stroke that have not previously been identified in the literature. One key finding is that in the immediate management of stroke, the starting point is to withhold any form of nutrition. The patient is placed NBM and receives fluids only. This position is created by the clinician's beliefs about what is in the patient's best interests immediately after stroke. This is supported by three main factors as follows

- The belief that nutrition is not essential immediately after stroke
- The belief that there is a high risk of aspiration after stroke
- The belief that nutritional interventions can contribute to prolonging a poor QoL after stroke

The swallowing assessment is the starting point from which nutritional decisions are made. There follows a variable pathway, based on the influence of four key aspects identified in the data. These relate to views about the patient's prognosis, beliefs about nutrition and hydration interventions, the perceived responsibilities of those involved and the impact of personal conscience on the decision process. The decision regarding commencing, withholding or withdrawing a nutritional intervention is at the discretion of the lead clinician.

Following analysis of the data, there remains a fundamental question. Why does nutrition have such little value in the immediate medical management of stroke?

This issue will be explored under the following headings

- The status of older people
- The evidence base for nutritional interventions in stroke care
- Customs in stroke care

14.2.1. The Status of Older People

There are many factors that may contribute to the current clinical approach in stroke. One pervasive issue in the data related to the status of older people and the implications for health interventions with this client group. These will be discussed as follows

- Healthcare provision to older people
- Confusion of goals for older patients
- Patient participation in decision making

14.2.1.1. Healthcare provision to older people

Stroke services invariably have their roots in the organisational structures and philosophy of elderly care services. There were twenty patient participants in this study with an age range of 60 to 90 years (with a mean age of 76.1) in keeping with the national statistics of stroke incidence. As stroke is a disorder predominantly affecting older people, it is possible that the approach to care may be strongly influenced by views about the value of older people in society.

It is acknowledged that healthcare services have made attempts to address 'ageist' or discriminatory practice over recent years. Policy documents such as the NSF for Older People (DOH 2001) proposed 'champions for older people', a role that was created to identify and eradicate discriminatory practices. Following this, 'A new ambition for old age' (DOH 2006) and the 'Dignity in Care' initiative (DOH 2006) reinforced the message that the NHS and Social Care services recognised the historical approaches to elderly care were outdated and exclusive. Throughout these documents, the historical undervaluing of older people is acknowledged. Stroke care sits within the NSF for older people, highlighting the similar historical undervaluing of stroke services. This issue was raised by participants within this study, where the service was referred to as a 'Cinderella service' having a 'passive' approach to care.

The relatively low value placed on older people in society is extensively covered in sociological literature. Authors such as Fennell, Phillipson and Evans (1988) cite the recurring references to older people as a 'social problem'. The implied social

'burden' of ageing on health, welfare and pension systems is evident in much of the literature and is clear in the words of Simone de Beauvoir (1972) as follows

> *"Not only are there many more aged people than there were, but they no longer spontaneously integrate with the community: society is compelled to decide upon their status, and the decision can only be taken at government level. Old age has become the object of a policy" (1972:222)*

The issue of ageism and policy making in the NHS has been extensively researched. To date, the primary indicators of healthcare inequalities have been linked to social deprivation scales rather than healthcare interventions (Feinstein 1993). That is to say, much of the evidence on age and inequalities has focussed on traditional measures of socioeconomic status. The impact of age on treatment decisions has been less extensively researched.

When reviewing the literature about treatment decisions, ageism is not apparent when looking at access to services, but it is most apparent when considering rationing or provision of specific treatments. For example, some authors have identified that there was no impact of age when making decisions about access to healthcare such as critical care beds, with older people gaining equal access to services. (Hubbard, Lyons, Woodhouse, Hillier, Wareham, Ferguson and Major 2003). On the other hand, when considering individual treatments, the negative impact of increased age has been cited in terms of 'undertreating' elderly patients with lung cancer (Peake, Thompson, Lowe and Pearson 2003). In these cases, the beliefs relating to the predicted survival of older patients encouraged clinicians to withhold treatments if prognosis was uncertain or considered to be poor.

In relation to stroke care, Shah (2006), highlighted the 'lack of aggression' when treating older patients after stroke and concluded that there are disparities of approach based on increasing age. This supports the findings of this research project and the notion that age may be a contributory factor to the approach of withholding nutrition.

14.2.1.2. Confusion of goals for older patients

It was clear from the data that there was some confusion over the goals of stroke care. This may in part be due to uncertainty about the extent to which 'aggressive' interventions should be provided to older patients as clinicians raised concerns over aiming for rehabilitation as an 'active' pursuit versus aiming to palliate and keep the patient comfortable. There was obvious uncertainty relating to which of these approaches was the most beneficial for an older patient. The ethical dilemmas

raised when treating older patients are well reported in the literature as seen, for example, in studies considering factors in treatment withdrawal. Diringer, Edwards, Aiyagari and Hollingsworth (2001) for example, cite age to be a factor supporting withdrawal of artificial ventilation, although acknowledge that this factor does not exist in isolation of co-morbidities and other health issues.

The specific ethical issues relating to goals of dysphagia management in the elderly are also documented. Sonies (1992), for example highlights the skills required in differential diagnosis in the elderly client group in order to separate 'normal ageing' from a 'disorder' requiring intervention. The author argues that the presence of dysphagia should not be dismissed as a 'normal' part of ageing without considering treatment. The dilemmas in assessment and treatment are therefore evident.

When considering artificial nutrition and hydration provision, the particular difficulties linked to determining best interests for stroke and older patients are recognised in guidance by the BMA, GMC and BGS as previously cited. In particular, the confusion over whether ANH constitutes treatment or basic care creates difficulties establishing goals for intervention. That is to say, ambiguities in classifying the nature of the intervention creates further confusion over what the clinicians are aiming to do. This reinforces the perception that the safest approach is to withhold intervention if uncertainty prevails.

In the field of dementia care, there is a groundswell of opinion that ANH prolongs the dying process in the later stages of dementia and should not, therefore, be offered. Supporters of this approach include Gillick (2000) and Finucane and Christmas (2003). However, this view may extend to include elderly patients in the acute stages of stroke, as anecdotal evidence from the Medical Ethics Alliance (MEA) suggests. In response to the draft incapacity bill consultation process, the MEA provided accounts of numerous individual cases where uncertainty over the nature of ANH had worrying consequences. In recognition of this problem, the Joint Committee for the Bill (Mental Capacity Bill 2005) made specific reference to the potential withholding of nutrition based on the perceived status of the patient.

> *'Parliament should note that many people with conditions that fall short of a permanent vegetative state are having life sustaining food and fluids withheld with fatal results. In some cases this amounts to euthanasia by omission. Elderly stroke patients who cannot swallow are at particular risk. The concept of "Best Interests" should be restricted to clinical best interests otherwise it can be open to misinterpretation and misuse.'*

This statement supports the finding from this study that 'best interests' incorporates a social analysis. In this study, there was evidence that Quality of Life (QoL) was a

marker for best interests. Clearly, clinicians in stroke care believed that their aims and role legitimately extended to considering this issue. However, the lack of clarity over the nature or definition of Quality of Life is of concern. The use of QoL as a vague concept with elderly care has been widely cited in the literature. Attempts have been made to explore definitions for patients (Farquhar 1995) and between different professional groups (McKevitt, Redfern, La-Placa and Wolfe 2003). Whilst most identify that 'future happiness' is a recurring theme linked to QoL, the authors of QoL studies acknowledge the inherent subjectivity of this issue. McKevvitt et al (op cit) conclude that 'clarification of the concept and its uses is required if recent calls to introduce quality of life assessment in clinical care are to be feasible.' This highlights the current position whereby QoL is recognized as a valid determinant of care, but one lacking definition. This was echoed in this research.

14.2.1.3. Patient participation in decision making

One significant aspect in this study relating to the status of older people was the degree to which patients were involved in the decisions about their care.

