

An in-depth inquiry into how stroke patients are supported with eating and drinking in stroke units

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The candidate confirms that the work submitted is her own and that appropriate credit had been given where reference has been made to the work of others.

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Abstract

Background

An estimated eighty percent of stroke patients have difficulties with eating and drinking, with over fifty percent requiring some form of assistance. Evidence suggests those receiving nutrition and hydration via enteral or parenteral routes receive adequate nutrition. In contrast, stroke patients who require assistance to eat and drink via the oral route do not always meet their nutritional requirements, affecting their well-being and recovery from stroke. This study explores this phenomenon in contemporary stroke unit settings.

Methods

A qualitative collective case study using non-participant observation, documentary analysis and semi-structured interviews was undertaken. The study gathered data from two sites incorporating acute and rehabilitation stroke services (cases). Forty-six multidisciplinary team (MDT) members, 31 patients and 13 informal carers (ICs) were recruited to the study. Data was thematically analysed using a six components approach developed by Braun and Clarke (2006).

Findings

All MDT members considered adequate nutrition paramount to stroke patients' recovery with nursing staff responsible for supporting eating and drinking. However, patients did not receive consistently adequate support to eat and drink. This was due to multiple, interwoven factors including lack of formalised assessment of eating and drinking abilities unless under SLT management; poor communication and monitoring of patients' support requirements, nutritional intake and nutritional status; other work/ tasks given priority over supervision at mealtimes; inconsistent provision of accessible, nutritious, appealing food. Knowledge to support this activity varied hugely across the MDT, particularly with HCAs who reported variable levels of training but predominantly carried out this work unsupervised.

Conclusion and implications for practice

Stroke patients do not receive consistent support with eating and drinking.
Further research and the inclusion of specific recommendations for support with
this activity in national guidance may promote this activity.

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List of Abbreviations

BAPEN	British Association for Parenteral and Enteral Nutrition
BDA	British Dietetic Association
CASP	Critical Appraisal Skills Programme
CCHMC	Cincinnati Childrens Hospital Medical Centre
CQC	Care Quality Commission
CRD	Centre for Reviews and Dissemination
DA	Dietetic Assistant
DH	Department of Health
DR	Doctor
DTN	Dysphagia Trained Nurse
FBC	Fluid Balance Chart
FCP	Feeding Care Plan
FOOD	Feed Or Ordinary Diet
GBD	Global Burden of Disease
GP	General Practitioner
HASU	Hyper Acute Stroke Unit
HCA	Health Care Assistant
HK	Housekeeper
HRA	Health Research Authority
IC	Informal Carers
IRAS	Integrated Research Application System
ISWP	Intercollegiate Stroke Working Party
LEGEND	Let Evidence Guide Every New Decision
LOS	Length of stay
MCA	Mental Capacity Act
MDT	Multi-disciplinary team
MUST	Malnutrition Universal Screening Tool
NCCCC	National Collaborating Centre for Chronic Conditions
NHS	National Health Service
NIC	Nutritional Intake Chart

NICE	National Institute for Health and Care Excellence
NPSA	National Patient Safety Agency
NS	Narrative Synthesis
NSFOP	National Service Framework for Older People
OT	Occupational Therapist
PICO	Population Intervention Comparison Outcome
PMI	Protected Mealtime Initiative
PT	Physiotherapist
RCP	Royal College of Physicians
RCT	Randomised Controlled Trial
REC	Research Ethics Committee
RN	Registered Nurse
SA	Site A
SAE	Serious Adverse Events
SAH	Sub Arachnoid Haemorrhage
SB	Site B
SIGN	Scottish Intercollegiate Guidelines Network
SLT	Speech and Language Therapist
SR	Sister
SSNAP	Sentinel Stroke National Audit Programme
TA	Thematic Analysis
TAP	Trainee Associate Practitioner
TIA	Transient Ischaemic Attack
UK	United Kingdom
USA	United States of America
WA	Ward Assistant
WHO	World Health Organisation
WM	Ward Manager

Chapter 1: Introduction

1.1. Thesis overview

This study was inspired from ten years' experience working as a nurse in stroke rehabilitation prior to my current role as a senior lecturer in nurse education. Despite the diverse nature of teaching and other allied work required in the latest role, my interest in stroke care has continued. Whilst working in this stroke setting, I found supporting patients to eat and drink often difficult and occasionally impossible to achieve to a standard acceptable to my colleagues and myself. We recognised that supporting patients with multiple deficits following stroke to eat and drink was often a complex and time-consuming process. The process was often hindered by a lack of time and staffing as well as attempting to maintain the busy routine of the stroke unit. At that time, any efforts to manage these issues within the organisation were met with placatory comments but no physical changes. One of my colleagues stated "they (management) just don't realise how long it takes to feed someone" during a shift where thirteen patients with complex needs required support to eat and drink, with only five staff to manage the process and deliver all other care to these patients and the remaining nine on the unit. This study explores support with eating and drinking and how this process can be managed to the benefit of stroke patients in the hospital setting.

The thesis is presented in nine chapters. Chapter one introduces the rationale for the study, examines what a stroke is, the situation with stroke care in the United Kingdom [UK] and internationally up to the commencement of empirical work for this study in 2013. It also highlights the effects of stroke and how these can affect a person's ability to eat and drink. The further progression of stroke policy and guidelines which continued up to the completion of empirical work for this study is acknowledged and brought up date with further discussion in chapter 9. Chapter 2 critically reviews current research relating to eating and drinking support in the hospital setting for stroke. Chapter 3 explores ontological

and epistemological underpinnings of the qualitative case study approach - the methodological approach employed for this study. Chapter 4 explains the study methods including the data collection methods of observation, semi-structured interviews and documentary evidence, and the thematic narrative and thematic analysis approaches employed for data analysis. Chapters 5 and 6 present the findings for the two case study sites, including a summary of eating and drinking support at each site. Chapter 7 synthesises the findings presented in chapters five and six responding to the study objectives and offering a summary of the situation with eating and drinking support. Chapter 8 presents the researcher's reflexive account of undertaking this study and supporting the rigour of the study process. Chapter 9 discusses the study findings including their implications and recommendations for future practice within the topic area of the study and how these could be implemented.

1.2. Stroke illness

A stroke occurs when the blood supply to part of the brain is cut off resulting in depletion of oxygen and cell death in that area (Intercollegiate Stroke Working Party [ISWP], 2016). The two main causes of stroke are ischaemic and haemorrhagic (Global Burden of Disease [GBD] Stroke Collaborators, 2019). Stroke is classified in part 160-169 of the International classifications of disease produced by the World Health Organisation [WHO] (WHO, 2015), and is defined as "rapidly developed clinical signs of focal or global disturbance of cerebral function, lasting more than 24 hours or until death, with no apparent none vascular cause" (WHO MONICA project principle investigators, 1988, p.108). Stroke is the second largest cause of death worldwide (WHO, 2013a).

1.3. Stroke in the UK - current situation

There are over an estimated 130,000 people who suffer a new stroke in the United Kingdom each year (GBD Stroke Collaborators, 2019) with an estimated

one million people living with the effects of stroke (King et al., 2020). Stroke incidence and prevalence are expected to continue rising over the next twenty years by 60% and 120% respectively (King et al., 2020). Age increases stroke occurrence, with most patients being over age fifty-five, though the average age is decreasing in the UK (Wang et al., 2013; Public Health England, 2018). The overall estimated financial cost of stroke to the UK is twenty-six billion pounds per year and estimated to rise to over seventy-five billion pounds by 2035 (Patel et al., 2017).

1.4. The effects of stroke

Stroke is the leading cause of disability in the UK, with two thirds of stroke survivors leaving hospital with a disability (Stroke Association, 2018).

Disabilities following stroke vary considerably in their degree of severity, with some deficits resolving soon after the stroke and others leaving the person with long-term disability, no two stroke survivors being affected in the same way (Langhorne et al., 2011; National Institute for Health and Care Excellence [NICE], 2016). Common effects include problems with limb weakness, speech, swallowing, cognition, vision, sensation, pain, fatigue, and bowel and bladder control. It is estimated that 84% of patients leave hospital with a disability that affects their activities of daily living (Royal College of Physicians Sentinel Stroke National Audit Programme, 2017).

1.5. The management of stroke in health care - a background

Traditionally stroke was viewed as an inevitable consequence of the aging process resulting in death or varying degrees of disability (NICE, 2008).

According to Langhorne and Dennis (2008), there has been published work exploring the organisation of stroke care since the 1950's. A seminal study by Langhorne et al. (1993) described by the authors as a 'statistical overview' of 10

Randomised controlled trials [RCTs] from seven different countries, compared stroke unit care with routine or non-specialist care in general medicine or neurology wards. They found a sustained reduction in mortality at both three- and six-months post stroke for those patients cared in in stroke units. In 1997 the Stroke Unit Trialists' Collaboration [SUTC] published a systematic review of 19 studies examining the intervention of stroke-unit care which confirmed that organised stroke-unit care reduced death, dependency and length of hospital stay (SUTC, 1997). The first National Sentinel Audit (1998) revealed that organised stroke care was sporadic with only a few stroke patients being cared for in stroke-units (Rudd et al., 1999). The findings of the 1997 SUTC review and 1998 Sentinel Stroke Audit contributed directly to standard five of the National Service Framework for Older People [NSFOP] (Department of Health [DH], 2001) making recommendations for the prevention and management of stroke and stating what practice areas must achieve to become a 'stroke-unit'. Particularly relevant to the topic of this research study, section 5.22 of the NSFOP, offering guidance for immediate care post stroke, recommended that patients and their informal carers are offered advice, information and explanations for treatment to help manage the effects of stroke. Further, this should include a formal swallowing assessment and planning for safe hydration and feeding, and such care should be co-ordinated by a member of the multidisciplinary stroke team (though which member specifically is not stated) and treatment and care plans clearly documented. The first national evidence-based guideline for stroke was developed by the ISWP (ISWP, 2000).

Guidance for stroke management continued to develop with the National Stroke Strategy (DH, 2007a), and the ongoing development of NICE Guidance for the Management of Acute Stroke and Transient Ischaemic Attack [TIA] (NICE, 2008) and Stroke Rehabilitation (NICE, 2013a). The ISWP national evidence-based guidelines for stroke had their fourth edition published in 2012 (ISWP, 2012). Monitoring of stroke services in the UK continues with the Sentinel Stroke National Audit Programme [SSNAP] which collects data in real time. This enables quarterly feedback on performance to stroke care providers in the UK and an annual report (Royal College of Physicians, 2014).

As stated at 1.2, stroke is the second largest cause of death worldwide (WHO, 2013a). As with the UK many individual countries including Australia, Canada, Ireland; New Zealand, Scotland, South Africa and the United States of America [USA] have developed guidelines for the management of stroke (Bryer et al., 2010; Irish Heart Foundation: Council for Stroke, 2010; Lindsay et al., 2010; Miller et al., 2010; National Stroke Foundation, 2010; Scottish Intercollegiate Guidelines Network, 2010; Stroke Foundation of New Zealand and New Zealand Guidelines Group, 2010).

Analysis of both the national and international stroke guidelines found all had guidance for the management of nutrition post stroke (Bryer et al., 2010; Irish Heart Foundation: Council for Stroke, 2010; Lindsay et al., 2010; Miller et al., 2010; National Stroke Foundation, 2010; Scottish Intercollegiate Guidelines Network, 2010; Stroke Foundation of New Zealand and New Zealand Guidelines Group, 2010; ISWP, 2008; 2012). These focused on assessment of nutritional status, nutritional supplementation, enteral and parenteral feeding, and management of dysphagia and some but not all on the monitoring of food intake. Apart from the Irish guidelines, none of these guidelines focused on assessing and managing patients' ability to eat and drink, only that they may require assistance. Further, except for the Irish guidelines it is not recommended who within the MDT should administer such assistance. The Irish guidelines suggest that stroke patients able to take nutrition orally should be assisted and encouraged, and state this is an integral part of the nurse's and healthcare assistant's role. They offer no further guidance about how this should be implemented (Irish Heart Foundation: Council for Stroke, 2010). The UK stroke guidelines both 2008 and 2012 incorporate profession specific concise guidelines including for nursing, but as stated these do not mention support with eating and drinking (ISWP, 2008; 2012). Findings from non - stroke specific UK guidelines and policies relevant to managing nutrition in the hospital setting are summarised in section 1.6.

1.6. Management of nutrition in hospital settings in the UK - a background

The guidance discussed in this section was published prior to my commencement of the narrative synthesis (reported in chapter 2) (Popay et al., 2006) in November 2013. The findings of the narrative synthesis informed the direction of the empirical study. None of the guidance discussed in this section was specifically written for or mentioned the management of nutrition with stroke patients. However, it is overarching guidance for hospitals and is included because it is relevant and transferable to stroke patients in the hospital setting. Guidance on managing nutrition and nutritional support for adults in hospital and community settings has increased over the past twenty years (1992-2012) (British Association for Parenteral and Enteral Nutrition [BAPEN], 2012). The next section summarises the guidance over this period and comments on the impact of the policy and guidance.

In 1995 Nutrition Guidelines for Hospital Catering (DH, 1995) gave guidance for minimum nutritional requirements for hospital patients and identified that different patient groups have different nutritional needs. In 2000, linked to the NHS Plan, further reforms of nutritional care in hospitals were indicated, including better quality food and 24-hour availability (DH, 2000). In 2006 NICE guidelines for nutritional support in adults included recommendations for when and where to screen patients for malnutrition; when to consider nutrition support; staff education; employment of specialist nutrition support nurses; and for all hospitals to have nutrition steering committees (NICE, 2006).

Subsequently a joint action plan developed by key stakeholders in nutritional care for health and social care was published (DH, 2007b). In 2009, the National Patient Safety Agency [NPSA] issued guidance for nutritional care in hospitals including Nutrition Fact Sheets incorporating ten key characteristics of good nutritional care. These describe actions staff should take to ensure good nutritional care (NPSA, 2009). The DH (2010) followed this with recommendations for action that stakeholders should follow performance benchmarks in these areas (DH, 2010). More recently, NICE published quality

standard 24 for nutrition support in adults (NICE, 2012a). In the same year Clinical Guideline 138, Patient Experience in Adult NHS Services, recommended regular assessment of patient needs including nutrition and hydration, though NICE did not define what they meant by regular (NICE, 2012b).

The Care Quality Commission [CQC] (2013) reported that the required standards for nutritional care were being met in 44 of the 50 (88%) hospitals they inspected in 2012, an increase of 5% from the previous year. In hospitals where nutritional needs were not met, common issues identified were staff not assisting patients to eat and drink; inaccurately recording care; not offering patients suitable food; delayed patient referral to specialist advice; lack of hand hygiene offered to patients before and after mealtimes

1.7. Initial exploration of patients' experience with eating and drinking support in the hospital setting - a mapping exercise

Following discussion with the supervisory team the researcher initiated a 'mapping' exercise for an initial exploration of any policy, guidance, or research literature to inform the study topic and further the development of a research question in the topic area. The completion of a mapping exercise is supported by Popay et al. (2006) to assist with the development of future systematic literature review questions and to help determine the scope of a future review. Further, Pope et al. (2007) suggest that a mapping exercise is useful in areas where there are no previous systematic reviews and evidence is likely to emerge from different disciplines. No specific guidance was identified as to how a mapping exercise should be implemented. An explanation of the mapping process completed for this study follows below with a diagrammatic interpretation of the results of the mapping exercise in appendix A.

The mapping exercise was initiated with a search of the Cochrane Library to identify any systematic reviews relevant to the topic area in November 2013. The search terms *Stroke, Eat, Drink, and Nutrition* used individually and in combination identified one review published in the Cochrane Database of Systematic Reviews authored by Geeganage et al. (2012). This review investigated “interventions for the treatment of dysphagia, and nutritional and fluid supplementation in patients with acute and subacute stroke (within six months of onset)” (Geeganage et al., 2012, p.1). Thirty-three randomised controlled trials were included in the meta- analysis with 6779 patients. This review concluded that there was insufficient data to establish the effectiveness of swallow therapies, feeding, nutritional, and fluid supplementation on patient functioning and death. This review focused on dysphagia and nutritional support in the form of nutritional supplementation post stroke. It did not address any other issues that may affect eating and drinking after stroke. A history search of citations within the review was used to identify further literature developing the researcher’s background knowledge relevant to the study topic.