Owing to the nature of stroke, a significant minority of the patients in this study had variable levels of consciousness and/or capacity during their admission. This inevitably meant that their involvement in decision making was limited. However, there was evidence from the data that some patients who had capacity to be involved were 'excluded' from the decision process without obvious explanation. It is possible that the age of the patient may have contributed to this practice in a number of ways.

Throughout the study, there were no examples of capacity assessment being carried out in relation to healthcare decisions. The presumption that patients have capacity unless shown to be otherwise was not supported by the study data, with more examples of the opposite position being held. The practice observed was that of defaulting to 'best interests' when making decisions about patients before establishing if they had the capacity (and therefore the autonomy) to be involved. This may, in part, be linked to the frequent association of cognitive or language disorders with stroke. However, it may also link to the general beliefs about the abilities of older people to be included in the discussions. The inconsistency of capacity assessment with older people is evident in the literature. Rosenbaum, Bravata, Concato, Brass, Kim and Fried (2004) considered capacity assessment and consent with older patients after stroke. They studied documentation

retrospectively in relation to patient involvement with treatment decisions for tissue plasminogen activator (tPA). They found that

> *'a substantial percentage of patients who received tPA for stroke had no consent documented. Surrogates often provided consent when the patients had capacity; conversely, patients with diminished capacity sometimes provided their own consent.'*

The authors acknowledge that inaccuracies in the records may have been responsible for this finding rather than omissions in clinical practice.

Age has been identified in other studies to be a factor affecting the extent to which patients are involved in their care. Vetsch, Uehlinger and Zuercher-Zenklusen (2002) studied Do Not Resuscitate (DNR) orders in an inpatient setting and reported that not only were there more DNR orders written on older patients, but that 'patient and/or surrogate involvement in decision-making for DNR orders was low' amongst the older patients. Other studies, such as Wildiers and Brain (2005) cite that older patients have previously been excluded from discussions about breast cancer treatment due to the clinicians concerns over whether the patients would want these details. The authors acknowledge that awareness of the need for patient involvement is improving, although the extent to which this happens in reality is still unclear.

In this study, it was evident that the patient participants were largely passive, accepting the healthcare offered to them. Further, there were examples where the clinicians made decisions with relatives rather than patients, despite patients having sufficient capacity to enable them to be involved in the decision. The lack of challenge (and in some cases, the examples of direct support) for this approach has been reported in previous studies in relation to the older patient group. Langewitz, Nubling and Weber (2006) carried out a survey of hospital patients in order to seek their views on shared decision making. They found that a substantial number of patients wanted the clinician to make the decisions about their care. Of these, the majority were older or 'less educated'. The possible issues relating to age and patient expectations of healthcare may support some of the patient passivity witnessed in this study. This was raised by clinicians in this study, as they reported feeling 'torn' when trying to 'force' patients to become involved in their healthcare. The past acceptability of paternalism in healthcare may account for some of this, but it is possible that there is a lack of congruence between patients and clinicians expectations of shared decision making. Some of the medical clinicians in this study had long term experience of working with older patients, and for the majority, this pre-dated the NHS policies about patient involvement. This may have contributed to

carrying a legacy of 'physician-only decisions' as identified by Beisecker, Murden, Moore, Graham and Nelmig in (1996). They found that more experienced clinicians advocated less patient involvement when compared to their recently trained colleagues. The reasons for this were not fully explored within this study. Quill and Brody (1996) considered models of patient participation and reported that the move from paternalism within healthcare left confusion over how to balance 'involvement' with 'independence'. They argue that the autonomous choice of the patient should not negate the contributions of the clinician, but that there is some evidence that doctors are now 'reduced' to giving information rather than actively becoming involved in helping the patient to make decisions. It is possible that there is passivity on the part of *both* the patient and the clinician as each adjusts to their new 'expected' roles in shared decision making.

The issue of what patients *want* in relation to shared decision making is emerging in the literature. Belcher, Fried, Agostini and Tinetti (2006) for example, carried out an investigation of what older patients wanted in terms of patient involvement with medication decisions. They found that there was a varied response from participants about how much involvement was desirable, and further that their definition of shared decision making was limited to receiving information rather than active involvement in the decision. This was evident in this study. The majority of participants did not actively pursue involvement, even in situations where they could have done. This goes some way to supporting the view that they were content to accept decisions being made on their behalf. There were two examples in the data, where patients challenged the healthcare professionals and vociferously demanded choice or inclusion in the decisions made about them. These participants were the youngest members of the sample group. This may be coincidence, but may offer support to the fact that 'exclusion' may be more prevalent (or at least more readily accepted) by the older generation.

As can be seen, the study raised issues in relation to the status of the older patient and the perceived value of nutrition. There are a number of factors contributing to passivity in approach. In this context, withholding nutrition may also be a symptom of cultural values rather than a clinical decision per se.

When considering the relatively low value of nutrition, a further issue is identified relating to the evidence base on which the clinicians operate. This will now be discussed.

14.2.2. The evidence base for nutritional interventions in stroke care

Research into stroke care has historically been sparse in comparison with other fields of medicine. This situation has improved over recent decades, as acknowledged in the literature. Baron (2005) for example, states that

> *'until the mid-70s, dogmas largely prevailed which underpinned the then nihilistic approach to stroke patients. Proving these dogmas wrong has been a major achievement of modern stroke research.'*

The historical situation has implications for the extent and quality of the evidence on which stroke care is based.

In this context, the studies relating to specific aspects of stroke care such as dysphagia management are patchy. This section will discuss this issue under the following headings

- The value of nutrition after stroke
- The impact of aspiration
- The implications of unclear evidence

14.2.2.1. The value of nutrition after stroke

The research evidence relating to nutrition is a hugely diverse field. There are numerous perspectives on the relative harms and benefits of nutrition on the human body. For example, research into 'over nutrition' identifies clinical disorders such as obesity and associated health risks. A poor 'balance' of nutrition can be implicated in cases where people develop clinical disorders such as diabetes, heart disease, bowel disorders, skin diseases etc. The implications of 'under nutrition' are also well 'evidenced', with the short and long term effects of 'starvation' being recorded in terms of metabolic and systemic implications. A review of all of these issues and the impact of nutritional 'lifestyles' is evident in literature, with a summary of the health promotion issues provided by (Weisburger 2000). At the current time, the value of food in terms of benefits to both individual health and the health of society is promoted in the media. Examples include the high profile drive to improve nutrition in schools (the 'Feed Me Better' campaign by celebrity chef, Jamie Oliver) and the demonstrated reduction in anti social behaviour observed when improving vitamin intake amongst young offenders (Gesch, Hammond, Hampson, Eves and Crowder 2002). As seen in the wealth of literature, the impact of good nutrition for an individual's development or recovery after illness (both physically and cognitively) has been demonstrated. There has been some attention in the literature to the

specific nutrition needs of elderly patients. Most of this has been in relation to metabolic illness management such as diabetes or vitamin deficiency linked to mental health status. Research into the general implications of nutritional status and the health of elderly patients is emerging. For example, Bartali, Frongillo, Bandinelli, Lauretani, Semba, Fried and Ferrucci (2006) identified direct links between low nutrient intake and increased frailty in older patients.

The British Geriatrics Society (BGS) policy and 'good practice' statement on nutrition after stroke is as follows

> *'A significant number of stroke patients are under-nourished on admission and, as with other under-nourished hospital patients; their nutritional status tends to worsen after admission. Furthermore, under-nutrition in hospital is a strong and independent predictor of morbidity and mortality after stroke'. (2006)*

The preference for withholding nutrition initially after stroke is therefore surprising. When considering the basis for the clinician's beliefs about nutrition, it is evident that previous research into nutritional intake and its relationship with stroke recovery has generated mixed results. There has been sparse attention in the literature relating to oral nutritional intake after stroke. Where this is evident, it is mostly in relation to the texture of oral diet (for example, Wilkinson, Thomas, MacGregor, Tillard, Wyles and Sainsbury (2002)) rather than the nutrient intake.