Following the search of the Cochrane library a wider search was undertaken. An electronic search employing the University of Huddersfield’s search engine ‘Summon’ was completed in November 2013. The search terms *Stroke, Eat, Drink, and Nutrition* and synonyms identified from Geeganage et al. (2012) - *self-feed, self-care deficit, oral feeding, and assisted eating* were used. As identified at 1.5, evidence supporting the management of stroke patients in specialist stroke unit care was being published in the mid-1990s. This along with constraints on researcher time led to search date parameters from 1995 to November 2013. Summon simultaneously searches the literature of 216 databases including CINAHL which focuses on nursing and allied health literature and MEDLINE focusing on life sciences and biomedicine literature (University of Huddersfield Library Services, 2021). A critical synopsis of the findings from the identified literature follows, organised by subject categories that emerged during the mapping process.

Subject category – investigating patients' nutritional status during the hospital stay

Empirical evidence investigating patients' nutritional status singly or in combination with other outcome measures during the hospital stay were identified. If stroke patients were well nourished, this would suggest any problems with eating and drinking were being adequately managed. Eight studies investigating this topic and published between 1995 and 2013 were identified (Finestone et al., 1995; Westergren et al., 2001a; Davis et al., 2004; Dennis et al., 2006; Martineau et al., 2005; Poels et al., 2006; Yoo et al., 2008; Mosselman et al., 2013). The studies originated from Canada, Sweden, UK, The Netherlands and Korea. Seven studies used a prospective observational design and one incorporated three multi-centre RCTs. The following data collection methods were used either singly or in combination to assess patients' nutritional status: blood serum analysis, anthropometric measurements, subjective global assessment tool, informal assessment, dietitian's assessment, weight/BMI, nutrition scoring. All studies included stroke patients receiving a combination of oral diet, oral diet with tube feeds or entirely tube fed. Sample sizes were small in seven of the eight studies ranging from (n = 49 - 185) the sample size in the eighth study by Denis et al. (2006) was large (n = 5033). Patient malnutrition on admission to stroke services was observed in seven studies ranging from 5% - 49% of the sample (Finestone et al., 1995; Davis et al., 2004; Dennis et al., 2006; Martineau et al., 2005; Poels et al., 2006; Yoo et al., 2008, Mosselman et al., 2013).

Malnutrition was found to increase in two studies during the hospital stay from 12.2% to 19.8% after one week (Yoo et al., 2008) and 9% to 26% during the first 10 days (Mosselman et al., 2013). In contrast, studies by Finestone et al. (1995) and Poels et al (2006) found malnutrition reduced from 49% to 34% and 3a% and 3% respectively from admission to one month of inpatient rehabilitation (Finestone et al., 1995; Poels et al., 2006). These findings suggest that some stroke patients enter the services already malnourished and for some this continues throughout their hospital stay. All the studies recommended further research and service development in managing stroke patient nutrition.

The multiple assessments and methods used to identify malnutrition in these studies mean systematic reviews and meta-analysis are not possible and supports the findings of Geeganage et al. (2012).

Subject category – investigating the effects of undernutrition

Three empirical studies investigated the effect of undernutrition on patient outcome following stroke. A study by the FOOD trial collaboration, (2003) incorporated three randomised controlled trials with 3012 patient participants from 16 different countries worldwide. They found that undernourished patients were at increased risk of pneumonia, other infections, pressure ulcers, gastrointestinal bleeds and were more likely to die than adequately nourished patients. The two observational studies discussed previously by Davis et al. (2004) and Yoo et al. (2008) found that undernutrition independently predicted post stroke complications including aspiration pneumonia, extra cranial haemorrhage, myocardial infarction and pressure ulcers and poor outcomes measured by increased mortality and increased scores on the Modified Rankin Scale.

Subject category – investigating the effects of stroke on eating and drinking ability

Corrigan (2011, p246) states that “Dysphagia refers to difficulty in swallowing as a result of disruption in the swallowing process during transit of solids or liquids from the mouth to the stomach”. Five empirical observational studies were identified focusing on dysphagia following stroke (Smithard et al., 1996; Mann et al., 1999; Westergren et al., 2001a; Crary et al., 2006; Crary et al., 2013). The studies were carried out in Sweden, the UK and the USA. The study sample sizes varied between 63-162 participants. The reported prevalence of dysphagia with stroke patients ranged from 25% to 64% (Mann et al., 1999; Westergren et al., 2001a). Early identification of dysphagia was recommended to enable adequate management of this condition and reduce associated morbidities – aspiration pneumonia, chest infection and undernutrition (Smithard et al., 1996; Mann et al., 1999; Westergren et al., 2001a; Crary et al., 2006). All

the national and international guidance for stroke discussed in section 1.5 acknowledges the importance of early detection of dysphagia and its management, recommending that patients should have a swallowing screen within four hours of admission to hospital and remain nil orally up to this time.

Other effects of stroke on patients eating and drinking ability have been identified in empirical observational studies and in the national and international stroke guidance identified in section 1.5. Reduced spatial awareness also known as neglect or sensory inattention causes patients to act as though they do not have full knowledge of their person or the environment, and it is identified that patients with this condition require assistance with food (ISWP, 2012; NICE, 2013). Other sensory problems following stroke including neurological pain, hemianopia, hearing loss and dysphasia (difficulties with communication) have the potential to affect stroke patients' ability to eat and drink and are identified in the national and international guidelines (SIGN, 2010; ISWP, 2012; NICE, 2013a). The deficits caused by stroke and reported to affect eating and drinking are presented below in figure 1.

Multiple physical deficits observed to affect patients' ability to eat and drink following stroke were identified in Westergren et al. (2001a; 2002a; 2008), Martineau et al. (2005), Crary et al. (2006) and Dennis et al. (2006). These deficits include upper limb weakness affecting ability to manipulate food on the plate and transport food to the mouth, fatigue, oral problems, facial weakness and sitting balance which singly or combined resulted in an inability to eat or aberrant eating speed. Deficits with cognitive function including executive functioning, concentration, memory and the effects of anxiety and depression were identified to affect eating and drinking ability in the national and international guidelines and in observational studies (Westergren, 2001a, b; 2002a; NCCCC, 2008; ISWP, 2012; NICE, 2013a). Despite the identification of these deficits, the studies and guidelines did not recommend specific management but rather more general statements indicating that support may be necessary with eating and drinking for such patients.

Subject category – the delivery of support with eating and drinking post stroke

Exploring the delivery of support with eating and drinking, a qualitative study by Heaven et al. (2012), a small mixed methods study - participants (n=32) by Illott et al. (2013) both from the UK, and a large systematic review incorporating studies from multiple countries by Perry et al. (2012) identified that nurses and health care assistants mainly provided support with eating and drinking. Perry et al. (2012) found that nutritional care in stroke nursing was essential but under-recognised with minimal high quality supporting evidence for nutritional care and support. In the study by Heaven et al. (2012) data were collected on wards caring for patients with a diagnosis of dementia, fractured neck of femur or stroke. Forty-seven semi-structured interviews were completed with a selection of National Health Service staff including catering staff, Consultants, senior and staff grade nurses, health care assistants, housekeepers, OT, PT, dietitians and SLTs, and other stake holder representatives including professional bodies, voluntary organisations of and for older people and government agencies with an interest in hospital nutrition. The views of former patients and carers (n=5) were explored in a focus group. The objective was to collect data that could be analysed to define current practices in the preparation and provision of food in hospitals, in order to identify opportunities for change (Heaven et al, 2012 p. 630). Findings suggested that despite food work (the authors' term to describe any work to provide food and support patients eating, drinking and nutritional intake) including feeding assistance being perceived as important in addressing malnutrition in hospitalised older people, adequate delivery food work was challenging. Food work was often inhibited by staff perceptions, regarded as lower order, unattractive work, and the delivery of food work was perceived as 'common sense' - not requiring any particular skills. Whereas the authors found food work at times difficult and time-consuming work drawing on many skills in order to be done well (Heaven et al., 2012).

Minimal mention is made of lay carers though NICE guidance (2013a) suggests they should have active participation in patients' rehabilitation including nutritional care. Educational interventions improved knowledge of dysphagia

management, modified diets and oral hygiene (Ilott et al., 2013). Ilott et al. (2013) in a pre and post-test study design, tested the effectiveness of a training programme developed with SLTs for dysphagia management for nurses and HCAs working with stroke patients. This comprised for nurses (n=22) one session 4 hours in length incorporating 2 STARS e-learning programmes and HCAs (n=10) - 2 hours in length including 1 STARS e-learning programme. Ilott et al. (2013) found that following the blended learning programme participants reported significantly more positive attitudes to dysphagia, increased knowledge of dysphagia management and this was reflected in practice with less disagreement on treatment recommendations though the authors recommended further research to investigate the longer-term sustainability of the learning effect.

In summary, the mapping exercise identified that stroke patients are often undernourished on admission to hospital and for some this continues throughout the hospital stay (Yoo et al., 2008). Some patients' deficits caused by stroke mean they require support to maintain adequate nutrition – see figure 1. For some this is achieved via enteral and parenteral methods of feeding (Dennis et al., 2006). Some stroke patients require support to eat and drink orally (Westergren et al., 2001a). Nurses and HCAs were identified as the staff group delivering day to day support with eating and drinking with direction from SLT for dysphagic patients (Heaven et al., 2012; Perry et al., 2012; Ilott et al., 2013). Patients' support requirements were inconsistently identified by the nurses and healthcare assistants caring for them (Westergren et al., 2001b). According to Heaven et al. (2012) food work was perceived as low status work across the stroke MDT. Activities to support eating and drinking are supported by minimal high-quality evidence (Perry et al., 2012). Ilott et al., (2013) found that a short education programme for understanding and managing dysphagia was viewed positively by nurses and HCA participants and had a positive effect on clinical practice at six months suggesting that nurses and HCAs would benefit from similar programmes which could include further education about supporting stroke patients eating and drinking. However, the findings reported from the small empirical studies by Heaven et al. (2012) and Ilott et al. (2013) as well as the systematic review by Perry et al. (2012), did not address in

sufficient depth or detail not only what was reportedly occurring in terms of supporting stroke patients to eat and drink but why this was occurring.

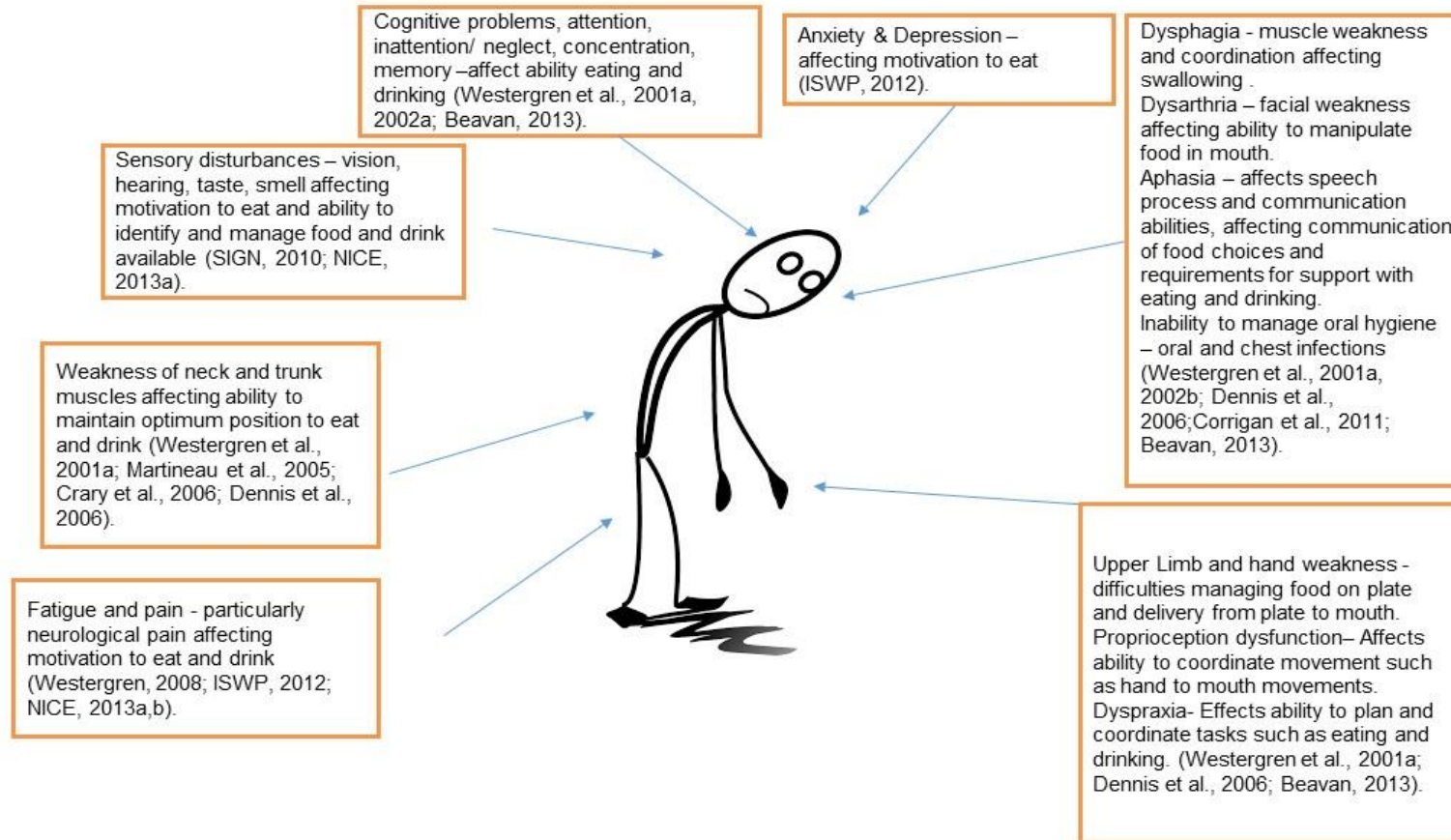


Figure 1. How stroke can affect eating and drinking ability

1.8 Patient and Public Involvement [PPI]

PPI is recommended in all stages of health research and is described as an “active partnership between patients, carers and members of the public with researchers that influences and shapes research” (National Institute for Health Research [NIHR], 2021, no page number). A systematic review of health research literature conducted by Boote et al. (2015) found that PPI has been an increasing feature in various stages of health research in the UK and internationally since at least 1995 (Boote et al., 2015). During the development of my study, I worked with a specialist Consumer Research Advisory Group [CRAG] comprising of stroke survivors and their informal carers supporting research in stroke conducted by the Academic Unit for Ageing and Stroke Research at the University of Leeds. The study and proposed methods were discussed with CRAG and were received positively. Both stroke survivors and informal carers within the group recognised and identified with the real life issues the study proposed to explore in supporting eating and drinking for stroke patients during the hospital stay. I was keen to explore their views of the proposed data collection methods - general and focused observations, semi structured interviews and documentary data. All group participants reported that they would have been interested in participating in such a study during their stroke unit stay. They did not perceive the data collection methods as being too intrusive, suggesting participation may have alleviated some of the boredom they experienced as a patient during the hospital stay. No changes were made to the study proposal following this consultation with the CRAG so there was no further consultation with them at this time.

1.9. Chapter summary

This chapter outlines how the effects of stroke frequently affect a patient’s ability to eat and drink, and that they subsequently require support with this activity (Westergren, 2008). Malnourishment has been identified in up to 45% of the general hospital patient population (Allard, 2015) and up to 61% of the hospital

stroke patient population (Foley et al., 2009), and has been implicated in complications affecting recovery including slowing recovery from stroke and increased length of hospital stay (FOOD trial collaboration, 2003; Gomes et al., 2013). Although considerable evidence was identified, the mapping review indicated that nutrition is still a problem in stroke care but mainly focused on this in conjunction with dysphagia management. Detailed exploration of how stroke patients are supported to eat and drink in the hospital setting has not been undertaken. How stroke patients are supported to eat and drink in the hospital setting has not been fully reported in the literature and will be explored in this study.

1.10 Statement of impact of COVID 19 on study progression

Fortunately, data collection and most of the data analysis for this study was completed prior to commencement of the COVID 19 pandemic in March 2020. However, from this point on, the effects of the pandemic greatly impacted the writing up period for this study. The intention was to complete writing up by October 2020 but the impact of COVID 19 increased work volume and pressure in the full-time work role of the researcher. This significantly reduced the available time to write up the study as work volume increased and pressure encroached on the annual leave allowances the researcher intended to utilise for this activity. The researcher requested and was granted two extensions to the writing up period to enable submission of the study for examination at the end of July 2021.

Chapter 2: Literature review utilising a narrative synthesis approach

2.1. Introduction

As identified in the previous chapter, despite patient nutrition being highlighted many times over the last twenty years in health guidance and policy, hospital patients and particularly those admitted with stroke are often unable to maintain adequate nutritional status (Davis et al., 2004; Yoo et al., 2008; Hafsteinsdottir et al., 2010; BAPEN, 2015). This chapter reports on a narrative synthesis of the literature regarding the provision of eating and drinking support for stroke patients in the hospital setting and employing the approach to narrative synthesis developed by Popay et al. (2006).

To determine the key issues related to post-stroke nutrition in hospital care, an initial mapping exercise was performed as discussed in chapter 1 section 1.7. A mind map was created as part of the mapping exercise that demonstrated topic areas pertinent to the subject of eating and drinking following stroke and including policies, protocols and empirical evidence - see appendix A. As Popay et al. (2006) indicated, the mapping exercise was instrumental in identifying the types of interventions evaluated, the types of study designs used, and the volume of potentially relevant literature to the subject area.

2.1.1. Preparatory work

The researcher is interested in how people are supported to eat and drink following stroke in the hospital setting. The narrative synthesis approach developed by Popay et al. (2006) was deemed the most suitable to conduct this review for the following reasons. Popay et al. (2006) suggest that the narrative synthesis approach allows the investigation of a wide range of questions not only questions investigating the effectiveness of an intervention. The researcher

wanted to explore the multiple ways to support people to eat and drinking after stroke in the hospital setting rather than explore a single intervention. Therefore, narrative synthesis was selected as it enables this exploration. Following the mapping exercise, it was anticipated that this exploration would help determine what occurs in the practice setting, which practises work and which do not, whilst identifying the key stake holders in this process. In addition, Popay et al. (2006) suggest narrative synthesis should help construct a story about the topic area. As well as summarising the available knowledge in the synthesis of evidence, which is the product of the review, it is also possible to develop an initial interpretation of why some actions work whilst enabling further identification knowledge gaps for the topic.

A second reason for the adoption of the narrative synthesis approach was that Popay et al. (2006) advise that the design of narrative synthesis enables the synthesis of methodologically diverse evidence. Most of the empirical studies retrieved during the mapping exercise described in section 1.7. were identified as non - trial based quantitative research studies utilising an eclectic range of study designs. The researcher reasoned that to fully explore the topic area then studies employing a range of research methods as identified in the mapping exercise would be required in the literature review. Multiple authors acknowledge that research evidence other than RCTs may be required to explore some review topics and the review questions (Popay et al., 2006; Pope et al., 2007; Centre for Reviews and Dissemination [CRD], 2009). For example, a traditional Cochrane systematic review requires the inclusion of Randomised Controlled Trial [RCT] studies only. This would mean omitting studies investigating topics potentially relevant to the review topic but using methods other than RCTs. Therefore, an approach to this literature review with the capability to produce a synthesis of findings from such papers was required and the narrative synthesis approach was identified to have that capability.

The final rationale for the adoption of narrative synthesis rather than another review design is as follows. The researcher was aware that Grant and Booth (2009) and Gough et al. (2012), identified multiple approaches for reviews

designed to synthesize findings from research employing diverse methods as with narrative synthesis. Petticrew and Roberts (2006) caution about the difficulties in managing large amounts of evidence produced in reviews incorporating research using diverse methods, though this potential difficulty was accepted by the researcher in the pursuit of identifying the relevant literature about such a broad topic area. Popay et al. (2006) acknowledge that ensuring the trustworthiness of the methods in reviews incorporating multiple research approaches can be problematic, affecting the utility of review findings for consumers of research such as policy makers. Following criticism that narrative approaches synthesising findings from studies with eclectic research designs are prone to bias, Popay et al. (2006) developed the narrative synthesis approach. This was designed to establish a trustworthy, transparent, and systematic process to evidence synthesis from eclectic study designs by adopting a mainly textual approach, (although statistical data can also be incorporated in the synthesis). Popay et al. (2006) stipulate that narrative synthesis should not be confused with the more traditional narrative review, seen as unsystematic and often lacking transparency in terms of searching for and selecting literature for inclusion in the review. Having considered the range of review methods available, narrative synthesis developed by Popay et al. (2006) was identified as fulfilling researcher's review requirements. In summary, this approach could manage the anticipated range of topics and study designs enabling identification of the current knowledge and knowledge gaps in the topic area. It also allows the researcher to interpret what support if any is being given to the stroke patients to eat and drink in the hospital setting. In addition, this approach allows the researcher to do this in a systematic and transparent way increasing the trustworthiness of the review findings.

Popay et al (2006) state that a narrative synthesis should consist of four elements:

- Developing a conceptual model of how the interventions work, why and for whom.
- Developing a preliminary synthesis.
- Exploring relationships in the data.

- Assessing the robustness of the synthesis product.

Table one below, includes explanations of each of these elements and their implementation in this review (Popay et al., 2006).

Table 1. Explanation of narrative synthesis adapted from Popay et al (2006)

<i>Element</i>	<i>Explanation of element</i>	<i>Reporting the Implementation of each element in this review</i>
Element one: Developing a conceptual model	Comes from understanding the theory that has led to the review question, concerned with what works, why and for whom. In this review, element one consists of the development of a conceptual model developed from the literature identified in the mapping exercise, which informs the review question	See section: 2.2.1.
Element two: Developing the preliminary synthesis	Where initial findings of included studies are organised and described. Data extracted and study quality appraisal commenced.	See section: 2.2.2.
Element three: Exploring relationships	Involves a more rigorous examination of results that emerged from the preliminary synthesis, the reviewer searching for explanations for different results and barriers and facilitators to interventions. The reviewers then investigate relationships within and between included studies such as characteristics and findings of individual studies and	See section: 2.2.3.

	between those of different studies. Thematic analysis was utilised to identify initial results of included studies.	
Element 4: Assessing robustness of the synthesis	Being explicit about the methods discussed previously, including the appraisal of evidence included in the review for relevance and quality to support the conclusions of the synthesis	See section: 2.2.4.

These four elemental stages enable the reviewer to develop then answer the review question. Popay et al. (2006) and McDermott et al. (2013) propose that this approach enables the reviewer to step beyond simple description of included studies, enabling the exploration of concepts that may impact the review question and developing deeper understanding of the subject under investigation.

2.2. Review method

An explanation of the review methods now follows describing how each element of the narrative synthesis was achieved.

2.2.1. Element (I) Developing a conceptual model - method.

As identified in table 1. above, this element for the narrative synthesis seeks to develop a research question underpinned by a conceptual model (Popay et al., 2006). The mapping exercise discussed in section 1.7. enabled the development of a conceptual model. When discussing this first element of the narrative synthesis Popay et al. (2006) comment that not all reviewers choose to do this. Indeed, where their guidance offers tools and techniques for other

elements of narrative synthesis, none is offered for this first element. Popay et al. (2006) acknowledge the use of theoretical models more commonly in reviews of 'effectiveness', although they confirm that narrative synthesis can be used with a wide range of review questions besides those relating to effectiveness. This narrative synthesis aimed to explore, understand and synthesise findings from the current evidence. This in turn would then inform the research questions and objectives to be addressed in the subsequent empirical study.

2.2.1.1 Narrative description of the conceptual model of stroke patients' nutritional support.

Conceptual models can be presented in narrative and diagrammatic form (Popay et al., 2006), with both methods utilised here to enhance understanding of the model developed as the first stage of the narrative synthesis - see figure 2 below.

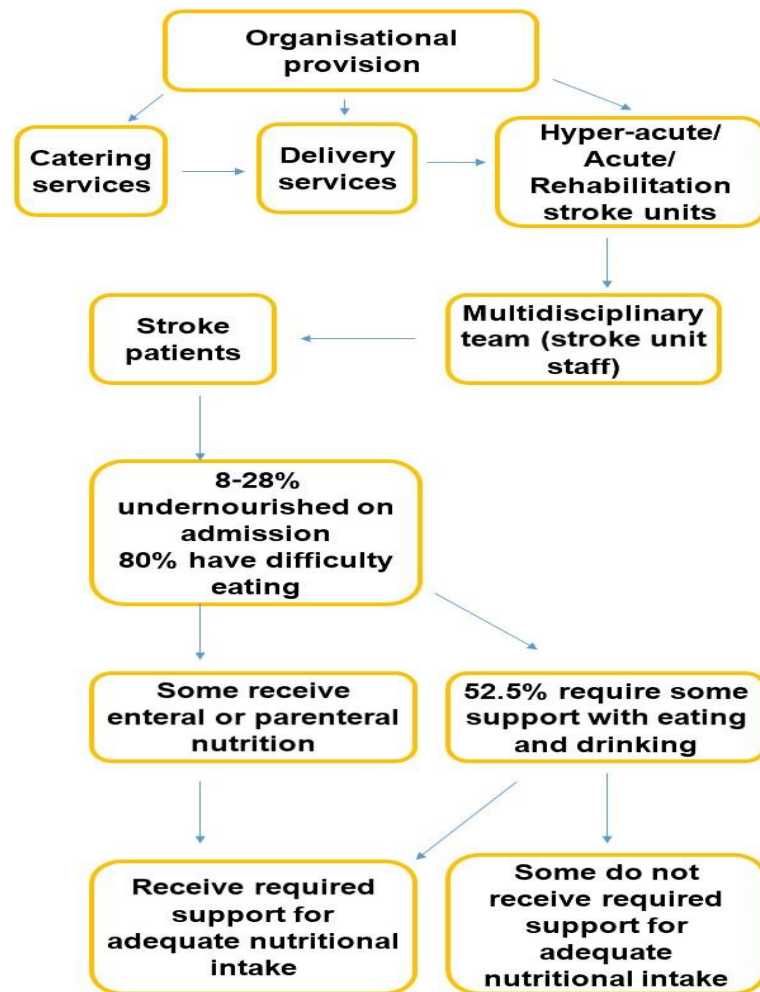


Figure 2. Conceptual model of stroke patients' nutritional care pathway during stroke unit care

The mapping exercise (section 1.7) identified evidence suggesting that a decrease in nutritional status for those taking diet and fluids orally post-stroke is likely to be due to a complex interaction of organisational and individual patient factors (SIGN, 2010). Contextual factors at an institutional (macro) level such as management of resources, including availability and delivery of suitable food and fluid and adequate staff provision are likely to play a part. Adequacy of the provision of education and training in nutritional care, and awareness of and availability of expert advice are potentially key contributors including the leadership and management of nutritional care at the patient interface (Ilott et al., 2013). Individual (micro) level staff factors such as staff perceptions of

nutritional care may also impact upon patients' nutritional status (Heaven et al., 2012; Perry et al., 2012).

The mapping exercise also identified evidence suggesting that stroke survivors commonly had difficulties with eating and drinking with some reliant on assistance for this activity (Westergren, 2002b, 2001a) and were often undernourished on admission to hospital, with nutritional status deteriorating for some during the hospital stay (Davis et al., 2004; Yoo et al., 2008; Hafsteinsdottir et al., 2010). Stroke patients who have a severe swallowing impairment may require enteral feeding via a nasogastric or a percutaneous endoscopic gastrostomy tube. Both orally and enterally fed stroke patients may require some level of support with nutritional intake. However, evidence suggests some stroke patients that continue to eat and drink via the oral route but require support to do so receive inadequate nutrition during their hospital stay (Mosselman et al., 2013).

Malnutrition caused by under nutrition and long-term dysphagia correlate with a slower rate of recovery (FOOD trial collaboration, 2003; Davis et al., 2004; Yoo et al., 2008). Slower recovery rates mean a longer hospital stay, poorer rehabilitation outcomes, increased incidence of chest infections, death and increased economic costs (Dennis et al., 2006; NCCCC, 2008; Hamilton and Boyce, 2013). The factors identified above and in figure 2, directed the search strategy and the remaining elements of the narrative synthesis described below.

2.2.1.2. Review question

Following the guidance of Popay et al. (2006) the conceptual model was used to inform the initial review question and the type of studies to be included in the search strategy. The conceptual model suggests that some stroke patients who are not enterally or parenterally fed do not receive adequate support to meet their nutritional requirements. A review question was formulated to enable

exploration of this topic. The development of a well-worded clinical question is key in guiding any literature review (Davies, 2011). Kloda and Bartlett (2013) suggest the development of a focused search question is aided by application of a question formulation tool, though they caution that the selection of one of the many available should be influenced by its relevance to the research question. The research evidence found in the mapping exercise consisted of mainly non - RCT observational studies, though that did not mean that qualitative studies do not exist that examine the topic. Therefore, a question formulation tool was required that could capture relevant research from both qualitative and quantitative research paradigms. The Population Intervention Control Outcomes [PICO] approach first developed by Richardson et al (1995) was identified to be suitable for this purpose. Despite some criticism that the PICO tool was developed to retrieve quantitative research studies, it has been found to be more sensitive than other specially developed tools in retrieving relevant qualitative studies (Cooke et al., 2012). The PICO tool was therefore used to develop the research question and is summarised in table 2. A definition of 'support' in the context of supporting eating and drinking was required. The mapping exercise discussed in section 1.7 identified that interventions to support eating and drinking were multiple and eclectic in origin (Westergren et al., 2001a; Perry et al., 2012). A definition of support was required that enabled inclusion of all possible aspects of support with eating and drinking. The definition chosen for this study was therefore purposely broad to ensure the inclusivity of relevant studies for a thorough investigation of the topic. The definition of support employed for the narrative synthesis and the following empirical study was adapted from the work of Westergren (2001a) and defined as 'any assistance offered to enable a person to eat and drink after stroke in the hospital setting'. For further clarification support with eating and drinking is concerned with direct actions: including placing food and drinks within reach of the stroke patient, ensuring food and drinks are of the correct consistency, providing adapted cutlery and crockery, providing direct assistance to move food/drink from a plate or dish or glass to the mouth, observing (where indicated) and physically assisting to ensure food is chewed and swallowed appropriately. Indirect actions include providing assistance to choose food which is consistent with stroke survivors' preferences, ensure the provision of adequate appropriate food and drink, encouraging eating and drinking,

assessing and recording food and fluid intake. Interventions delivered by both qualified and unqualified healthcare staff and informal carers were included as studies identified during the mapping exercise revealed such persons supported eating and drinking with stroke patients at some point in the hospital stay (Carr and Mitchell, 1991; De Pippo et al., 1994).

Table 2. Application of the PICO approach in the review question development

Population	Intervention	Comparison	Outcome
Stroke patients in hospital with eating and drinking difficulties	Support (provided with eating and drinking)	none	Adequate nutrition

Review question: 'Does the support provided for hospital in-patients with eating and drinking difficulties after stroke result in adequate nutrition?'

This review aimed to identify and synthesize evidence from research focusing on support for eating and drinking via the oral route in patients soon after stroke in the hospital setting and examine the reported impact on nutritional status.

The objectives were to determine:

1. The nature of support provided for stroke patients with eating and drinking difficulties in hospital settings.
2. The reported effectiveness of identified support on nutritional status.
3. Reported barriers and facilitators to provision of support for eating and drinking post-stroke in the hospital setting.

2.2.1.3. Search strategy

A search strategy was developed in consultation with an information retrieval specialist. Text terms and Medical Subheadings [MeSH] descriptors for stroke developed by the Cochrane Stroke group were utilised along with the terms

eating, drinking and support and their synonyms as per the PICO approach (O'Connor et al., 2008), see appendix B. An initial search was conducted in Medline to assess the specificity of the search strategy - see table 3 below.

Table 3. Demonstration of the initial search using Medline

Database	Date of search	Stroke with MeSH descriptors	Eating Drinking with synonyms	Support with synonyms	Combined results	Limits English language 1990-present	Initial screen for relevance of title and abstract
MEDLINE	16.4.14	60133	42368	901768	2403	2195	45

The Medline search resulted in 2195 hits. Individual studies were screened for relevance using a tool designed by the researcher (Higgins and Deeks, 2011). The search was extended, as the previous Medline search had identified literature that cut across different health professions and topics regarded as fulfilling the 'support' definition. The Information specialist also advised on relevant databases and ensured that the controlled vocabulary for each database was appropriate to that specific database as advised by Stevinson and Lawlor (2004). Petticrew and Roberts (2006) further suggest that research design terms are not used in searches to enable inclusion of studies from both quantitative and qualitative research paradigms.

In consultation with the information retrieval specialist for health subjects and following their advice as to where relevant literature for the study topic was likely to be found, the following databases were selected and searched: Cochrane central register of controlled trials (CENTRAL); EMBASE; CINAHL; Cochrane Reviews; PsycINFO; TRIP; Web of Science; ProQuest Dissertations and Theses; ProQuest IBSS; ProQuest Social Services abstracts; ProQuest ASSIA; ProQuest Sociological Abstracts. All databases were searched between 14th of June 2014 and the 18th of July 2014, see appendix C. Search date limits were 1st January 1990 to 18th July 2014 and language was limited to English. This search was updated in September 2019 – see section 2.4. Reference lists of retrieved articles were also scanned for relevant studies. For evidence of existing reviews and to identify interventions and clinical practices

already evaluated, key references identified in policy documents on nutritional care and management in general hospital populations were also searched (Armstrong et al., 2011).