When looking at general nutritional intake in hospitalised patients, the incidence of malnutrition has been reported to be high, with Beck et al. (2002) reporting incidence of 40-50%. They attributed this to five major factors, as cited by Antal (2004). These are

> *'1) lack of clearly defined responsibilities in planning and managing nutritional care, 2) lack of sufficient educational level with regards to nutrition among all staff groups, 3) lack of influence of patients 4) lack of cooperation between different staff groups, 5) lack of involvement from the hospital administration.'*

These findings are supported by the current study.

The majority of research in stroke that has addressed the issue of nutrition has mainly focused on the effects of artificial nutrition, either through NGT or PEG tube feeding. These studies have produced contradictory findings.

Iizuka and Reding (2005) and Niv and Abuksis (2002) were amongst authors who presented that the 30 day mortality rate after PEG insertion was high. However, James, Kapur and Hawthorne (1998) reported that feeding older stroke patients with PEG tubes within two weeks of admission was beneficial. This was supported by

Bussone, Lalo, Piette, Hirsch and Senecal (1992) and Janes, Price and Khan (2005) who independently reported that mortality rates with PEG feeding was not as high with older stroke patients as had previously been reported.

The recent FOOD trial (Dennis, Lewis et al. 2005) assessed the value of early nutrition in patients following stroke and considered the timing of ANH in relation to outcome. Unfortunately, the study did not look at feeding from day 1, (relating early feeding to patients enrolled within 7 days of admission) and did not include those patients for whom prognosis was deemed to be poor in the early stages after admission. Data from this current study identified that it is precisely these patients who generated the most uncertainty, and therefore the most inconsistent approaches in terms of nutritional interventions.

Despite the general evidence linking nutrition with good health, the evidence base for nutrition after stroke is both sparse and inconsistent. Clinicians remain unconvinced of the benefits of nutrition immediately after stroke. More research is required in this area, particularly to ensure that withholding nutrition after stroke is not, in fact, contributing to a poorer outcome in reality.

14.2.2.2. The impact of aspiration

As stated, one of the key drivers behind the 'not to feed' pathway after stroke lies in the beliefs about the risks of aspiration and the subsequent harms to the patient. The links between pneumonia and dysphagia after stroke are evident in the literature as reported by Martino, Foley, Bhogal, Diamant, Speechley and Teasell (2005). However, despite some papers suggesting that there is a sevenfold increase in pneumonia in patients with dysphagia, (Singh and Hamdy 2006) there is little data to support the direct causal links between aspiration and subsequent development of pneumonia.

A patient developing a respiratory condition after stroke may do so for a number of reasons. For example, patients may be susceptible to pulmonary effusions, pulmonary embolisms or exacerbation of chronic obstructive pulmonary disease. There is some evidence to indicate that patients with basal ganglia strokes experience more frequent aspiration of saliva and reflux during sleep and that this may lead to pneumonia (Nakagawa, Sekizawa, Arai, Kikuchi, Manabe and Sasaki 1997). However, there is no evidence linking *oral diet* aspiration to aspiration pneumonia after stroke.

Awareness of the possible influence of aspirate acidity on subsequent development of pneumonia has been reported through tracheal pH monitoring after stroke

(Clayton, Jack, Ryall, Tran, Hilal and Gosney 2006). Although identifying a mechanism to measure tracheal acidity, this study failed to acknowledge whether pH changes were due to the acidity of the food swallowed or to any presence of gastro oesophageal reflux. Further, they did not link this to any subsequent development of pneumonia.

Whilst acknowledging that a differential diagnosis between the types and nature of respiratory problems can be problematic (Szakacs 2002), it seems that there are mechanisms for assessment and diagnosis that were not observed in this study. Best practice within respiratory medicine suggests that in order to differentially diagnose aspiration related problems, at the very least, a sputum culture should be taken so as to identify the type of infection and treat it with the correct antibiotics (Johnson and Hirsch 2003). Random prescription of broad spectrum antibiotics has wider implications for the prevalence of antibiotic resistant infections, hence 'targeted' approaches would be advantageous. There is also evidence in the literature to support radiological examination of patients in order to differentially diagnose pneumonia (Gil, Fernandez and Sabbagh 2005). The authors state that

> *'clinical diagnosis of pneumonia without radiological confirmation lacks specificity because clinical presentation (history and physical examination) does not allow to differentiate pneumonia from other acute respiratory diseases (upper respiratory infections, bronchitis, influenza).'*

In this study, the identification of aspiration and pneumonia was not supported by these clinical procedures. As a consequence, the definitive diagnosis and targeted management was not possible. In the absence of this specific information, the clinicians were observed to adopt a routine approach to withhold nutrition when there were what they perceived to be 'risk factors' for aspiration. This practice was not supported through interviews with participants in acute neurology or ITU settings where patients may equally present with reduced consciousness or dysphagia. As indicated, the relative insignificance of the risks of aspiration in ITU, Head Injury or Acute Neurology services indicates that the beliefs about aspiration risk are not widely demonstrated or accepted. It may well be the case that these environments 'grade' the risks of aspiration as low compared to the other risks that are often associated with the setting. D'Escrivan and Guery (2005) considered the management of aspiration pneumonia in ITU settings. They proposed measures such as semi-recumbent position, the surveillance of enteral feeding, the use of promotility agents, and avoidance of excessive sedation in order to minimize aspiration risk. At no point did they consider that withholding oral diet or enteral feeding was an appropriate management option. They conclude that

'aspiration pneumonia is a frequently encountered disease that can be prevented by relatively simple measures.'

This marked difference in both beliefs and management of the patient according to the clinical environment is interesting and warrants further consideration.

As previously indicated, there is emerging research that further challenges the view that placing a patient NBM minimises the risk or impact of aspiration. Shay, Scannapieco, Terpenning, Smith and Taylor (2005) outline evidence to link pneumonia directly to 'microbe-laden' saliva. Placing a patient NBM reduces effective oral hygiene for patients, thereby exacerbating the presence of harmful bacteria. It is possible, therefore, that in some cases, withholding oral diet may be promoting aspiration pneumonia rather than preventing it. As seen therefore, the current practice to withhold oral diet or enteral feeding in order to minimise aspiration risk is not supported by the evidence.

14.2.2.3. The implications of unclear evidence

The evidence base supporting the management of dysphagia in stroke is unclear. There has been little research in this area to date and there are inconsistent findings in the available evidence. This situation has implications for clinical practice where Evidence Based Practice (EBP) is expected of clinicians. In the absence of clear evidence, clinicians adopted instead, what they perceived to be 'good practice' approaches.

The 'safe' approach to care in terms of the 'precautionary principle' has been advocated by the government in cases where there is little or unclear research evidence. In this study, it was evident that clinicians view withholding nutrition as a precautionary measure. This approach to clinical care is observed in other clinical fields where risks are suspected and unquantifiable, but believed to be of sufficient harm to the patient. Examples of this include the harm minimisation approach within drug and alcohol use services, (Wazaify, Hughes and McElnay 2006) approaches to new variant Creutzfeldt Jakob disease, (DOH 1999) and more recently, the prescription of the drug Herceptin to breast cancer patients (DOH 2006). The precautionary principle as stated by Richter and Laster (2004) 'shifts the burden of proof from showing presence of risk to showing absence of risk', and this justifies harm minimisation approaches. In this study, the 'wait and see' approach to feeding mirrors 'watchful waiting', a harm minimisation philosophy in prostate cancer management (Chodak and Warren 2006). In effect, the potential interventions are perceived to generate more harm than 'doing nothing' for a prescribed period.