All articles retrieved were uploaded to Endnote x7 (Thomson Reuters, 2013) and a de-duplication process performed. Further references were identified from searching reference lists and added to ENDNOTE x7. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses [PRISMA] flow diagram developed by Moher et al. (2009) reports the search process and outcome - see figure three.

2.2.1.4. Study selection - Eligibility criteria

The following explanations of eligibility criteria have been summarised in table 4 below.

Table 4. Summary of study eligibility inclusion and exclusion criteria

<i>Inclusion</i>	<i>Exclusion</i>
Primary research or systematic review	Not primary research or systematic review
Stroke patients aged 18 years and over	Stroke patients aged under 18 years
Stroke patients are being cared for in a hospital setting (acute or rehabilitation)	Stroke patients are NOT being cared for in a hospital setting
Stroke patients are receiving support with eating and drinking	Stroke patients are NOT receiving support with eating and drinking
Stroke patients are not receiving enteral or parenteral nutrition	Stroke patients are receiving enteral or parenteral nutrition
Study published in the English language	Study NOT published in the English language
Study published after January 1990	Study published prior to January 1990

Types of Studies: To address the objectives set out above, and in keeping with the rationale for the narrative synthesis (Popay et al., 2006) studies utilising a range of research methodologies were eligible to ensure inclusivity. Eligible studies had to be empirical research or systematic reviews. Only studies published in English language from January 1990 were included due to limitations in resources for translation. Date limits were applied, as Stroke Units were the recommended pathway for all stroke patients from the early 1990's, the context of stroke care being very different prior to this time (Stroke Unit Trialists' Collaboration (SUTC), 2013). The mapping exercise carried out prior to the main review revealed minimal relevant research around the subject area prior to this date. Studies describing interventions that support oral eating and drinking with stroke patients were included.

Types of Participants: Studies of participants with a clinical diagnosis of stroke and requiring support with oral eating and drinking were included. The definition of stroke utilised is "rapidly developed clinical signs of focal or global disturbance of cerebral function, lasting more than 24 hours or until death, with no apparent non-vascular cause" (WHO MONICA project investigators, 1988, p.108). There is no age barrier for experiencing a stroke, though research with participants under the age of 18 years was excluded.

Studies including participants who were entirely fed enterally or parenterally were excluded. The following definition for both feeding methods developed by NICE (2006, p4) was employed, "enteral tube feeding is the delivery of a nutritionally complete feed directly into the gut via a tube; parenteral nutrition is the delivery of nutrition intravenously". Studies including participants where parenteral and enteral feeding methods were utilised in addition to provision of support with oral feeding were included if results had been analysed and presented separately for both types of participants (CRD, 2009). Participants of included studies had to be in the hospital setting, though no specification was placed on whether the level of care at the time of the study was acute or sub-acute.

Types of outcome measures: Individual studies reporting primary outcome measures of the effectiveness of nutritional support offered by anthropometric indices and biochemical indices were included as discussed by Mosselman et al. (2013). Studies reporting secondary outcome measures of the complications of requiring assistance with eating and drinking such as: incidence of aspiration; aspiration pneumonia; chest infection; functional outcomes; length of stay; pressure ulceration and death were included.

2.2.1.5. Selection process

An adapted PRISMA diagram describing the search process and study selection is shown in figure 3 below. The titles and abstracts of retrieved records were screened to identify relevant material using the screening tool, see appendix D (Higgins and Deeks, 2011). The reviewer was overly inclusive at this stage to avoid excluding potentially relevant papers (CRD, 2009). Criteria for identifying and managing multiple reports of the same study provided by Higgins and Deeks (2011) were employed during the assessment of studies for inclusion. The opinion of a second reviewer was sought to confirm the suspicion of multiple reporting and the duplicate publications removed. Ten percent of records were independently screened by two independent screeners (20% in total) to minimise the risk of relevant papers being rejected. Any doubt about study inclusion or exclusion at this stage was resolved in all cases through discussion as advocated by Liberati et al. (2009).

Remaining papers were retrieved. An eligibility proforma for inclusion and exclusion was developed to assist with the task of deciding which papers were relevant to the review aim and objectives, see appendix E. The reviewer used the proforma to assess papers for inclusion or exclusion, which were independently assessed by a second reviewer to increase reliability. Differences in views about the inclusion of studies were resolved through discussion with a third reviewer. Decisions about inclusion and exclusion were recorded along

with a rationale for exclusion of studies, see appendix F. As recommended by CRD (2009) and Booth et al. (2012) the screening tool and eligibility proforma had been pilot tested on a sample of records by the supervisory team to assess reliability for classifying and interpreting studies correctly at each stage.

2.2.1.6. Data Extraction

With reference to the review question, a data extraction form was developed to guide the extraction of relevant information from the included studies (Popay et al., 2006). Consideration was given that the included studies may potentially use both qualitative and quantitative research methods, hence the data extraction form needed to be sensitive enough to extract the required data from all the included studies. The form was developed from guidance published for data extraction in systematic reviews with adaptations made for the inclusion of qualitative research from the Cochrane collaboration (Higgins and Deeks, 2011; Noyes et al., 2011). The data extraction form was piloted on ten randomly selected studies as advised by Liberati et al (2009), see appendix G.

Petticrew and Roberts (2006) acknowledge that data extraction completed by a single reviewer can lead to data extraction bias. To minimise bias and for completeness and accuracy, a second reviewer checked six sets of data extracted by the reviewer. Supported by Higgins and Deeks (2011), agreement on the data extracted was reached by discussion for all six sets of data checked for completeness and accuracy.

2.2.1.7. Quality Appraisal

As advocated by Popay et al. (2006), quality appraisal of included studies for the narrative synthesis was carried out using published appraisal tools appropriate for the methodology employed by a particular study. Appraisal tools have been developed to manage the appraisal of evidence from multiple

quantitative study designs such as the GRADE tool developed by Atkins et al. (2005). This tool was designed to appraise quantitative research evidence for systematic reviews including RCTs and observational studies of non-randomised trials. However, as previously stated, the researcher intended to include evidence from both the qualitative and quantitative research methods for this narrative synthesis if such evidence was retrieved. Polit and Beck (2014) advocate that rigour in quantitative research studies is measured by the validity of the conduct of the study and findings of the study, and by the credibility of methods and study findings for qualitative research. Therefore, the decision to use quality appraisal methods purposely designed to appraise specific research methods was employed. Booth et al (2012) recommend appraisal tools developed by the Critical Appraisal Skills Programme [CASP]; the latest CASP tools were used in this review for randomised controlled trials and cohort studies (CASP, 2013). Studies utilising cross sectional and more descriptive study methods were appraised using the Let Evidence Guide Every New Decision [LEGEND] appraisal tools developed by the Cincinnati Children's Hospital Medical Centre [CCHMC] (2012). These tools were designed specifically for appraising these types of study, whereas CASP have not produced specific tools for these types of study appraisal. Table 5 below identifies which appraisal tools were used to assess the quality of included studies.

Table 5. Methods of Quality appraisal of included studies

<i>Type of study</i>	<i>Appraisal tool applied</i>
Randomised Controlled trails [RCTs]	Critical Appraisal Skills Programme [CASP] – RCT checklist
Cohort studies	Critical Appraisal Skills Programme [CASP] – Cohort study checklist
Cross sectional design studies	Let Evidence Guide Every New Decision [LEGEND] - Cross-sectional study

Descriptive design studies	Let Evidence Guide Every New Decision [LEGEND] – Descriptive study
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Petticrew and Roberts (2006) and Booth (2012) advocate tabulation of the quality assessment process for all included studies to aid clarity of information and discussion of the review findings - see appendix I. Studies were rated as good quality (++); lesser quality (+); poor quality (-) adapting these rating from CCHMC (2012), CASP (2013) and NICE (2014). The reviewer completed the quality assessment. To minimise the risk of bias, a second reviewer independently appraised 20% of the studies, as recommended by Pope et al. (2007).

2.2.2 Element (ii) Preliminary synthesis - method

A characteristic of included studies table was developed using guidance from Popay et al. (2006), CASP (2013), NICE (2014). Pope et al. (2006) recommends using such tools which can assist later in the narrative synthesis process with the identification of patterns and the development of themes at the preliminary synthesis stage. The characteristics of the included studies table records the reference, country where the research originated, study design, the intervention or topic investigated, type and number of participants, outcome measures, data collection methods, setting, results/ key themes and quality assessment - see appendix H.

2.2.3. Element (iii) Exploring relationships - method

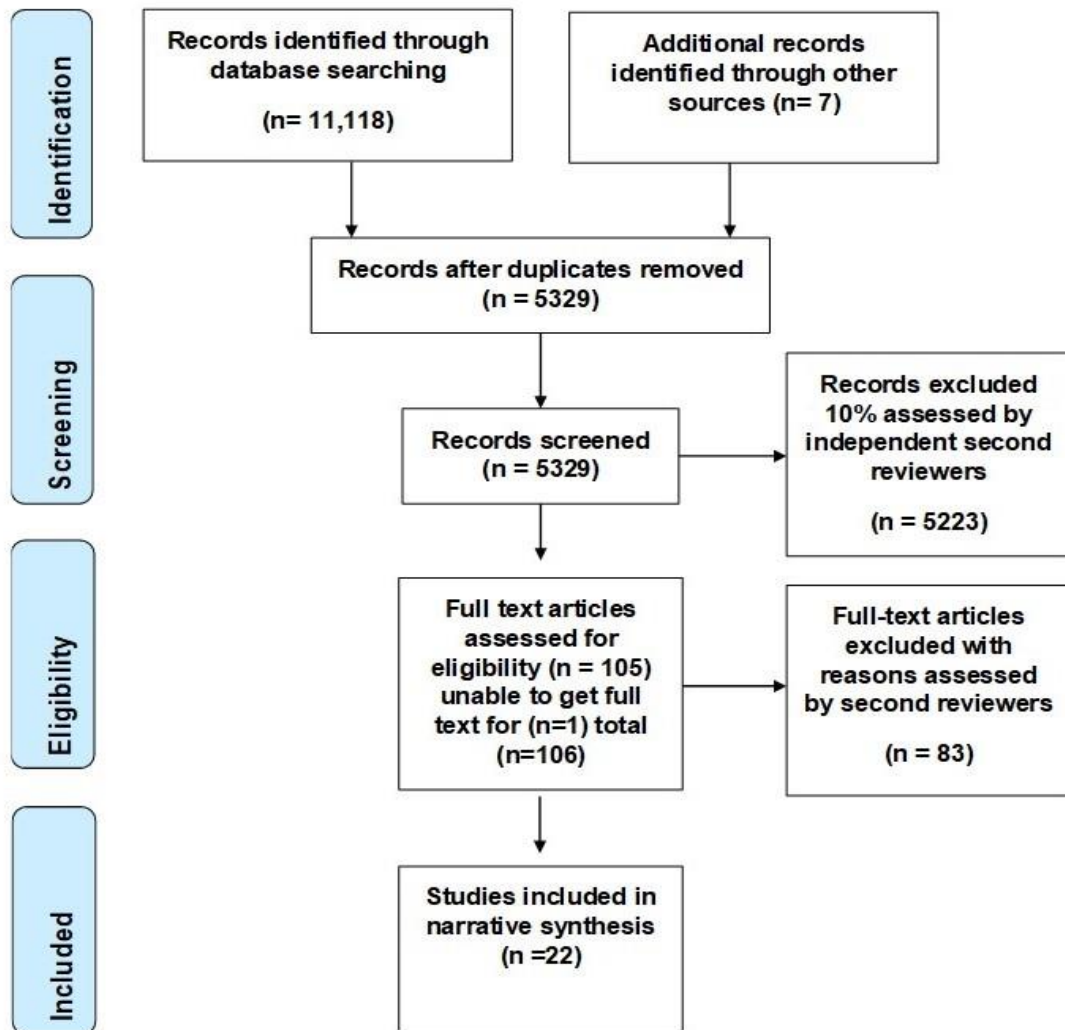
Popay et al. (2006) advise that this element of the narrative synthesis involves a more rigorous examination of results that emerged from the preliminary synthesis. It involves the reviewer searching for explanations for different study outcomes and relationships within and between included studies. Data from included studies were analysed using thematic analysis. This approach to data analysis was chosen for its ability to systematically identify themes across mixed methods studies, and Popay et al. (2006) support its application in narrative synthesis. A lack of transparency has been identified as a potential criticism of thematic analysis. In answer to this, Popay et al. (2006) recommend that the conduct of the thematic analysis process be reported in detail. Included studies were read, re-read and annotated. Data was extracted to a common matrix, organised then refined to develop substantive themes (Polit and Beck, 2014). The reviewer developed themes inductively identifying findings relevant to the review question from the included studies. Themes were developed from the identification of recurrent findings. Identified themes were reviewed and authenticated by the study supervisors.

2.2.4. Element (iv) Assessing the robustness of the synthesis - method

This aspect of a narrative synthesis is concerned with being explicit regarding the methods employed and incorporating the appraisal of evidence included in the narrative synthesis for relevance and quality (Popay et al., 2006). This transparency should support the conclusions of the narrative synthesis. This element is demonstrated in the methods discussed above and in the reporting of the results and conclusion of the narrative synthesis.

2.3. Search results

Following implementation of the search methods discussed above, the results of the search process are presented in figure 3. Differences in views about the inclusion of 10 studies were resolved at the screening stage through discussion with two independent screeners and excluded. Agreement for full text review prior to inclusion was reached for 106 studies at this stage with 5223 papers excluded. Full text of 105 of the remaining 106 studies was retrieved (one study was unobtainable). The reviewer and six second reviewers using the eligibility proforma see appendix E, reviewed all 105 studies. Agreement for inclusion/exclusion with reasons was reached for 91 studies; recourse to a third reviewer was required for decisions on 14 studies. Twenty-two studies were retained for inclusion in the narrative synthesis.



Adapted from PRISMA flow diagram (Moher et al, 2009)

Figure 3. PRISMA diagram of study selection 2014 literature search

2.3.1 Description of included studies

Popay et al. (2006) recommend a description of the characteristics of the included studies table presented in appendix H, to aid with interpretation of the included data which now follows. The twenty-two included studies were conducted in eight different countries including Australia (Carnaby et al., 2006); Canada (Foley et al, 2006); China (Huang et al., 2006; Xia et al., 2011); Japan (Takahata, 2011; Nakamura and Fujishima, 2013); Netherlands (Poels et al., 2006; Mosselman et al.,2013); South Africa (Blackwell and Littlejohns, 2010); Sweden (Unosson et al., 1994; Westergren et al., 2001a,b; Westergren et al., 2002; Carlsson et al., 2010; Medin et al., 2011); UK (Carr and Mitchell, 1991; McLaren and Dickerson, 2000; Perry, 2004; Rosenvinge and Starke, 2005; Mould, 2009) and the USA (DePippo et al.,1994; McGrail and Kelchner, 2012). The studies investigated diverse topics that were seen to relate to supporting eating and drinking in stroke patients and are discussed in section 2.3.1.1 below.

The study designs of the twenty-two selected studies were eclectic. These consisted of three RCTS (DePippo et al., 1994; Carnaby, 2006; Xia et al., 2011); one cross over study (Nakamura and Fujishima, 2013); three quasi-experimental studies using before and after designs (Rosenvinge and Starke, 2005; Huang et al., 2006; Takahata et al., 2011); one prospective cohort study (Foley et al.,2006); two retrospective case note audits (Blackwell and Littlejohns, 2010; Carlsson et al., 2010); one observational audit (Mould, 2009) and eleven non-experimental designs (Carr and Mitchell, 1991; Unosson et al., 1994; McLaren and Dickerson, 2000; Westergren et al 2002; 2001a; 2001b; Perry, 2004; Poels et al., 2006; Medin et al., 2010; McGrail and Kelchner, 2012; Mosselman et al., 2013).