Where this approach is questionable in the current study is that withholding nutrition is perceived to be safe for the patient and this cannot be supported by the evidence. Throughout the study, the lack of clear clinical guidance was seen by clinicians to place them 'in the spotlight' when making decisions. It was evident that clinicians were influenced on occasions by their own position, their personal conscience and the possible 'ripple effect' of their actions. This position is recognised in the literature as Fuller (2004) and others report that the clinicians role in the current NHS climate is to manage 'indecision and uncertainty, balanced against needs to preserve professional roles'. That is to say, when making decisions, the clinician now legitimately protects themselves as well as the patient. Included in this philosophy is the issue of accountability and avoidance of blame. This was repeatedly observed in this study as the accountability for an 'observable' harm (respiratory decline) was more acutely felt than the accountability for a 'covert' harm (malnutrition). It is possible that clinicians cite 'double effect' when withholding nutrition, acknowledging that they are accountable for not providing an intervention, but justifiably so if the intent is to avoid the perceived harm of aspiration. However, as reported by Nuccetelli and Seay (2000), this is no defence if clinicians 'abuse the notion of unintended consequences' in their actions. It is evident from this study that gaps in evidence may generate a lack of accountability for the 'creeping malnutrition' observed.

As shown, in the absence of clear evidence, clinicians also adopted an individualistic approach to patient care. When considering the harm/benefit analysis, it was clear that the 'social' aspects (such as QoL) played a significant role, despite uncertainties over whether this 'soft science' was legitimate evidence. The result was that decision making for nutrition in stroke care was influenced by 'value-based' thinking as much as evidence based practice. Value based practice (VBP) is increasingly recognized as a legitimate factor in healthcare decision making, particularly within the field of Mental Health Services (Fulford 2005). However, by nature of its subjectivity, VBP is not considered to be 'hard evidence' within the current system (Sackett et al, 1996, op cit).

It could be this latter fact that underpins the clinicians' reluctance to openly acknowledge their personal views or influences within the decision process under study. That is to say, despite VBP being somewhat in evidence in this study, the perception that 'instinct' or personal beliefs are unscientific, excluded them from overt discussion. The implications of this are such that some of the most powerful influences to decision making for nutrition after stroke remain 'hidden' from discussion or acknowledgment.

As seen, the sparse clinical evidence underpinning decisions for nutrition after stroke generates beliefs and approaches that maintain the practice of withholding nutrition. Raising awareness of these issues is required in order to further develop both the evidence and clinical practice.

14.2.3. Customs in stroke care

The study identified a number of 'ways of working' in stroke care that reinforced the practice for withholding nutrition immediately after stroke. These organizational aspects of care in hospital had a significant impact on the decision process and will be discussed as follows

- Processing the patient
- Doing – or being seen to be done?

14.2.3.1. Processing the patient

The data in this study revealed valuable insights into the systems behind decision making and their contributions to problem solving. It was evident that many of the 'structures' designed to standardize and improve care may in fact, have been unhelpful distractions from the task in hand.

In the interviews, clinicians universally cited the stroke care pathway as a tool to facilitate decision making about nutrition. Despite this, few clinicians were able to state when nutrition should be commenced as per 'guidance' within the pathways. This highlights one of the negative implications of pathway based approaches, as seen in this study. Far from being used to generate solutions to problems, the pathway served at best as an aide memoire, and at worst as a hindrance to flexible thinking. In short, the existence of a pathway appeared to justify the expressed lack of detailed knowledge about the decision process.

Clinical pathways have a mixed press in the literature. Advocates of clinical pathways in healthcare suggest that setting clear standards improves clinical practice and competence (Johnson, Dracass, Vartan, Summers and Edington 2000). Others suggest that in patients with complex conditions, clinical pathways

> *'present the potential for being misunderstood or misapplied; and practitioners often find them time-consuming, restrictive, and intrusive' (Matthews 2005).*

When considering stroke care pathways, studies have revealed improvements in patient care. Esteve, Serra-Prat, Zaldivar, Verdaguer and Berenguer (2004) for

example, cited reduction in the length of hospital stay and the number of inpatient complications with an integrated care pathway.

Sulch, Evans et al. (2002) found that stroke pathways improved the communication within stroke units. However, an earlier study by the same authors (Sulch, Perez, Melbourn and Kalra 2000) identified that clinical outcomes were less favourable when compared to 'conventional' care. More recently both a Cochrane review (Kwan, Hand, Dennis and Sandercock 2004) and a study by Taylor, Wong et al.(2006) identified that when looking at acute stroke care pathways, outcomes such as of length of stay and the patients functional status may have worsened since the introduction of clinical pathways. The authors were unable to explain the results of the study, but proposed that

> *'It may be that the complexity of acute stroke care cannot be adequately described within a clinical pathway and that simple guidelines cannot hope to replace experienced, knowledgeable staff who can think flexibly.'*

This finding is supported by the results of this current study, where the pathway appeared to rigidly create a 'mindset' of 'not to feed' rather than encouraging critical reflection about *when* to feed. There were numerous examples in the data where the nature of 'pathway thinking' was exposed. For example, the swallow screen was often carried out, as per the pathway, within a few days of admission. However, the screen itself was viewed as the 'box ticked' rather than the outcome of the screen. That is to say, if the patient was placed NBM after the screen, a referral was sent to Speech and Language Therapy with no evident plan for nutrition in the interim. The patient appeared to be processed on the pathway 'production line' rather than the pathway signposting clinical solutions. One glaring example of this was the duration of NBM and the lack of scope within the pathways to identify this. The data identified that many patients were NBM for prolonged periods, the most extreme case being participant 22a who was without nutrition for 36 days. Across all of the patients recruited, it was seen that they were NBM, on average, for 54% of their hospital admission. Some periods of NBM were accrued whilst waiting for procedures such as NGT or PEG placement. The stark reality was such that patients recruited to this study were without nutrition of any form for just over half of their stay. There is no system for highlighting this omission within the current pathway driven approach, hence the clinicians may be missing information through a misplaced confidence in the pathway.

Another aspect of organizational structure identified in the data was that of a 'compartmentalized' approach to care. The clinicians reported working in integrated multidisciplinary teams. In reality, each department and professional group worked

to uniprofessional clinical standards and 'waiting lists'. This created 'silo' thinking as targets were set for each discipline rather than joint goal setting for each patient. This is widely reported in the literature (Conway 1997; Ray 1998) but the impact of hindering efficacy is less widely reported. In this study, this approach created delays (such as waiting lists for PEG placement) and inhibited teamwork (such as the examples of 'blaming' other professional groups when delays occurred). The MDT approach therefore generated inefficiencies in care as opposed to improving care as believed by those involved.

The working patterns of staff and the high degree of patient transfers within the hospital further affected efficiency and continuity of care. The increase in patient transfers was acknowledged by some participants to be the result of waiting list initiatives in each part of the hospital system. Ironically, the government policies to improve continuity of care (as in the NSF for Older People) are directly at odds with their policies to reduce waiting lists across the system.

The combination of issues described created little scope for individual patient care, and more importantly did not allow clinicians to exercise their clinical skills in problem solving. The observed culture for target setting and standardized care minimized the clinician's ability to respond individually to patient need.

14.2.3.2. Doing – or being seen to be done?

The implications of explicit and non-explicit communication were raised in chapter 13. It was clear from the data, however, that 'customs' about how to communicate across the teams affected the decision process. In particular, these related to how the clinicians verbally communicated across teams and how they recorded information.

Clinicians reported that most of the team planning about patients occurred in the MDT meetings. They valued these forums and particularly on site a, clinicians reported the existence of the MDT meeting in itself served as evidence that group planning occurred. This belief is reinforced by the RCP's sentinel stroke audit targets which state that 'weekly team meetings have been identified as one of the significant factors in a coordinated stroke service leading to improved clinical outcomes' (RCP 2006). This satisfaction with 'structure' was reported by Nair and Wade (2003) who studied the perceptions of meetings by those MDT members who attended. Interestingly, this study considered positive outcomes to relate to issues such as the degree of participation by members at the meeting rather than looking at the clinical outcomes for the patients. In the current study, analysis of the interaction

in the MDT meetings revealed that decisions were rarely made, although information was exchanged in an almost formulaic fashion. It is possible that the meeting 'ticks a box' in terms of MDT team structure, but in fact does not facilitate decision making or group planning. When considering the literature, there is evidence that a 'structured' approach to goal setting is beneficial. Duff, Evans et al. (2004) for example, reported improvements in the speed and quantity of targets achieved with patients when using a 'needs assessment and goal planning framework'. MDT meetings for stroke are included as targets in the NSF for older people. However, as observed in this study, the mere existence of the meeting did not improve the quality of planning for patients and may have generated complacency amongst MDT members.