Twenty-one studies included participants or records of participants that had been diagnosed with stroke. In the study by Mould (2009) participants included ward staff and stroke patients but the number of patients or staff observed was

not reported. Eleven studies described the type of stroke diagnosed; ischaemic (n= 798) (Unosson et al., 1994; Westergren et al., 2001a; 2001b; Westergren et al., 2002; Carnaby et al., 2006; Foley et al., 2006; Poels et al., 2006; Medin et al., 2010; Xia et al., 2011; McGrail and Kelchner, 2012; Mosselman et al., 2013; Nakamura and Fujishima, 2013); haemorrhagic (n=140) (Unosson et al., 1994; Westergren et al., 2001a;2001b; Westergren et al., 2002; Carnaby et al., 2006; Foley et al., 2006; Poels et al., 2006; Takahata et al., 2011; Xia et al., 2011; Mosselman et al., 2013; Nakamura and Fujishima, 2013), other (n=50) - this category included stroke of unknown aetiology (Carnaby et al., 2006; Medin et al., 2010; Xia et al., 2011), Transient Ischaemic Attack [TIA] in one study (Unosson et al., 1994) and Sub Arachnoid Haemorrhage [SAH] in another (Nakamura and Fujishima, 2013). Stroke severity was recorded in seven studies with some using more than one assessment method hence the higher number of assessments than studies (Westergren et al., 2001a; 2001b; Westergren et al., 2002; Carnaby et al., 2006; Foley et al., 2006; Medin et al., 2010; Takahata et al., 2011; Mosselman et al., 2013). Assessments included the Modified Rankin scale (n=3); Barthel index (n=3); Glasgow coma score (n=1); Katz' ADL index (n = 3); Canadian neurological scale (n=1); National Institute of Health Stroke Scale (n=1); Severity assessed subjectively by Speech and Language Therapists (SLT) (n=1).

To summarise, the review included three RCTs, one crossover study, three quasi-experimental studies, one prospective cohort study, two retrospective audits, one observational audit and eleven non-experimental design studies.

2.3.1.1. Discussion of the methodological quality of included studies

As advocated by Popay et al. (2006), studies were rated for quality as good quality (++) n=7; lesser quality (+) n=11; poor quality (-) n=4, and the results tabulated in appendix I (CCHMC, 2012; CASP, 2013; NICE, 2014). The tabulated results are supported by the following description of the studies' methodological quality.

The methodological quality of the included studies varied considerably. Three studies employed RCT methodology which is widely regarded to deliver the most reliable research results (Polit and Beck, 2014). These studies investigated interventions for improving swallowing, which were reported as support for eating and drinking. Two RCTs investigated the effects of different training interventions provided by Speech and Language Therapists [SLTs] (DePippo et al., 1994; Carnaby, 2006). The third study investigated the effects of a dysphagia treatment using Vitalstim© (a form of electrical stimulation therapy) Xia et al. (2011). A strength of all three RCT's was that they used consecutive sampling techniques which were appropriate to meet the study objectives and were explicit in how these were recruited with explicit inclusion and exclusion criteria. The RCT by Carnaby et al. (2006) compared high and low intensity SLT therapy with usual care. Study strengths were that the number of participants met the requirements of the sample size power calculation and treatment allocation was randomised with the outcome assessor blinded to treatment allocation all reducing the chance systematic bias. Study weaknesses were identified with both patients and the therapist treating them being aware of treatment allocation introducing the possibility of treatment and outcome reporting bias. Attrition rates of 21% within the follow up period of six months were reported, which Polit and Beck (2014) assert can increase the risk of biased results, though this was adjusted for in the statistical analysis of Carnaby et al. (2006) results. Despite meeting the power calculation for sample size, the number of patients and outcomes events were statistically small meaning the treatment effect was less precise. This as well as being a single centre study reduces the generalisability of results.

A second smaller RCT by DePippo et al. (1994) compared three levels of dysphagia therapist control of diet and therapy. A study strength was that patients were blindly randomised into the three treatment groups reducing the risk of systemic bias. No mention is made as to whether the patients or therapists administering the three separate treatment protocols were blinded, though this would be unlikely in such a study as it would be obvious to

therapists and participants what treatment they were receiving, this raises the potential for treatment and reported outcome bias. It is not reported who collected the study data but potentially this could have been the same therapist who was delivering the treatment options, leading to potential bias in data collection. No power calculation was reported and no rationale given for the sample size but the study was carried out over a two-year period including 93% of eligible dysphagic patients identified in that time. Attrition was reported as less than 1% with minimal risk of attrition bias on results. The authors suggested that this was a representative sample of dysphagic patients during in-patient stroke rehabilitation making results more generalisable, though being a single centre study generalisability is limited.

Xia et al. (2011) compared the use of VitalStim therapy with conventional swallowing therapy in this small-scale RCT. There was no power calculation reported for sample size, therefore it is not clear whether the sample was adequately sized for the statistical conclusions potentially leading to errors in results Polit and Beck (2014). Patients were randomly allocated to treatment groups though not blindly leaving a potential for group bias. It was reported that there were no significant differences between the group participants for age, gender, cause and duration of dysphagia increasing the validity of results. Therapists blinded to the experimental design carried out the assessments, and delivered the therapies, reducing potential bias in reported therapy effect. There was no attrition of participants reported in this study therefore impact of attrition bias on the results was not a concern. The small scale of this study reduces the generalisability of the study results.

Despite some of the methodological oversights in the reporting of these three RCT studies, they were appraised to be of good quality - see appendix I. The studies were relevant to this review as they discuss dysphagia with post stroke patients identified as affecting their eating and drinking in the hospital setting, they also offer further knowledge of the role of the SLT with dysphagia treatment and management and their role within the stroke MDT working on stroke units.

A cross over study (Nakamura and Fujishima, 2013) tested the usefulness of ice massage to elicit a swallowing response. A cross over design is of benefit with reduced sample sizes as each participant acts as their own control and within subject variance is less than between subject variance as with a separate control group adding validity to the study results (Hui et al., 2014). The study consecutively recruited a small sample with clearly defined inclusion and exclusion criteria and reported no attrition of participants, though 5 of the 24 subjects could not complete the full set of swallow trials. A power calculation is not reported, so it cannot be stated that this was an adequately sized sample to test the study hypothesis. Participants were randomly allocated to one of two treatment conditions though the randomisation method was not reported increasing the risk of systematic bias. In addition, there was no discussion of blinding of the assessors with potential assessor bias and blinding of participants was not possible potentially influencing the study results and reducing the validity of the study findings. The small scale of this study severely limits the generalisability of the results. Overall, this study was appraised as being lesser quality –see appendix (I) but was included in the review offering further evidence of post stroke problems that can affect patients' ability to eat and drink and require some aspect of support with this activity.

Three quasi-experimental studies used before and after designs testing a range of interventions and included in house training on compliance with SLT recommendations (Rosenvinge and Starke, 2005); training in swallowing for stroke patients with dysphagia (Huang et al., 2006); intensive oral care and use of behavioural intervention when being fed (Takahata et al., 2011). Only Takahata et al. (2011) included a control group increasing the validity of the results of this study. All studies used a single centre one-group pre-test - post-test design limiting the generalisability of their results. All used consecutive samples appropriate for the recruitment of participants to the studies. None of the three studies reported a rationale or power calculation for sample size with the studies potentially being under powered affecting the validity of the study results (Polit and Beck, 2014). Two studies did not report who collected data

from patient records and the observers were not blinded which increased the risk of bias with the study results (Huang et al., 2006; Takahata et al., 2011). Rosenvinge and Starke (2005) used an observational method to collect data; they report that all data were collected by one SLT who was not blinded to the study increasing the risk of observer bias on the estimated effect of the intervention and therefore the results (Karanicolas et al., 2010). Though patient and staff participants were blinded reducing the potential for the Hawthorne effect on the effectiveness of the intervention strengthening the validity of the study results (Polit and Beck, 2014). The methods reported by these three studies incorporated several design weaknesses impacting the validity of the study results, thereby suggesting these results should be viewed and used with caution. All three studies were appraised as lesser quality - see Appendix (I).

A small prospective cohort study by Foley et al. (2006) compared nutritional intake between three groups of stroke patients requiring different methods of feeding, group one - enteral feeding, group two - oral feeding with normal diet and group three - oral feeding with modified diet. Prospective cohort studies are viewed as weaker by design than other research designs as patients are not randomised and potential confounding variables may affect the validity of results (Polit and Beck, 2014). Inclusion and exclusion criteria were explicitly reported though sample sizes were small potentially reducing statistical power to detect differences between the three groups receiving different interventions (Foley et al., 2006; Polit and Beck, 2014). Ward nurses collected data and had no direct involvement in the study reducing the risk of data collection bias, though the authors could not verify the accuracy of the data collected. Some patient participant attrition occurred prior to the study end points and was acknowledged within the statistical analysis adding validity to the statistical analysis. Due to the methodological limitations this study was appraised as lesser quality - see appendix (I).

Two small studies employed retrospective case note audits to examine stroke patient's records to determine how MDT care was represented in records and what information was transferred to future care providers (Blackwell and

Littlejohns, 2010; Carlsson et al., 2010). Limitations of these study methods are the reliance on the accurate documentation in patients records which potentially affects the validity of the study results. Blackwell and Littlejohns (2010) despite randomly selecting their sample from multiple centres reducing the risk of researcher bias in sample selection, generalisability was reduced as the included care providers investigated were not representative of all South African stroke care providers. In addition, the method of randomisation for case note selection was not reported a potential source of bias affecting the study results. They reported multiple data collectors; interrater reliability was reported using Cohen's kappa coefficient, scores ranged from 0.65 - 1, and percentages of assessor agreement when the kappa score was unsatisfactory, increasing confidence in the consistency of observations and the conclusions drawn in the study. Carlsson et al (2010) data was collected by a single researcher though data selection was tested by a second researcher on 10% of the audited records and inter-rater reliability reported as medium to good. The use of consecutive sampling from one site reducing the generalisability of results. Both studies used a data collection tool and report statistical testing of tool reliability increasing confidence in results. Due to study limitations predominantly in size, both studies were appraised as poor quality - see appendix (I).

Eleven further studies used non-experimental designs to investigate a range of topics relevant to this review (Carr and Mitchell, 1991; Unosson et al., 1994; McLaren and Dickerson, 2000; Westergren et al 2002; 2001a; 2001b; Perry, 2004; Poels et al., 2006; Medin et al., 2010; McGrail and Kelchner, 2012; Mosselman et al., 2013). All eleven studies reported the use of consecutive sampling methods that were appropriate for the studies reported aims. None of the studies offered a rationale or power calculation for the sample size. Sample sizes varied but all were relatively small reducing confidence in the validity of their results. Data collection methods varied in the eleven studies including non-participant observational methods, data from patient records, biophysical measurement data and self-reported data all of which can result in varying degrees of bias potentially affecting the validity of the study results (Polit and Beck, 2014). Seven of the eleven studies reported multiple data collectors. Training of data collectors and / or the use of data collection tools was reported

in nine studies reducing potential subjectivity bias in data collection and increasing validity of results (McLaren and Dickerson, 2000; Westergren et al 2002; 2001a; 2001b; Perry, 2004; Poels et al., 2006; Medin et al., 2010; McGrail and Kelchner, 2012; Mosselman et al., 2013). Though, interrater reliability was only reported in two studies using Cohen's kappa coefficient, scores ranged from 0.65 - 1, increasing confidence in the consistency of observations and the conclusions drawn in these two studies only (McLaren and Dickerson, 2000; Perry et al 2004). Two studies did not report who collected the data or how data collectors had been prepared increasing the likelihood of researcher bias (McLaren and Dickerson, 2000; Medin et al., 2010). None of these eleven studies reported blinding data collectors which increased the potential for biased results. Some studies strengthened their results by including data from patients' records and self-reported data, triangulation of these results increases confidence in these study findings (Westergren, 2001a; 2001b; Mosselman et al., 2013). Data were analysed using parametric and nonparametric statistical methods relevant to sample size giving increased confidence in the reliability of reported results (Polit and Beck, 2014).

In summary three studies were appraised as being of good quality (DePippo et al., 1994; Carnaby, 2006; Xia et al., 2011). Fourteen studies were appraised as being of lesser quality (Unosson et al., 1994; McLaren and Dickerson, 2000; Westergren et al., 2001a; 2001b; 2002; Perry, 2004; Rosenvinge and Stark, 2005; Foley et al., 2006; Huang et al., 2006; Poels et al., 2006; Medin et al., 2010; Takahata et al., 2011; McGrail and Kelchner, 2012; Nakamura and Fujishima, 2013). Five studies were rated as poor quality due to methodological weaknesses including small sample sizes, sample size not reported, lack of sample randomisation, risk of bias in data collection methods and non-reporting of information such as timing of data collection (Carr and Mitchell, 1991; Mould, 2009; Blackwell and Littlejohns, 2010; Carlsson et al., 2010; Mosselman et al., 2013). Despite the variation in the quality, all studies were included in the narrative synthesis in line with the rationale for the adoption of the narrative synthesis approach to the literature review offered in section 2.1.1.

2.3.2. Element (II) Preliminary synthesis - results

Preliminary synthesis of the three RCTs investigating interventions for swallowing improvements yielded the following findings. Investigating training interventions by SLT, Carnaby et al. (2006) found trends towards favourable outcomes for reduction of death and institutionalisation/ dependency ($p \leq 0.06$), and significant reduction of medical complications including chest infection at six months ($p \leq 0.003$). DePippo et al. (1994) found patients receiving minimal interventions of changes to diet and compensatory swallow recommendations alone had statistically less pneumonia than those receiving increased SLT led therapy interventions ($p = 0.03$). Xia et al. (2011) found all groups improved after the therapeutic interventions under scrutiny, with significant improvement in the participants receiving Vitalstim© with conventional therapy ($p < 0.01$). One cross over study (Nakamura and Fujishima, 2013) tested the usefulness of ice massage to elicit a swallowing response. Results reported that ice massage significantly triggered a faster swallow reflex in dysphagic stroke patients.

Findings of the three quasi-experimental studies using before and after designs and testing a range of interventions: Rosenvinge and Stark, (2005) found that input from a dysphagia link nurse, improved staff training, use of pre thickened drinks and use of advice sheets significantly improved patient compliance with fluid consistency and amount, adherence to safe swallow guidelines and use of supervision. No significant compliance with dietary modification or swallow strategies was found. Huang et al. (2006) found that patients who had received SLT training on swallow techniques were significantly less likely to develop pneumonia than those fed by family members receiving general nursing information from a video. Findings from Takahata et al. (2011) demonstrate that early intervention with a SLT developed policy of oral feeding and oral care compared to usual care, significantly increased toleration of oral feeding. They also reported a trend towards reduced incidence of chest infection, length of stay and improved swallow function. The prospective cohort study by Foley et al. (2006) compared nutritional intake between three groups of stroke patients requiring different methods of feeding. They acknowledge an unexpected

finding that those requiring modified diet had no difference in protein or calorie intake from those taking a normal diet may be due to the relatively small sample sizes (less than 30) for each group.

Two retrospective case note audits by Blackwell and Littlejohns (2010) and Carlsson et al. (2010) presented findings of how MDT care was represented in records and what information was transferred to future care providers. Blackwell and Littlejohns (2010) found that of 47% of patients on oral diet were able to feed independently whilst 38% required assistance. A bedside assessment of swallow was achieved for 98% of patients with 10% receiving video fluoroscopy, though no timeframe for this was reported. They recommend that nurses in stroke care could help identify dysphagia and call to increase nursing knowledge in South Africa around monitoring swallowing, diet consistency, performance of sensorimotor interventions, feeding dependent patients. Carlsson et al. (2010) found nurses made 78% of multidisciplinary notes about eating difficulties and that written care plans for eating difficulties were unstructured, containing minimal management for the condition. Notes contained few traces of multidisciplinary collaboration for these issues. The authors anticipated that nurses consider themselves as having the major responsibility for nutritional assessment.

The findings of the eleven non-experimental studies were as follows and are also described on table 6 below. Carr and Mitchell (1991) found that nurses are less involved at mealtimes when meals are plated in hospital kitchens as opposed to on the wards. Nurses are more likely to offer assistance and mealtimes more likely to be observed by qualified nurses when meals are plated on the ward. Unosson et al. (1994) reported that feeding dependence in stroke patients was significantly associated to loss of body cell mass, that dependent patients consumed 64% of their food compared to independent patients who consumed 75% of their food. McLaren and Dickerson (2000) found impaired arm movement at 89% and posture at 84% the most prevalent eating disabilities. They also found a moderate negative correlation between energy provided and increased eating disability score and strong correlation between

dietary energy consumed and increased eating disability score, and the use of an eating disability assessment by nurses could assist in identifying patients at nutritional risk. McGrail and Kelchner (2012) found that stroke patients were unlikely to consume sufficient fluid whether they had normal or thickened fluids. In addition, those patients on thickened fluids were less likely to be offered drinks, had less choice of drinks and were more likely to be offered drinks of the incorrect consistency. Westergren et al. (2001a) reported 32% of stroke rehabilitation patients were at risk of or were already undernourished and this was significantly greater for patients requiring assistance with eating, and increased incidence of pressure ulcers in patients requiring assistance with eating. Mosselman et al. (2013) identified that stroke patients' nutritional status deteriorated significantly during the first ten days of admission ($p \leq 0.005$). In contrast the study by Poels et al. (2006) found that two or more eating difficulties and being dependent on feeding was significantly associated with malnutrition ($p < 0.05$) at admission but not at 4 weeks into the hospital stay.

The study by Westergren et al. (2001b) assessing patients on admission to rehabilitation and again at 3 months post stroke found those with swallowing difficulties on admission (66.7%) had improved swallowing at three months post admission with the requirement for compensatory strategies significantly reduced ($p < 0.0005$). In addition, the number of patients with malnutrition at 3 months was significantly increased ($p < 0.012$) from admission. The occurrence of respiratory infections significantly less at 3 months than on admission ($p < 0.007$). The transition to more regular food at three months was significant ($p < 0.0005$). They identified three subgroups in their sample as those unable to complete a meal, those who could complete a meal with great difficulty and those who could complete a meal with minor difficulties. Eating and swallowing difficulties were heterogeneous problems among patients after stroke with reduced alertness and energy an important obstruction for those with the most severe eating difficulties (Westergren et al., 2001b). Westergren et al. (2002) found that patients with fewer eating difficulties had shorter length of stay ($p < 0.002$). More women than men had low food intake on admission (women 86%, men 70% $p < 0.040$) and at discharge (women 77%, men 52% $p < 0.010$). Findings from Medin et al. (2011), also identified significant gender differences

with women having significantly more eating difficulties ($p=0.031$) and were more likely to be malnourished - statistically associated with the eating difficulty of inadequate food consumption. Perry (2004) identified that stroke patients with communication problems were more likely to have eating disabilities than those without communication problems. The findings of the eleven non-experimental studies though all related to eating and drinking with stroke, were heterogeneous in topic.

Table 6. Comparison of eleven non - experimental design studies

Study design	Consecutive sampling appropriate for study aims	Rationale reported for Sample sizes	Sample size √>(n=30) X<(n=30)	Data collection methods	Multiple data collectors	Test of interrater reliability	Training of data collectors or use of collection tool	Quality rating: Lesser Quality + Poor Quality -
Mosselman et al. (2013) Prospective descriptive	√	X	√(n=73)	Bio phys measures	√	X	√	-
McGrail and Kelchner (2012) Cross sectional survey	√	X	X(n=20)	Record analysis	√	X	√	+
Medin et al. (2010) Cross sectional comparative	√	X	√(n=104)	Non-part' obs	x	X	√	+
Poels et al. (2006) Case series	√	X	√(n=69)	Bio phys measures	√	X	√	+
Perry (2004) Descriptive case series	√	X	√(n=36)	Bio phys measures	√	√	√	+
Westergren et al. (2002) Descriptive observational	√	X	√(n=108)	Record Analysis/ interview	x	X	√	+
Westergren et al. (2001a) Descriptive	√	X	√(n=162)	Bio phys measures	x	X	√	+

observational Westergren et al. (2001b) Descriptive observational	√	X	X(n=24)	Non-part' obs Bio phys measures	x	X	√	+
McLaren and Dickerson (2000) Cross sectional	√	X	√(n=75)	Non-part' obs	√	√	x	+
Unosson et al. (1994) Descriptive observational	√	X	√(n=50)	Bio phys measures	x	X	√	+
Carr and Mitchell (1991) Comparison study	√	X	√(n=40)	Non-part' obs	x	X	√	-

2.3.3. Element (III) Exploring relationships in the data - results

Themes were developed using the process described in section 2.2.2.1. Themes were reviewed twice by supervisors and further developed following these discussions. Five themes were developed in response to the review outcomes identified in section 2.2.1.2 and are identified in table 7 below followed by a discussion of the identified themes.

Table 7. Themes in response to review objectives

<i>Review objective</i>	<i>Related themes</i>
Objective 1 - The nature of support provided for stroke patients with eating and drinking difficulties in hospital settings	Theme 1 - Multiple agents provide support with eating and drinking
Review objective 2 - The reported effectiveness of identified support	Theme 2 - Changes of nutritional status during the post -stroke hospital stay suggest inadequate or ineffective support with eating and drinking
Review objective 3 – Reported barriers and facilitators to the provision of support for eating and drinking post-stroke in the hospital setting	Theme 3 - institutional barriers to eating and drinking
	Theme 4 - patients' characteristics post stroke can be barriers to eating and drinking adequately
	Theme 5 - facilitators to eating and drinking post stroke

2.3.3.1. Review objective 1 - The nature of support provided for stroke patients with eating and drinking difficulties in hospital settings

2.3.3.1.1 Theme 1 - Multiple agents provide support with eating and drinking

A range of MDT members were identified as providing some form of support with eating and drinking within the included literature. Nurses were identified to offer some support in twelve studies (Carr and Mitchell, 1991; DePippo et al.,

1994; McLaren and Dickerson, 2000; Westergren et al., 2001b; Rosenvinge and Starke, 2005; Huang et al., 2006; Mould, 2009; Blackwell and Littlejohns, 2010; Carlsson et al., 2010; Takahata et al., 2011; Mosselman et al., 2013). SLT were identified to offer some level of support in six studies (DePippo et al., 1994; Carnaby et al., 2006; Blackwell and Littlejohns, 2010; Takahata et al., 2011; Xia et al., 2011; Nakamura and Fujishima, 2013). Carlsson et al. (2010) identified evidence of limited support from physicians, occupational and physiotherapists. Dietetic support was identified only in the study by Blackwell and Littlejohns (2010). In addition to MDT members, informal carers identified as the patients' family members were identified as supporting eating and drinking in two papers (DePippo et al., 1994; Huang et al., 2006).

Varying MDT activities in some way supporting stroke patients to eat and drink were reported in the literature. Reported nursing activities included meal delivery and preparation to enable eating such as cutting up food, assistance with body positioning, verbal and physical prompting with eating and drinking, directly feeding diet and fluids, recording of patients' food and fluid intake in various records (Carr and Mitchell, 1991; DePippo et al., 1994; McLaren and Dickerson, 2000; Westergren et al., 2001b; Rosenvinge and Starke, 2005; Huang et al., 2006; Mould, 2009; Blackwell and Littlejohns, 2010; Carlsson et al., 2010; Takahata et al., 2011; Mosselman et al., 2013). SLTs assessed patients swallow, delivered various therapies designed to improve patients swallow ability and prescribed support for nurses and informal carers to deliver (DePippo et al., 1994; Carnaby et al., 2006; Blackwell and Littlejohns, 2010; Takahata et al., 2011; Xia et al., 2011; Nakamura and Fujishima, 2013). Physicians, occupational and physiotherapists were identified to diagnose problems associated with eating and drinking activities (Carlsson et al, 2010). Dietitians were identified to prescribe dietary modifications and provide nutritional counselling (Blackwell and Littlejohns, 2010). Informal carers were reported to support patients to eat and drink but not the precise nature of these activities (DePippo et al., 1994; Huang et al., 2006).

Carlsson et al. (2010) in their audit of stroke patients discovered that 78% of recordings in patients' MDT records pertaining to patients eating and drinking

were made by nurses suggesting that nurses delivered most of the support for patients with this activity. This finding is supported in that twelve of the included studies mention activities and interactions by nurses in supporting patients' eating and drinking. The second largest professional group identified to offer some level of support with eating and drinking was the SLT with their activities the focus of six of the included studies. As reported above other professional groups - physicians, OT, PT and dietitians had limited activity reported to support eating and drinking.

2.3.3.2 Review objective 2 - The reported effectiveness of identified support on nutritional status

2.3.3.2.1 Theme 2 - Changes of nutritional status during the post -stroke hospital stay suggest inadequate or ineffective support with eating and drinking

Stroke patients' nutritional status was assessed at varying times during the hospital stay (DePippo et al., 1994; Unosson et al., 1994; Westergren et al., 2001a and b; Perry, 2004; Poels et al., 2006). Some stroke patients were assessed as malnourished on admission to hospital services with reported rates of 8% to 78% (Unosson et al., 1994; Westergren et al., 2001a and b; Poels et al., 2006). Nutritional status continued to decline for some stroke patients not receiving enteral or parenteral nutrition during the hospital stay (Unosson et al., 1994; DePippo et al., 1994; Westergren et al., 2001b; Perry, 2004; Foley et al., 2006) though for others nutritional status improved during the hospital stay (Poels et al., 2006). Some stroke patients not enterally or parenterally fed have inadequate nutritional intake during their hospital stay (Perry, 2004; Foley et al., 2006). Poels et al. (2006) suggests that the lack of agreed definitions and consistent measures for assessing adequate nutrition and malnutrition post-stroke makes comparison difficult, with 14 different measures to assess for malnutrition identified - see appendix K (DePippo et al., 1994; Unosson et al., 1994; Westergren et al., 2001a; 2001 b; Poels et al., 2006; Medin et al., 2010). Poels et al (2006) suggest development and adoption of a 'gold standard measure' would alleviate this issue. That stroke patients are becoming

malnourished during the hospital stay suggests they may not be receiving adequate support to eat and drink.

2.3.3.3 Review objective 3 – Reported barriers and facilitators to provision of support for eating and drinking post-stroke in the hospital setting

2.3.3.3.1 Theme 3 - institutional barriers to eating and drinking

Institutional factors controlled from without the direct stroke unit environment were seen to influence stroke patients eating and drinking. Rosenvinge and Starke (2005) and McGrail and Kelchner (2012) found the meal delivery systems and the appropriateness of food and drink available affected how much patients ate and drank, and the amount of support offered with eating and drinking. Carr and Mitchell (1991) found more nursing support with eating and drinking on stroke units where meals were plated on the ward rather than arriving already plated from the hospital kitchens.

The lack of provision of appropriate food and fluid resulted in stroke patients not attempting to eat the food provided or having difficulties ingesting food and fluid of an inappropriate texture (Rosenvinge and Starke, 2005; McGrail and Kelchner, 2012). The choice of beverage offered from catering departments was more restricted for patients requiring thickened fluids, which affected some patients' intake, as they did not like the flavour of drinks offered (McGrail and Kelchner, 2012)

2.3.3.3.2 Theme 4 - patients' characteristics post stroke can be barriers to eating and drinking adequately

Several studies identified patient characteristics post stroke associated with eating and drinking difficulties. These difficulties affected how much patients ate and drank which led to deterioration in their nutritional status and development

of further complications such as pressure ulceration. The identified characteristics are described in table 8 below.

Table 8. Characteristics associated with changes in nutritional status

<i>Characteristic</i>	<i>Study reporting characteristics</i>
Gender - women had more identified difficulties than men with eating and drinking postulated to be due to the average age of women being higher than that of men at onset of stroke.	Medin et al. (2010); Westergren et al. (2002b)
Requiring assistance with eating such as being fed or with physical closure of the lips or help maintaining sitting balance.	Westergren et al. (2001a) McLaren and Dickerson (2000) Unosson et al. (1994)
Requiring thickened fluids was a barrier to adequate hydration	McGrail and Kelchner (2012) Rosenvinge and Starke (2005)
Reduced alertness and energy levels	Westergren et al. (2001b)
Severity of communication difficulties	Perry (2004)
Requiring modified consistency of food	McGrail and Kelchner (2012) Rosenvinge and Starke (2005)
Inability to remove food coverings and packaging	McGrail and Kelchner (2012) Rosenvinge and Starke (2005)

2.3.3.3.3. Theme 5 - facilitators to eating and drinking post stroke

In one study receiving support from informal carers was reportedly as effective as an SLT programme incorporating modified diet and daily rehearsal of compensatory swallowing techniques in preventing dysphagia related

complications post-stroke which facilitate eating and drinking (DePippo et al., 1994). In another study, Huang et al (2006) found patients fed by family members were more likely to develop pneumonia than patients fed by an experienced nurse who had been trained to instruct patients on specific swallowing techniques. This suggests that informal carers can support patients eating and drinking but require adequate training and supervision with this activity.

In another study early initiation of oral feeding after sufficient preparation of patients by SLT's and mouth care delivered three times daily during the hospital stay facilitate adequate nutrition (Takahata et al., 2011). Rosenvinge and Starke (2005) reported that being cared for on a dedicated stroke-unit rather than a general ward increases compliance to SLT recommendations by nursing staff and further facilitating patients eating and drinking

Multiple SLT interventions were identified in the literature including swallowing exercises, dietary modification, ice massage, and Vitalstim© swallowing therapy system and were found to improve patients' swallowing ability therefore facilitating patients their ability to eat and drink (DePippo.,1994; Carnaby et al., 2006; Takahata et al., 2011; Xia et al., 2011; Nakamura and Fujishima, 2013).

2.3.3.4 Discussion of further relationships and characteristics of the included studies

Further relationships within and between the characteristics of the included studies and their findings are discussed in this section. Popay et al. (2006) and Rodgers et al. (2009) suggest that variability in outcomes, study design, study populations, interventions and settings should be explored to explain differences in the effects reported in the included studies. As stated previously not all studies included in this review tested interventions. Therefore, not all studies reported effects. Appraisal of quality of the included studies has been discussed previously in section 2.3.1.

All twenty-two studies included hospitalised stroke patients. The study findings reported on eclectic topics though this was to be expected as the definition of 'support' with eating and drinking adapted from Westergren (2001a) and used in this review question was purposely broad to capture as much data on topics pertinent to the subject as possible.

Relationships between individual study outcomes - Three studies measured outcomes related to SLT interventions for improvement in swallow function (DePippo et al., 1994; Carnaby et al., 2006; Xia et al., 2011), two of the studies comparing the incidence of medical complications such as aspiration pneumonia with changes in swallow function (DePippo et al., 1994; Carnaby et al., 2006). The third study measured improvement in swallow ability only, using four different tools designed for this purpose (Xia et al., 2011). There was great variability in the interventions evaluated and outcomes across the included studies making comparisons difficult.

Relationships between study samples and settings - The settings varied across the include studies. All but one study by Nakamura and Fujishima (2013) stated the setting where the study was carried out. Settings were described as acute medical (Carnaby et al., 2006; Takahata et al., 2011); acute stroke unit (Mould, 2009; Medin, 2010; Mosselman et al., 2013); stroke rehabilitation (DePippo et al., 1994; Westergren et al., 2002; Poels et al., 2006); neurology and rehabilitation (Unosson et al., 1994; Foley et al., 2006; Xia et al., 2011); geriatric rehabilitation (Westergren et al., 2001a; 2001b) general rehabilitation (Blackwell and Littlejohns, 2010); combined acute and rehabilitation stroke unit (Carlsson et al., 2010); stroke ward (Rosenvinge and Starke, 2005); acute hospital (McLaren and Dickerson, 2000; Perry, 2004; Huang et al., 2006; Mc Grail and Kelchner, 2012); medical ward (Carr and Mitchell, 1991). Such heterogeneity of settings makes comparison between settings and outcomes difficult. Seventeen of the studies were carried out in countries other than the UK, possibly explaining the diversity of clinical areas in which hospitalised stroke patients

were reported to be cared for. Five of the studies were from the UK, but despite there being guidance for stroke care published in the National Service Framework for Older People (DH, 2001) suggesting stroke patients should be cared for in dedicated stroke units, one of these five studies study describes the setting as an acute trust hospital offering no further detail as to the type of ward (Perry, 2004). Studies reported pre 2001 were set in an acute hospital - type of area not stated (McLaren and Dickerson, 2000) and medical wards (Carr and Mitchell, 1991) areas that were not stroke specific.

Relationships between study outcomes and results - The outcomes and results of the 22 included studies explored support with eating and drinking in some way and related to stages in the initial conceptual model, see figure 2. Health professional support with eating and drinking was largely characterised by SLTs providing specific therapeutic interventions or prescribing interventions to be implemented by other MDT members (DePippo et al., 1994; Rosenvinge and Starke, 2005; Carnaby et al., 2006; Blackwell and Littlejohns, 2010; Takahata et al., 2011; Xia et al., 2011; Nakamura and Fujishima, 2013). Direct assistance with eating and drinking when not associated with specific therapy sessions came mostly from qualified and unqualified nursing staff. This was alluded to in four studies (Carr and Mitchell, 1991; Rosenvinge and Starke, 2005; Huang et al., 2006; Mould, 2009) but was a discrete outcome measure in one study only (Carlsson et al., 2010). Whether feeding by carers influenced the development of medical complications was unclear. Two studies reported outcomes measuring the efficacy of lay carer support with eating and drinking (DePippo et al., 1994; Huang et al., 2006). DePippo et al. (1994) reported no increase in complications in those fed by carers rather than professionals. Huang et al. (2006) reported that those fed by carers were more likely to develop medical complications such as chest infections and pneumonia than those fed by professionals.