Another communication forum observed in this study was the ward round. Once again, the purpose of this forum was questioned through analysis. As with many traditional inpatient settings, both sites had consultant ward rounds once or twice a week, with 'junior' medical staff ward rounds in the interim. The consultant ward rounds generated more tangible decision outcomes, with the junior ward rounds largely noting information and deferring decisions to a later point. This had a marked effect on the efficacy of decision making in that it left the inaccurate impression with staff that decisions were 'underway'. When reviewing the literature, there is little evidence exploring the contribution of ward rounds to decision making. Much of the focus has been placed on the structure of ward rounds, predominantly 'training' rounds. McLeod (1986) and Stanley (1998) for example, provide accounts of the best structure to facilitate learning. Once again, it seems that structure has been considered in terms of achieving targets, with little reflection on the effect of structure on the patient plan or interventions. Given the observed impact of this practice on decision making, this is an interesting omission in the literature.

One final aspect of 'being seen to be done' related to the use and purpose of clinical records. Despite both sites reporting a multidisciplinary approach to stroke, the clinical records were not fully integrated. Over the years, there have been numerous papers extolling the virtue of integrated care plans. For example, Gifford and Maberry (1979) amongst others, reported that integrated care plans improved care and efficiency in all stages of the patients journey through in-patient services. Over time, the move towards electronic records has been explored in research, with some consensus that these systems achieve improved patient care and management objectives (Rigby and Robins 1995). There has been some report of negative outcomes with integrated systems, as in the study by Gibbon, Watkins et al. (2002). The authors introduced integrated team notes and pathways into the stroke care

environment and found no improvement in team working, communication and attitudes amongst staff. The reasons for this are unclear, but it may be that the high number of professionals and systems involved proves too complex for these systems to be effective.

The case notes in the current study proved to be variable as a mode of communication. Each professional group held separate clinical notes, but recorded summaries in the main medical and nursing records which served as the main channel for communication. The use and purpose of this document was questioned in analysis when considering the impact of open ended statements or the use of the 'query' (?) in notes. The extent to which medical records are an effective means of communication between clinicians is under researched. Most studies to date, have considered audits of case note entries whereby the presence of information in itself is regarded as effective communication (Klapper, Lecher, Schaeffer and Koch 2001). There is little research to date looking at how the notes are used or the value placed on them by clinicians. Further, the extent to which there is shared interpretation of the contents is unknown. In this study, there was evidence of ambiguities that affected the speed and nature of decision making. There were also indications that the notes were used to record evidence of having *thought* about interventions as opposed to recording what would happen. As indicated, some clinicians intimated that this practice may be motivated by leaving a 'paper trail' of defensive practice. This may be a cynical interpretation, but the dearth of literature regarding the use and potential misuse of clinical records does little to address this area. The extent to which these issues are limited to stroke care is impossible to determine from this study. It is evident, however, that the uncertain aims in stroke care may encourage communication systems that suggest more active management than may actually be the case. In short, it is possible that clinicians perpetuate systems of unclear communication in order to 'disguise' their lack of certainty in clinical care. Investigations into the value and purpose of communication systems would be beneficial in order to further explore the legitimacy of this claim.

Having outlined the possible factors contributing to the clinician's beliefs about nutrition after stroke, the implications for clinical practice will now be explored.

14.3. The Implications for Clinical Practice

These findings have implications for clinical practice which will now be discussed.

14.3.1. Increasing the value of nutrition

The belief that withholding nutrition in the early days after stroke is best practice is questionable. It is clear from reviewing the literature that there is currently insufficient evidence to either support or refute this practice. There are undoubtedly cases where providing nutrition will not affect the outcome for patients. However, there are equally cases where offering nutrition will have a positive effect. This needs more open discussion to ensure that nutritional decision making occurs as efficiently as possible and is targeted to those where its benefit is, at the very least, uncertain.

Although further research is needed to establish whether feeding makes a difference for patients, the current practical management of nutrition should be challenged. It is no defence to omit feeding based on poor organizational systems, rather than lack of evidence. It is argued therefore, that there should be regular review points specifically to monitor nutrition in order that the *actual* duration without nutrition is clear. This could be achieved in a number of ways. Firstly, the role of the dietitian, dietetic assistant or nursing auxiliary could be reviewed to include responsibility for monitoring all patients who are NBM, not just those for whom clinical nutrition has already been indicated. This requires little more than an initial administrative responsibility to highlight the actual days without nutrition, thereby ensuring that the team has comprehensive information on which to base their decisions. In addition, the current organizational forums could be reviewed to have defined structures and aims. If, for example, the ward round or MDT meeting had a defined remit to review nutritional intake, this would ensure that an explicit discussion would occur, even if the result of the discussion was to maintain a 'wait and see' approach. This would address problems with the current situation where omission to make a decision can be the result of an omission to acknowledge the *need* for a decision.

14.3.2. Improving the clinical assessment of respiratory conditions

There needs to be a more rigorous approach to assessing and differentiating between respiratory conditions which develop in the context of stroke. In order to

successfully carry out a harms/benefits analysis of the patients needs, the clinicians require more accurate information about the definite occurrence of aspiration rather than heavily relying on aspiration 'risk' in their assessments. Information from sputum cultures and radiological examination for example, would greatly enhance the quality of information available to the clinicians. In short, challenging practice that assumes all respiratory changes to be aspiration related would allow clinicians to more accurately assess and diagnose their patients. On this basis, nutritional decisions would be made more in line with clinical evidence rather than procedural risk aversion.

14.3.3. Challenging the culture of stroke care

The compartmentalized approach to care was a significant factor in affecting continuity of care and joint goal planning. As a result, the aims of stroke care were never routinely discussed or shared by the team.

Particularly on site a, there were MDT meetings in place that could immediately be improved through reviewing the structure and purpose of the group. On both sites, ward rounds could be structured so as to ensure routine discussion about nutritional status and interventions.

The confusion about aims and roles resulted in passivity that was both observed and acknowledged by participants. This requires open discussion within the teams in order to create change. The stroke care culture identified in both of these hospital sites would benefit from more detailed inspection by those involved to eradicate any hidden and potentially 'unhealthy' values. This challenge has been discussed in plans for dementia care services in the UK but has not obviously been extended to stroke care organizations. As stated by Kitwood, (1999) healthcare culture in each specialty has three aspects.

> *'first, its 'regime of truth' (Foucault, 1967). Second, there are norms, meaning standards and patterns of acceptable behaviour, particularly for the performance of the more visible roles. Third, there are beliefs, both about what is real and true, and what ought to be'*

Kitwood argues that cultural transformation tackles all of these aspects in order to 'reconsider' the clinical disorder. It is possible therefore, that beliefs about stroke need to be challenged from *within* the service as much as across medicine and healthcare. In particular, the goals for these patients need to be clear and universally agreed.

In order to improve nutritional decision making after stroke, the cultural issues that may be reinforcing inequalities should be explored. A key recommendation is therefore for stroke services to reconsider the basis of their decisions in comparison with other fields of medicine.

14.3.4. Promoting structure in decision making

From the data, the four key aspects identified as influencing factors (views on prognosis, beliefs about nutrition and hydration interventions, perceived responsibilities and personal conscience) are complex and comprise a combination of objective and subjective factors. This study has identified tangible factors that are influential to the decision process, all of which need to be considered in future research and clinical practice. With further definition in context, the model presented as figure 1 in chapter 10, could be used as a tool to facilitate debate and develop insight into the team's values and views. This reflective practice (for individuals and as a team) would bring additional benefits of transparency in decision making, but also a mechanism to explain and justify the ultimate determination of best interests and clinical outcomes. As previously identified the relative harms and benefits associated with nutritional interventions are variable and uncertain at any given point in time. Use of the model could facilitate insight into perceptions about harms and benefits that would at least serve to raise some awareness of the relative values attributed to aspects of care. If used as a discussion tool, clinicians could be encouraged to examine their beliefs through an objective framework.

14.4. Recommendations for Future Research

Some key areas for future research were identified through this study.
The first recommendation as previously indicated, relates to establishing an evidence base about the consequences of oral diet aspiration. The actual 'harm' requires further explanation before relative risks in nutritional decision making can be adequately understood. Deeper understanding over some of these objective clinical issues will undoubtedly facilitate the process of weighing up both the clinical and social aspects seen within nutritional decision making.
The current national guidance on decision making for nutritional interventions has been generated from a medical perspective, based on legal cases involving clients in Persistent/Permanent Vegetative State (PVS) (BMA & GMC op cit). By its nature, the focus is directed more towards the clinical management of such cases within a hospital setting. The current position within the literature is that guidance either

adopts a 'prescriptive approach', as per the decision aids described in chapter 6, or conversely is too philosophical to be practically useful. For example, the rigid algorithm presented by Rabeneck, et al. (1997) leaves little flexibility and contrasts greatly with the subjective terminology of establishing whether the patient has a 'demonstrably awful life' as presented by Doyal and Wilsher (1994). Both approaches have merits, but do little to help the clinician in day-to-day decision making. Further work is, therefore, required to generate guidance that draws from both prescriptive and value based approaches.

Other areas for future research relate to considering nutritional decision making on behalf of patients who lack capacity to be involved in the process. This issue is not exclusive to the area of stroke care, but has implications for clients with cognitive problems (for example dementia and learning disabilities) and clients with mental illness.

In replicating this study, it would be particularly useful to focus on the issue of 'mental capacity' in stroke care. As seen in this study, assessment of mental capacity is rarely conducted with patients who have had a stroke and is certainly not a routine part of the process in decision making for nutrition. The implications of this for clinical practice and patient care undoubtedly need further explanation within the context of the forthcoming Mental Capacity Act.

It would be worthwhile replicating this study using a larger population and on different sites with alternative models of stroke care delivery. Further, comparison with a younger age group would be advantageous. This would further knowledge in terms of either supporting or developing the concept that 'not to feed' is a normative pathway approach. Areas for comparison might include decision making for stroke patients who are admitted to intermediate care establishments rather than hospital settings, or indeed the decision making approaches in chronic presentations rather than acute neurological conditions.

A new research study using a larger population experiencing care in different settings would enable the findings in this study to be examined in more detail. This study found that nutritional interventions in the early days after stroke was not accorded a high priority. For a number of reasons, patients drifted along a NBM pathway for a considerable period and without attracting much clinical concern. The findings suggest a need for a paradigm shift in clinical practice, moving from a focus on wholesale avoidance of aspiration, to positive consideration of nutrition in the early days after stroke. In raising awareness of this issue, this study challenges current clinical practice and generates deeper insight into the acute care of stroke.

Beck A. M., Balknäs U. N. et al. (2001) state that

> *'Good nutrition is essential for avoiding illness and regaining health. All persons, including the healthy, the sick and the aged, are entitled to adequate nutrition suited to their individual needs and medical conditions.'*

It is hoped that this study challenges the diminished value of nutrition for patients after stroke, and in doing so, will lead to an improvement in clinical practice for older people following a stroke.

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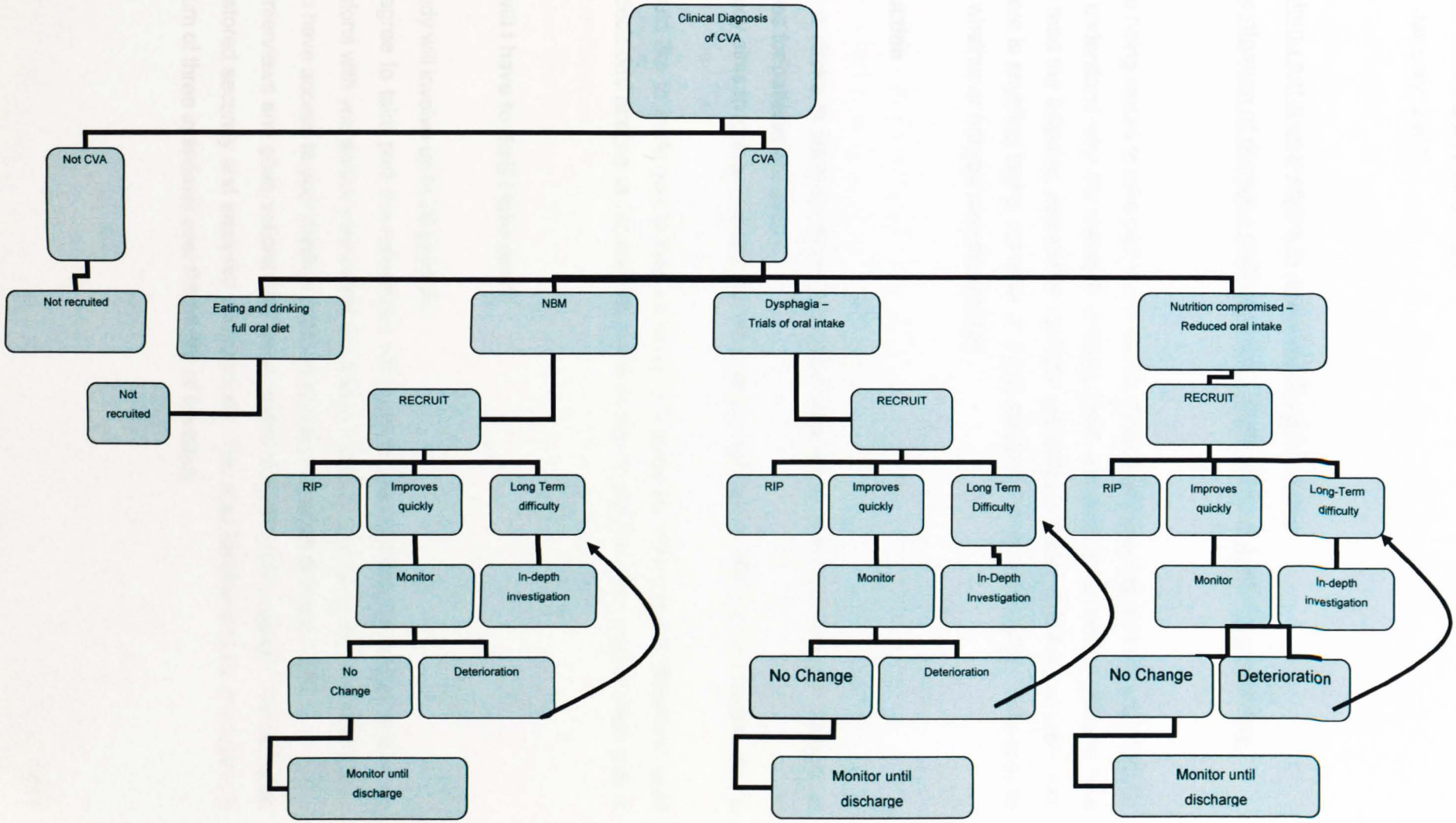
Appendix 1 - Sampling Criteria for Patient Participants



Appendix 2a - PATIENT INFORMATION SHEET

PATIENT INFORMATION SHEET

January 2003

Maintaining nutritional status in patients following stroke:

An investigation of decision making and its implications for patient outcomes.

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Introduction

Having a stroke is likely to be a distressing experience that may cause a number of difficulties for patients and carers.

This study aims to look at one aspect - how people maintain nutrition and hydration after a stroke.

We would like to invite you to help us study how patients, carers and professional staff make decisions relating to maintaining nutrition and hydration after a patient has had a stroke.

What will I have to do if I take part?

The study will involve up to 30 patients.

If you agree to take part the researcher will conduct observations, interviews and short discussions with you and/or your carers at various points in your recovery. The researcher will also have access to your medical notes or documents relating to your care.