Although not a stated outcome of any of the studies, organisational factors were reported to affect the provision of suitable diet and fluids in two studies. Catering services were not delivering meals and drinks of the prescribed

texture, or a choice of food and fluid that was favourable to patients (Rosenvinge and Starke, 2005; McGrail and Kelchner, 2012). Timing of drinks delivery was also reported to affect patients' fluid intake (McGrail and Kelchner, 2012).

Nine studies explored outcomes measuring the nutritional status of stroke patients during the hospital stay (DePippo et al., 1994; Unosson et al., 1994; Westergren et al., 2001a; 2001b; Perry, 2004; Foley et al., 2006; Poels et al., 2006; Medin et al., 2010; Mosselman et al., 2013). Six of the studies reported deterioration in patients' nutritional status during the hospital stay (DePippo et al., 1994; Unosson et al., 1994; Westergren et al., 2001b; Perry, 2004; Foley et al., 2006; Mosselman et al., 2013), with only one study reporting an increase in nutritional status during the hospital stay (Poels et al., 2006). One study measured nutritional status at one point only so did not report changes to nutritional status (Medin et al., 2010). The reported duration of the data collection period varied in these studies from being not reported (DePippo et al., 1994); 21 days post admission (Foley et al., 2006); one month post admission or at discharge (Perry, 2004); four weeks post admission (Poels et al., 2006); up to day 12 post admission (Mosselman, 2013); up to week nine post admission (Unosson et al., 1994) and three months post admission (Westergren et al., 2001b).

Patient characteristics were reported against measured outcomes in seven studies investigating the nutrition and hydration status of stroke patients during the hospital stay (Unosson et al., 1994; Westergren et al., 2001a; Perry, 2004; Foley et al., 2006; Poels et al., 2006; Medin et al., 2010; McGrail and Kelchner, 2012). Characteristics varied, those requiring modified diet and fluid and those eating normal diet and fluids (Foley et al., 2006; McGrail and Kelchner, 2012); eating difficulties (Perry, 2004; Poels et al., 2006; Medin et al., 2010) gender (Medin et al., 2010); Communication difficulties (Perry, 2004); needing assistance with feeding (Unosson et al., 1994; Westergren et al., 2001a). Multiple methods of measuring for malnutrition were employed by these studies - a summary of methods can be seen in appendix K. Heterogeneity in data

collection periods, methods of measuring malnutrition and patient characteristics makes comparison of these study findings difficult

2.3.4. Element (IV) Assessment of the robustness of the synthesis - results

Popay et al (2006) suggest authors of narrative synthesis reflect critically on the synthesis process in assessment of the robustness and trustworthiness of the review. The synthesis process commences with the development of a theoretical model. As discussed in section 2.2.1. this review developed a conceptual model. Clarity on the development of a theoretical or conceptual model was difficult to find in publications describing the methodology of the narrative synthesis approach. Examples of reviews used in the published guidance by Popay et al. (2006) either did not include a theoretical or conceptual model or included a brief textual theoretical model but did not describe how this was developed (Rodgers et al., 2009). In this review and following the guidance of Popay et al. (2006), a conceptual model was developed from the evidence sourced in the mapping exercise discussed in section 1.7. the conceptual model then supported the development of the review question.

In this narrative synthesis as directed by Popay et al. (2006), the search strategies, inclusion / exclusion criteria, data extraction methods and characteristics of the studies are clearly presented in section 2.2. The transparency of these processes supports the trustworthiness of the review findings.

This narrative synthesis includes 22 studies published from 1990 to 2013. The preliminary synthesis reports and organises the findings of the included studies in section 2.3.2. Studies focused on a range of factors related to the support provided for patients with eating and drinking difficulties post-stroke in hospital

and utilised a variety of quantitative research designs. No qualitative data were identified in the included studies. All included studies were critically reviewed, and the methodological quality of studies presented and discussed in section 2.3.1.1 and appendix I.

Element (III) of the narrative synthesis - exploring relationships in the data is reported in section 2.3.3. Thematic analysis was used to synthesize the textual descriptions of findings from the studies. Popay et al. (2006) support this method of analysis for the narrative synthesis approach as it enables findings from research using varied methods as identified from the literature search to be organised and summarised. Popay et al. (2006) acknowledged limitations around the transparency of the thematic analysis process and the subjectivity of the researcher developing the themes. These limitations have been addressed as far as possible in this literature review by the provision of 'characteristics of included studies' - see appendix H and description of and tabulation of the thematic analysis - see example in appendix J, the thematic analysis was reviewed by a supervisor with recommended changes being discussed and agreed (Pope et al., 2007).

2.4. Literature search update 2019

As the original search for literature was undertaken in late 2014. In consultation with an information specialist, a further search to capture literature on stroke and eating support published since 1st January 2014 was undertaken in September 2019 to determine if there was new evidence relevant to the review questions and determine if this new evidence would alter the findings of the narrative synthesis. The search comprised three concepts: Stroke and Eating and Support. Searches consisted of subject headings and text words for the three concepts, with the date limit 1st January 2014 to September 2019 and English language where these limits were available. A minor change to the search strategy was made for the 2019 search, see appendix B. Appendix C describes the databases included in the 2019 search. Because of this change,

the 1990 - 2014 search was re-run with the updated search strategy. No new relevant studies were found from this search.

The electronic search from 1st January 2014 to September 2019 identified 7430 records that were reduced to 5862 after duplicates were removed. The researcher assessed the titles and abstracts from the electronic searches, with obviously irrelevant studies from the 5862 excluded. A second reviewer independently checked ten percent of removed studies at this point for accuracy and agreement was achieved for the excluded studies. Full text articles for the remaining 15 studies were obtained. These were assessed for relevance against pre specified inclusion criteria by the researcher, see appendix E. The second reviewer independently assessed all 15 studies. There were no disagreements with the decisions made, 12 studies were excluded, and three studies remained as per the example in appendix F. Data were extracted from the three remaining studies independently by the author and the second reviewer. The search process is demonstrated in an adapted PRISMA diagram, see figure 4 below.

The three papers identified from the updated search were reviewed and assessed for methodological quality using the same appraisal tools and process employed for the literature search completed in 2014 see section 2.2. The three studies varied in design and quality, one was rated as poor quality (Payne et al., 2015) and two as good quality (McGrail and Kelchner, 2015; Robertson et al., 2019). Two studies explored a range of topics relevant to supporting stroke patients with eating and drinking in stroke rehabilitation settings (Payne et al., 2015; Robertson et al., 2019), and one study across a neuroscience unit and stroke rehabilitation unit (McGrail and Kelchner, 2015).

A prospective observational study by McGrail and Kelchner (2015) investigated if fluid consistency determined how often fluids were offered to stroke patients, how much fluid was consumed and if functional deficits based on a Functional Independence Measure and dysphagia could predict fluid intake for post stroke

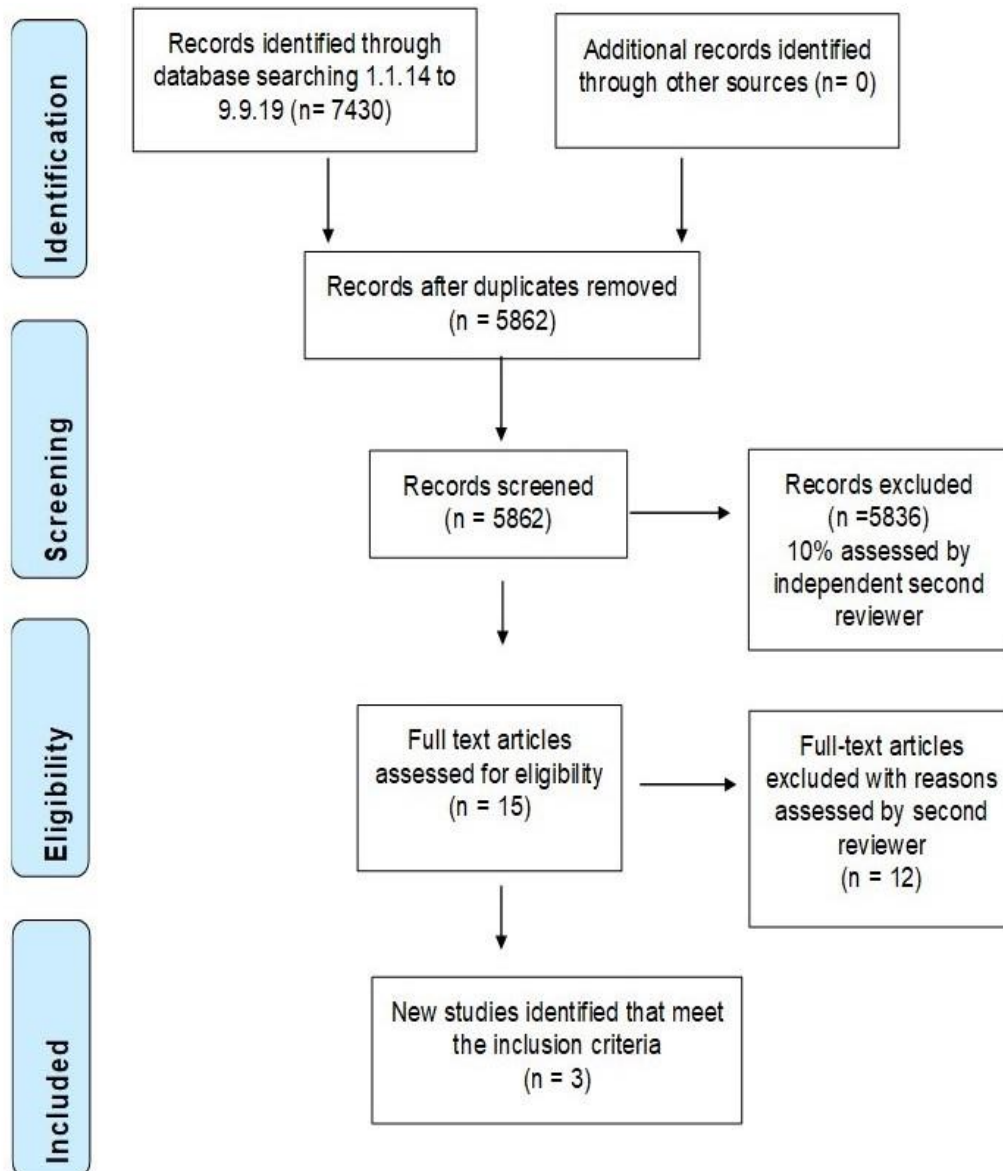
patients. Those patients on thin fluids consumed significantly more fluid than those on thickened fluids. The patients' increased level of dependence for eating negatively affected fluid intake for those patients taking thin fluids, but not those patients taking thickened fluids. Patients with greater independence in eating and drinking consumed more fluid whether this was thin or thickened fluid. The patients' level of cognition significantly predicted fluid intake for patients taking thickened fluids, but not for those on thin fluids. Viscosity of fluids negatively affected how much fluid was offered to patients, with patients on thin fluids offered significantly larger amounts than those on thickened fluids. The findings of the study suggest that hospitalised stroke patients consume substandard amounts of fluid regardless of fluid consistency. These findings support those reported from the 2014 review in theme 5 patients' characteristics post stroke can be barriers to eating and drinking - see section 2.3.2.3.2.

An action research study by Payne et al. (2015) explored the implementation of a collaborative Feeding Care Plan [FCP] and the effects of this on eating independence for stroke patients. The study found no difference to eating independence for either the control or intervention group, though as the study was completed at what are considered the early stages of post stroke recovery 7 - 19 days this may have had some effect on the outcomes. The FCP group did have a significant improvement in upper arm independence. Although interdisciplinary staff collaboration was not one of the study objectives it was noted by the authors that this improved during the education programme and implementation of the FCP. Support with eating and drinking offered by MDT members was explored in section 2.3.3.1.1 theme 1 - *Multiple agents provide support with eating and drinking*, in the original 2014 narrative synthesis. However, none of the studies discussed in that theme directly explored interdisciplinary team working or rehabilitation of upper limb in promotion of independence with eating and drinking. These new findings add to the narrative synthesis demonstrating that interdisciplinary working within the MDT may benefit stroke patients' upper limb recovery thereby potentially developing their independence with eating and drinking and reducing their support requirements.

Robertson et al. (2019) used a before and after design to explore the intervention of enriched environments. These consisted of meals taken in communal areas with assistance offered and nutritional intake reminders placed at bedsides. This group was compared to a standard care group - where meals were delivered to patients' rooms and assistance given if required by nurses and assistants. Whole group comparisons found no significant difference in energy and protein intake between the two groups with neither group achieving daily requirements for energy and protein. However, when grouped by stroke severity the results demonstrated different trends, though none reached statistical significance. Mild strokes showed no difference between groups, moderate strokes intake of protein and energy were higher in intervention group, severe strokes had a slightly greater energy intake in standard care group than intervention though these were small groups and received some enteral nutrition (n=4 vs n=3). Mean body weight dropped in both groups and was not significantly different between the two groups. Length of stay [LOS] and protein or energy intake independently predicted malnutrition on discharge from hospital. The findings of this study support those reported in section 2.3.3.2.2 theme three- *Changes of nutritional status during the post stroke hospital stay*, in the original 2014 literature review. They suggest that LOS and protein and energy intake can predict malnutrition during the hospital stay.

None of the three studies included from this updated literature search reported any significantly different findings to those in the 2014 review despite the five-year progression in in-hospital stroke care and management. Included in the thematic analysis from 2014, these new findings fitted into and strengthened the existing themes. This suggests that the conclusions of the 2014 narrative synthesis were still relevant in late 2019.

Figure 4. PRISMA diagram of study selection 2019 literature search



Adapted from PRISMA flow diagram (Moher et al, 2009)

2.5. Discussion

A narrative synthesis was conducted to allow the exploration and interpretation of current knowledge and the gaps in knowledge from studies utilising eclectic research designs to further understand the concept of supporting stroke patients to eat and drink in the hospital setting. This narrative synthesis followed guidance from Popay et al. (2006) ensuring a systematic and transparent process leading to the development of the synthesis findings. A systematic search of twelve established health databases using search terms and synonyms suggested by the review question cast a wide net for articles related to the research question. A limitation of the review is that only English language articles could be included due to the lack of availability of translation services. Egger et al., (1997) suggests this may have led to some bias in results with some pertinent studies potentially lost to the review due to being published in a different language. They propose that authors from non - English speaking countries tend only to publish studies with statistically significant results in English language journals and any studies with non-significant results are often published in native language journals that can lead to publication bias. To increase inclusivity of unpublished evidence the Proquest Dissertation and Theses database formed part of the search strategy though this did not identify relevant unpublished studies. A search for other grey literature was not completed due to accessibility and time constraints.

The variation in quality of the primary studies in this review has been discussed previously. Quality appraisal was not used to exclude papers though inclusion of weaker evidence has previously been a criticism of the narrative synthesis approach (Popay et al., 2006). Overall, the methodological quality of the studies reviewed was limited meaning the study findings should be viewed with caution (Polit and Beck, 2014).

Thematic analysis was used in the development of the narrative synthesis. The choice of this technique was guided by the large variation in the designs of the

included studies and the ability of this technique to manage both quantitative and qualitative findings (Popay et al., 2006). Thematic analysis has been criticised for its lack of transparency in the development of themes (Pope et al., 2007). In this review, substantive themes were developed inductively using an iterative process. Themes were developed by the author and were reviewed by the supervisor with agreed changes made as deemed appropriate.

In response to the three review objectives, five themes emerged following thematic analysis. In response to objective 1 - *The nature of support provided for stroke patients with eating and drinking difficulties in hospital settings*. Studies revealed limited evidence of the specific roles of MDT members in supporting stroke patients to eat and drink except for SLT. Though these studies focused on specific SLT interventions for improving dysphagia rather than all aspects of the role of the SLT in supporting eating and drinking. Nurses were identified in numerous activities that could be seen to support eating and drinking though no study focused specifically on the role of the nurse in supporting the process of eating and drinking. The role of other MDT members including physicians, dietitians, OT, and PT, in any activity supporting eating and drinking was extremely limited suggesting they had a minimal participation in this aspect of stroke patients' care. No studies investigated or reported on the specific the roles and responsibilities of any of the professions identified in the stroke MDT in relation to supporting eating and drinking. There was some limited evidence of informal carers [ICs] reported as family members supporting patients to eat and drink after stroke, though the evidence was conflicting as to the benefits of patient receiving IC support. The dearth of studies investigating lay carers' roles in supporting eating and drinking was a surprising finding, as several agencies in the UK (NPSA, 2009b; DH, 2010; NICE, 2013a) support the role of lay carers in assisting patients with eating and drinking. The two studies discussed here were from the United States of America [USA] and China. The literature searches found no studies that investigated the views of stroke patients or lay carers regarding support with eating and drinking.