Some interviews and observations may be recorded with an audio cassette. These tapes will be stored securely and analysed confidentially. You may be asked to be involved in a maximum of three interviews over the period of the study.

The research will take place during your time in hospital, and may continue after your discharge. As much of the research will be observing events, the researcher will not ask you to give up much time for the study.
With your permission, we would want to inform your GP that you are taking part, If you do decide to take part you will be given this information sheet to keep and will be asked to sign a consent form.

Do I have to take part?

No, taking part is completely voluntary.
If you would prefer not to take part you do not have to give a reason and your treatment would not be affected. If you take part but later change your mind you can withdraw at any time and this will not affect the standard of care you receive.

What are the possible risks of taking part?

It is possible that the questions asked on occasions may cause you to think about what has happened to you and you may become upset. If this happens and you feel that it is difficult to carry on, then you are free to withdraw from the study at any point. You may wish to contact your Consultant or GP to discuss your concerns, and the researcher will be able to help you arrange this.

Are there any possible benefits?

The research does not offer any direct help for you following your stroke. However, the information that we gain from this study will help us to improve our care for future patients after stroke.

Will my taking part in this study be kept confidential?

All information which is collected about you during the course of the research will be kept strictly confidential. Any information about you will have your name/address removed so that you cannot be recognised from it.

What do I do now?

The researcher will be available to discuss any concerns you have regarding the study and you can let her know if you are interested in taking part. You will then be asked to sign a consent form.

Thank you very much for considering taking part in our research.
Please discuss this information with your family, friends, Consultant or GP if you wish.

CONTACT FOR FURTHER INFORMATION

Heulwen Sheldrick.
Research Fellow
Health and Community Care Research Unit (HaCCRU)
University of Liverpool, Thompson Yates Building
The Quadrangle, Brownlow Hill,
Liverpool L69 3GB

Tel : 0151 794 5489

Appendix 2b - CARER INFORMATION SHEET

CARER INFORMATION SHEET **January 2003**

Maintaining nutritional status in patients following stroke:

An investigation of decision making and its implications for patient outcomes.

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Introduction

Having a stroke is likely to be a distressing experience that may cause a number of difficulties for patients and carers.

This study aims to look at one aspect - how people maintain nutrition/hydration after a stroke. You are being asked to participate on the basis of your being a relative or carer of a patient who has had a stroke.

We would like to invite you to help us study how patients, carers and professional staff make decisions relating to maintaining nutrition/hydration after a patient has had a stroke.

What will I have to do if I take part?

The study will involve up to 30 patients.

If you agree to take part the researcher will conduct observations, interviews and short discussions with you at various points in the patients recovery.

Some interviews and observations may be recorded with an audio cassette. These tapes will be stored securely and analysed confidentially. You may be asked to be involved in a maximum of three interviews over the period of the study.

The research will take place during the patients time in hospital, and may continue after their discharge. As much of the research will be observing events, the researcher will not ask you to give up much time for the study.
If you do decide to take part you will be given this information sheet to keep and will be asked to sign a consent form.

Do I have to take part?

No, taking part is completely voluntary.
If you would prefer not to take part you do not have to give a reason and the patients treatment would not be affected. If you take part but later change your mind you can withdraw at any time and this will not affect the standard of care the patient receives.

What are the possible risks of taking part?

It is possible that the questions asked on occasions may cause you to think about what has happened to you and you may become upset. If this happens and you feel that it is difficult to carry on, then you are free to withdraw from the study at any point. You may wish to contact your Consultant or GP to discuss your concerns, and the researcher will be able to help you arrange this.

Are there any possible benefits?

The research does not offer any direct help for you following your stroke. However, the information that we gain from this study will help us to improve our care for future patients after stroke.

Will my taking part in this study be kept confidential?

All information which is collected about you during the course of the research will be kept strictly confidential. Any information about you will have your name/address removed so that you cannot be recognised from it.

What do I do now?

The researcher will be available to discuss any concerns you have regarding the study and you can let her know if you are interested in taking part. You will then be asked to sign a consent form.

Thank you very much for considering taking part in our research.

Please discuss this information with your family, friends, and the medical team if you wish.

CONTACT FOR FURTHER INFORMATION

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Liverpool. L69 3GB
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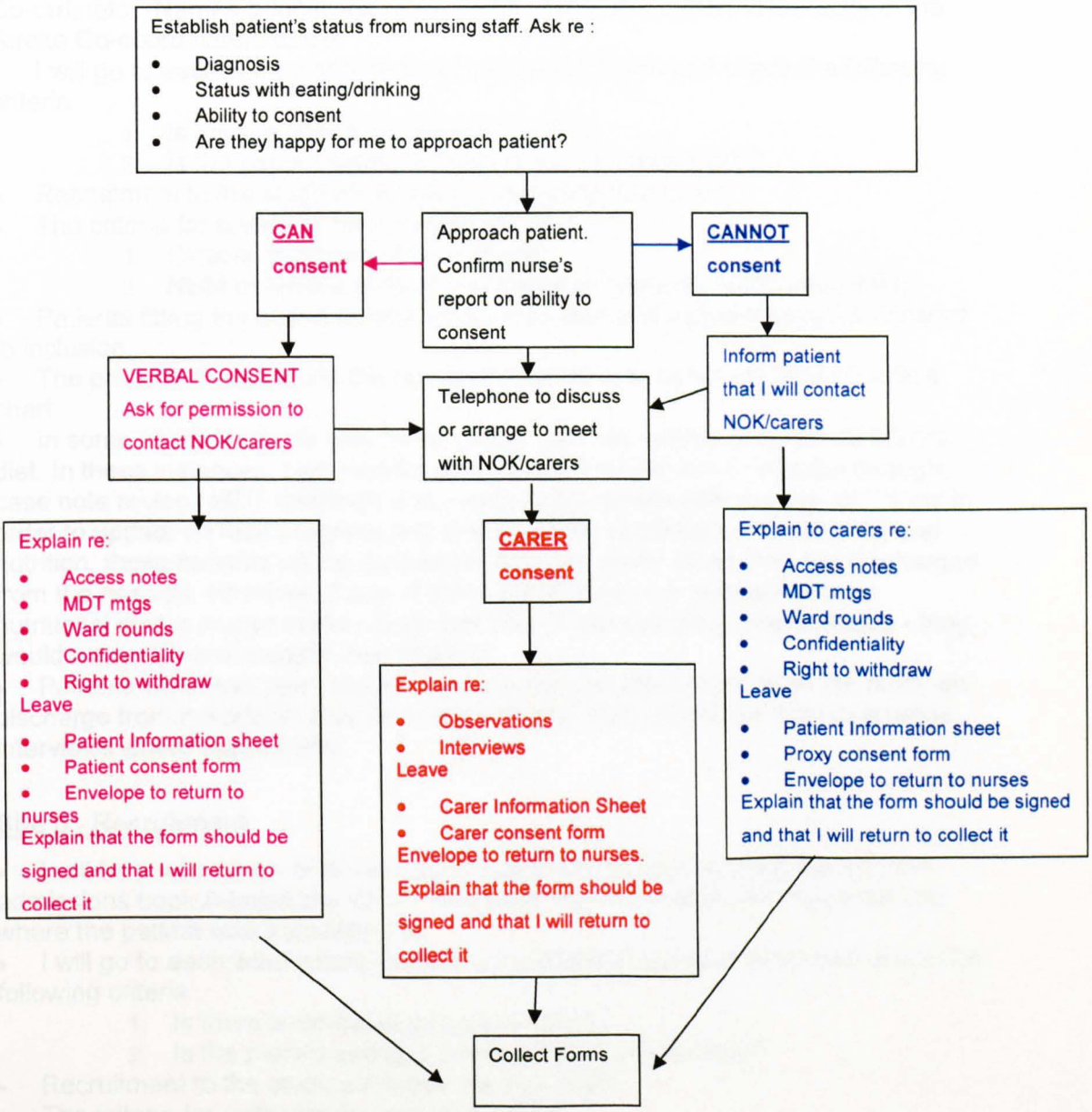
Appendix 3 – Flowchart to show the process for seeking consent from the patient participants



Appendix 4 – Recruitment Process and Criteria

Site a - Recruitment

- All new admissions with suspected CVA will be alerted to me through the Stroke Co-ordinator. Names & locations of new admissions are written in the diary in the Stroke Co-coordinators office.
- I will go to each ward where there is a new admission and check the following criteria
    1. Is there a clinical diagnosis of CVA?
    2. Is the patient eating & drinking full amounts orally?
- Recruitment to the study will follow the sampling flow chart.
- The criteria for suitability for inclusion will be
    1. Clinical diagnosis of CVA **PLUS**
    2. NBM **or** limited trials of oral intake **or** reduced nutritional intake
- Patients fitting the above criteria will be recruited and asked to give full consent to inclusion.
- The process of explaining the research & seeking consent will follow the flow chart
- In some cases, patients may be recruited, but may quickly progress to full oral diet. In these instances, I will monitor them whilst they remain in hospital through case note review, MDT meetings and general discussions with nurses, SLT's etc in order to update on their progress and status. If they continue to maintain full oral nutrition, these patients will be discharged from the study when they are discharged from the hospital. However, if any of these patients have a 'relapse' in their nutritional status or oral intake - such that they fit the sampling criteria above - they would warrant more in-depth investigation.
- Patients who have been studied in-depth may be discharged from the study on discharge from hospital or may be contacted after their discharge from to arrange interviews where appropriate.

Site b - Recruitment

- I will be made aware of all new admissions with suspected CVA through the admissions book Admissions Ward. This book lists the provisional diagnosis and where the patient was transferred to.
- I will go to each ward where there is a transferred new admission and check the following criteria
    1. Is there a clinical diagnosis of CVA?
    2. Is the patient eating & drinking full amounts orally?
- Recruitment to the study will follow the flow chart
- The criteria for suitability for inclusion will be
    1. Clinical diagnosis of CVA **PLUS**
    2. NBM **or** limited trials of oral intake **or** reduced nutritional intake
- Patients fitting the above criteria will be recruited and asked to give full consent to inclusion.
- The process of explaining the research & seeking consent will follow the flow chart
- In some cases, patients may be recruited, but may quickly progress to full oral diet. In these instances, I will monitor them whilst they remain in hospital through case note review, MDT meetings and general discussions with nurses, SLT's etc in order to update on their progress and status. If they continue to maintain full oral nutrition, these patients will be discharged from the study when they are discharged from the hospital. However, if any of these patients have a 'relapse' in their

nutritional status or oral intake - such that they fit the sampling criteria above - they would warrant more in-depth investigation.

- Patients who have been studied in-depth may be discharged from the study on discharge from hospital or may be contacted after their discharge from to arrange interviews where appropriate.

Appendix 5 – Summary of the full Patient Participant Data

Identifier	Data
p1b	**Documents** – Medical notes, SLT notes, dietetic notes
p2b	**Documents** – Medical notes, SLT notes, dietetic notes **Observations** - Ward Round 03/12/02
3b	**Documents** – Medical notes, SLT notes, dietetic notes **Observations** - D/W staff 06/02/03, Ward Round 10/02/02
4b	**Documents** – Medical notes, SLT notes, dietetic notes
6b	**Documents** – Medical notes, SLT notes, dietetic notes (for both sites) **Observations** - Dietitians (HGH) comments 03/03/03, MDT mtg 12/03/03, MDT mtg 26/03/03, MDT mtg 02/04/03, MDT mtg 09/04/03, MDT mtg 16/04/03, MDT mtg 23/04/03, MDT mtg 30/04/03, MDT mtg 07/05/03, MDT mtg 21/05/03, Ward Round 24/02/03

7b	**Documents** – Medical notes, SLT notes **Observations** - Ward Round 13/02/03
9b	**Documents** – Medical notes, SLT notes **Observations** - Ward Round 24/02/03, Ward Round 27/02/03
11b	**Documents** – Medical notes, SLT notes, dietetic notes
23b	**Documents** – Medical notes, SLT notes, dietetic notes **Observations** - Ward observation 13/03/03, Ward observation 20/03/03, SLT discussion 25/03/03, Ward round Dr 27/03/03
P1a	**Documents** – Medical notes, SLT notes **Observations** - MDT mtg 15/01/03, MDT mtg 05/02/03, MDT mtg 19/02/03, MDT mtg 12/03/03, MDT mtg 26/03/03, MDT mtg 02/04/03, MDT mtg 09/04/03, MDT mtg 16/04/03, MDT mtg 23/04/03, MDT mtg 30/04/03, MDT mtg 07/05/03, MDT mtg 21/05/03
P2a	**Documents** – Medical notes, SLT notes, dietetic notes **Observations** - MDT mtg 15/01/03, MDT mtg 05/02/03, MDT mtg 19/02/03, MDT mtg 12/03/03, MDT mtg 26/03/03, MDT mtg 02/04/03, MDT mtg 09/04/03, MDT mtg 16/04/03, MDT mtg 23/04/03, Meeting with SALT 09/04/03

7a	**Documents** – Medical notes, SLT notes **Observations** - MDT mtg 19/02/03, W/R Dr 19/02/03
12a	**Documents** – Medical notes, SLT notes **Observations** - My d/w relatives 11/02/03, MDT mtg 19/02/03
16a	**Documents** – Medical notes, SLT notes, dietetic notes **Observations** - My d/w 16a (13/02/03), MDT mtg 19/02/03, My d/w 16a (24/02/03), MDT mtg 12/03/03, MDT mtg 26/03/03, MDT mtg 02/04/03, MDT mtg 09/04/03, MDT mtg 16/04/03, MDT mtg 23/04/03, MDT mtg 30/04/03, MDT mtg 07/05/03, MDT mtg 21/05/03, Ward Round Dr 27/02/03
22a	**Documents** – Medical notes, SLT notes **Observations** - MDT mtg 05/02/03, MDT mtg 19/02/03, My d/w Dr (19/02/03), My d/w family (24/02/03), Ward Round Dr (27/02/03)
34a	**Documents** – Medical notes, SLT notes **Observations** - Ward round Dr (27/02/03)
58a	**Documents** – Medical notes, SLT notes, dietetic notes **Observations** - Ward notes (17/03/03), Ward notes (26/03/03), MDT mtg 26/03/03, MDT mtg 02/04/03, MDT mtg 09/04/03, MDT mtg 16/04/03, MDT mtg 23/04/03, MDT mtg 30/04/03, Ward observation 21/05/03, DR mting with relative (20/03/03)

65a	**Documents** – Medical notes, SLT notes **Observations** - MDT mtg 26/03/03
68a	**Documents** – Medical notes, SLT notes **Observations** - MDT mtg 26/03/03, Ward observation 02/04/03, MDT mtg 02/04/03, MDT mtg 09/04/03, Dr meet with rels (03/04/03)
82a	**Documents** – Medical notes, SLT notes, dietetic notes **Observations** - MDT mtg 26/03/03, MDT mtg 02/04/03, MDT mtg 09/04/03, MDT mtg 16/04/03, MDT mtg 23/04/03, MDT mtg 30/04/03, MDT mtg 07/05/03, MDT mtg 21/05/03, HO d/w rels re : PEG 26/03/03

Appendix 6 – The vignette used during interviews with the clinicians

Mrs J, aged 72 and with a history of angina is admitted with signs of a stroke. It is now four days after her admission and she remains unconscious. She has IV fluids in situ and has been NBM since admission. Today, Mrs J has a temperature of 39.5 degrees and has a 'bubbly' chest.
Mrs J's family are constant visitors and are very anxious about her condition.
What would you consider in Mrs J's case and what would you do?

Followed up with :

Day 9.
Mrs J remains unconscious, and remains NBM with IV fluids. There were attempts to place an NGT on day 5, but these curled in her throat.
Her general condition is unchanged to that reported on day 4.