In response to objective 2. *The reported effectiveness of identified support on nutritional status.* Multiple different measures of patients' nutritional status were identified in the literature making comparisons between studies difficult. This was acknowledged in the literature with one author suggesting that the development of a gold standard of nutritional measurement would alleviate this issue (Poels et al., 2006). The evidence commonly identified malnourishment in stroke patients at admission to stroke services but for some this continued throughout the hospital stay. This suggests that some stroke patients do not have adequate nutritional intake during their hospital stay potentially impacted by inadequate identification of their reduced nutritional state and further compounded by lack of support required to eat and drink adequate amounts of food and fluid. The undernutrition of hospitalised stroke patients was not an unexpected finding as undernutrition is also evident in the general hospital patient population and is recognised as an international concern with evidence from Australia, UK and the USA (Barker et al., 2011; DeLegge and Kelly, 2013; Corkins et al., 2014). Relating to role responsibility with supporting eating and drinking, the literature did not identify which professionals within the MDT were responsible for assessing or monitoring stroke patients' nutritional status during the hospital stay.

In response to objective 3. *Reported barriers and facilitators to provision of support for eating and drinking post-stroke in the hospital setting,* multiple barriers to adequate support with eating and drinking were identified. The inconsistent provision of adequately prepared food and drink for patients requiring modified diets was seen to affect how much patients ate and drank (Rosenvinge and Starke (2005). Further evidence identified that stroke patients did not receive a nutritionally adequate diet whilst in hospital (Perry (2004). The provision of food in the hospital setting is usually organised by catering departments and not within control of individual hospital wards or in this case stroke units and has long been a concern in the UK and internationally (BAPEN, 2012; Williams et al., 2014). No evidence was found of communication or co-working occurred between stroke unit MDT and catering departments to ensure that stroke patients were provided with the correct consistency of diet and fluids or that dietitians who are specialist in managing patients' nutrition

communicated with catering departments regarding the nutritional content of food and drink.

Meal delivery processes could influence the level of support offered to stroke patients with eating and drinking. Patients receiving meals that were pre-plated and trayed in catering departments in contrast with those plated by nurses on wards received less support with eating and drinking (Carr et al., 1991). There was no evidence as to why this occurred, but the insinuation as that trayed meals were quicker to deliver so less time was spent with patients. Meal delivery methods are controlled without individual wards or stroke units at higher hospital organisational level. There was no awareness that stroke unit MDT members were aware that the meal delivery method could affect the level of support with their stroke patients eating and drinking, therefore deficits in such support may persist.

Further barriers to eating and drinking were the individual characteristics of stroke patients. Although individual characteristics affecting eating and drinking are common after stroke as identified in section 1.4, these patients were identified as being less likely to have adequate nutritional intake. Why this should be has not been clearly addressed in the literature at this time, though one implication being that these patients are not being offered adequate support to eat and drink. Why adequate support to eat and drink is not directly addressed in the literature though it may be surmised that the MDT either do not recognise these individual patient characteristics predicting that the patients may require support, or the characteristics are recognised but inadequate support is offered. There was no evidence identified in the literature reporting training or education about how to support stroke patients to eat and drink and support their nutritional wellbeing for the MDT, the patients or their informal carers (ICs).

Behaviours identified as facilitating support with eating and drinking were effective SLT therapies which promoted recovery from post stroke dysphagia (Huang et al., 2006; Takahata et al., 2011). Although such therapies were not directly measured against patients' nutritional intake in the literature, the supposition would be that improved swallowing would support food and fluid

intake and thereby patients' nutritional intake. Evidence investigating the role of ICs in supporting stroke patients to eat and drink reported as part of SLT interventions and was limited and conflicting. There was no evidence directly investigating ICs the benefits or non-benefits of ICs supporting their relatives with stroke to eat and drink in the hospital setting. Though some evidence from the general hospital population suggest IC support at mealtimes could be perceived to support patients to eat and drink, potentially improving their nutritional wellbeing (Walton et al., 2013)

2.6. Conclusions

The conclusion of this narrative synthesis is that stroke patients with the ability to take oral food and fluid remain at risk of undernourishment during their hospital stay on general medical wards but also on dedicated stroke units. The potential causes of this are multiple and complex involving actions and interactions from key stakeholders including the stroke patients and their ICs, hospital management and hospital departments other than stroke units and the stroke unit MDT. Some individual interventions have been investigated by the studies discussed above, employing quantitative research methods which are associated with supporting stroke patients to eat and drink and maintaining or improving their nutritional status or not. However, no evidence has been identified that investigated the whole concept of supporting stroke patients to eat and drink in the hospital setting. There were no studies found that employed methods enabling in-depth qualitative investigation of the day-to-day provision of care and support for stroke patients. As a result, the behaviours, beliefs and perceptions of the MDT staff, stroke patients and their informal carers in relation to the provision of support for eating and drinking were largely unknown in UK stroke units. An in-depth understanding of the concept of support with eating and drinking and the provision of such support in the hospitalised stroke population is needed to inform those with responsibility for stroke patients and their nutritional wellbeing at this time. The researcher proposed such a study and the research question, aims and objectives are presented in chapter 3.

Chapter 3: Methodology

3.1. Introduction

This chapter reports the development of the research question, aims and objectives from the findings reported from the narrative synthesis discussed in chapter 2. This is followed by an explanation and justification of the research methods designed to achieve the aims and objectives and thereby answering the research question.

3.2. Study aims and objectives

Findings from the narrative synthesis discussed in chapter two identified gaps in our current knowledge in relation to how stroke patients are supported to eat and drink in the hospital setting. This raised the following questions:

- What support with eating and drinking is delivered by the stroke unit MDT to stroke patients?
- What involvement do informal carers have with supporting eating and drinking with stroke patients?
- What organisational factors are in place to support eating and drinking?

In order to investigate these findings, the following research question, aim and objectives were developed.

Research question, aim and objectives

Research question:

How are stroke patients supported with eating and drinking in stroke unit care?

Research aim:

The overall aim of the project is to develop an in-depth understanding and explanation of the observed and perceived level of support with eating and drinking for stroke patients during their stroke unit care. This knowledge will be used to make recommendations, which could be used to inform a future intervention for supporting stroke patients with eating and drinking.

The objectives of the study are:

1. To determine how and by whom a requirement for support with eating and drinking is identified.
2. To identify how and by whom support is prescribed when a requirement for support is identified.
3. To investigate how and by whom prescribed and unprescribed support is delivered and monitored.
4. To explore how support with eating and drinking is perceived by patients, informal carers and MDT members.
5. To understand how organisational and contextual factors influence provision of support with eating and drinking.

3.3. Rationale for employing a qualitative methodology: ontological and epistemological considerations

Ontological philosophy within social research relates to our understanding of the social world, and can be viewed from two separate paradigms, positivist and constructivist (Guba and Lincoln, 1989). The positivist paradigm propounds that social reality exists independently to our individual beliefs and understanding of it. The constructivist paradigm refutes the idea of positivism, considering that our social world is only known via our own mind and our understanding that has developed and been conditioned by socially constructed meanings. The

influence of our mind and understanding means that external reality cannot independently exist (Guba and Lincoln, 1989; 1994).

Epistemology relates to how we study and acquire knowledge about the social world we inhabit and was traditionally guided by the researcher's ontological position. Latterly, it is suggested that the epistemology should be guided by the question posed, with consideration as to how it may be best answered (Polit and Beck, 2014). It is theorised that knowledge can be acquired inductively, developed from observation, or deductively where a pre-theorised hypothesis is applied to observations then confirmed, strengthening the theory or refuting it - weakening it (Polit and Beck, 2014). The researcher's relationship with the phenomena under investigation depends on which of the previous approaches are employed. In an inductive approach, it is suggested that the researcher cannot help but interact with the phenomena under investigation thus, results cannot be value free. In a deductive approach, the researcher strives to be as independent as possible and results are viewed as being value free (Ritchie et al., 2014). Our epistemological position and the research question guide the use of either qualitative or quantitative methodologies (Polit and Beck, 2014).

Findings from the narrative synthesis and the researcher's previous experience identified that some stroke patients require support to eat and drink. Findings of the narrative synthesis were developed from research employing positivist methodologies and quantitative methods, where the researchers developed and tested their hypotheses trying to find a single truth (Creswell, 2013). This evidence was of mixed quality and did not provide an in-depth exploration of support with eating and drinking for stroke patients. It was identified that support with eating and drinking does not consist of a single action that can be measured and analysed, rather it consists of multiple phenomena that enable the recognition of supporting eating and drinking as a social reality (Creswell, 2013). Consideration was given as to how the social reality of supporting eating and drinking could be investigated in-depth to elicit understanding of this social reality. To better understand the social reality of support with eating and drinking, the researcher identified that investigation of the multiple phenomena

making up support for eating and drinking - identified in section 2.2.1.2 and developed from the multiple perspectives of those individuals involved in the process was required. In doing this, the researcher acknowledged that the individuals under investigation would construct what they perceive as reality from their life experiences and is described by Carter and Little (2007) as the relativist or constructivist view of research knowledge. In practice, this meant the investigation of peoples' realities of support with eating and drinking was required to explore and develop further understanding of the topic.

Acknowledging that relativist ontological and epistemological theory underpin the study, a qualitative method of enquiry was required that enabled the exploration of participants realities, their behaviours, experiences practices and how these are recorded.

3.4. Rationale for the study design using a qualitative collective case study approach

The case study approach was employed for this study and there now follows a justification for this decision. To achieve the five research objectives and meet the study aim identified in section 3.2. a research approach that enabled the exploration of the process of providing support including both prescribed and unprescribed support for stroke patients with eating and drinking as required. To explore this process, Creswell (2013) stipulates that the researcher needs to see this process in action, and the case study approach allows the researcher to do this. Achievement of the research objectives also require the researcher to see how different stakeholders support eating and drinking with stroke patients in practice and their views on how such support is provided. Creswell (2013) establishes that the case study approach allows the collection of multiple sources of data from multiple stakeholders to explore this issue. Simons (2009) corroborates Creswell's views suggesting that one of the strengths of the case study approach is the ability to triangulate data from different data sources in the development of the research findings. Triangulation of qualitative data does not have the same purpose as triangulation of quantitative data. It does not set out to corroborate different sets of data, and manage potential bias, but enables

the issue to be viewed from different perspectives allowing more in-depth interpretation and understanding. It is argued that this type of triangulation strengthens the validity of qualitative research (Simons, 2009), see figure 5 below.

Achievement of the study objectives required the researcher to move further from an in-depth description of the support provided, to understand why support happens the way it does. The case study approach allows the researcher to build an in-depth understanding of an issue, which according to Creswell (2013) then informs the development of an explanation of the issue. Both Simons (2009) and Yin (2009) support Creswell's assertion further suggesting that demonstrating cause-and-effect relationships and generalisation of findings to large populations as with quantitative research is not the aim of case study research. Case studies can explain 'how' or 'why' rather than just a cause and effect and inferences can be made from case studies and applied to other cases and contexts (Simons, 2009; Yin, 2009). Given the variability of stroke unit set up in terms of structure and including staff making up the MDT and other support staff, it made sense to design a case study incorporating stroke units from more than one site. Stake (1995) describes case studies incorporating more than one case as collective case studies, with the aim of finding a collective understanding of the issue of phenomena under investigation.

One of the research objectives is concerned with understanding organisational and contextual factors and their potential influence on the provision of support with eating and drinking for stroke patients. Creswell (2013) purports the case study approach allows investigation of the issue (in this case support with eating and drinking) 'in progress' – within a real-life bounded setting. This enables in-depth exploration of this issue in context.

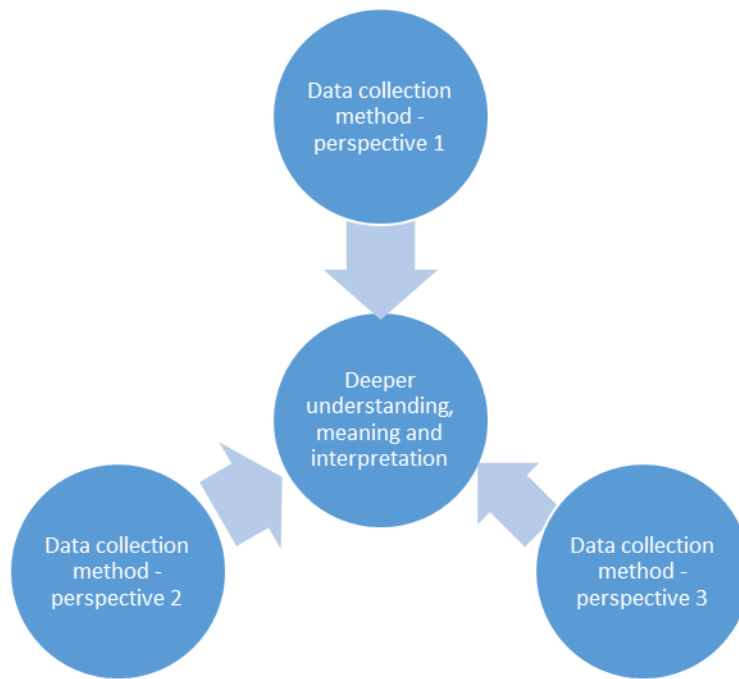


Figure 5. Triangulation in qualitative case study adapted from Simons (2009)

Simons (2009) advises that to achieve an in-depth understanding of the phenomenon under investigation, in this study support with eating and drinking, data collection methods are required with the ability to collect data from multiple perspectives and observations. The choice of data collection methods for this study are discussed in section 3.4.1 below.

3.4.1. Data collection – design

Data collection was planned consecutively from the two stroke units (cases). The rationale for this was twofold. Firstly, constraints on the researcher's time meant that the time spent at each site weekly for data collection would be diluted if done concurrently. The researcher, following guidance from Hammersley and Atkinson (2007) predicted that timing issues associated with concurrent data collection could affect rapport building with gate keepers affecting access to the sites, and rapport building and relationships with participants. Whereas consecutive data collection focusing on one site at a

time, would allow the researcher a fuller immersion at each site enabling rapport and relationship building increasing access to sites, participants and situations of interest to the topic. The second reason for consecutive data collection identified from Simons (2009) was that initial analysis of data collected at the first site could reveal developing areas of specific interest to the topic and more precisely guide data collection at the second site.

The qualitative collective case study approach requires more than one case for investigation to develop a collective understanding of the issue; Stake (1995) advises a minimum of two cases are required to allow within and across case analysis to occur. Following Gobo and Molle (2008), cases were purposively selected that had available attributes enabling exploration of the concept of support with eating and drinking during stroke unit care. Stroke units are defined as “a multi-disciplinary team including specialist nursing staff based in a discrete ward which is geographically defined and has been designated for stroke patients” (On behalf of the Intercollegiate Stroke Working Party, 2016, p.85). Stroke units are further subdivided to hyperacute, acute or rehabilitation stroke units. Hyperacute stroke units are defined by the ISWP (2016, p. xix) as “a stroke unit that treats patients in the first few days of symptom onset” and typically up to 72 hours post admission. These units offer continuous monitoring and life support where required with a high nursing staffing level (Stroke Unit Trialists Collaboration (SUTC), 2013). Acute stroke units are described by the SUTC (2013) as semi-intensive or none-intensive depending on whether continuous monitoring is available. They also have high nurse staffing but no life support facilities. Patients are usually discharged from acute to rehabilitation stroke services within 7 days. Rehabilitation stroke units usually accept patients following treatment on hyperacute or acute stroke units and focus on rehabilitation (SUTC, 2013).

As case studies are carried out within a bounded system Simons (2009) argues that clear criteria for case selection which match the bounded system are applied – in this study stroke units. With awareness that stroke patients are only in the hyperacute stroke units for up to 72 hours post admission to hospital, and

with consideration of the time taken to recruit participants to a research study, the decision was taken not to recruit participants from hyper acute stroke units. Additionally, hyperacute stroke patients are often critically ill and categorised as high dependency often requiring airway life support and adjunct therapies that mean they do not receive nutrition orally, hence do not receive support to eat and drink and could not participate in the study. Acute and rehabilitation stroke settings were identified in the narrative synthesis as the bounded systems most likely to provide participants with the characteristics required for this study.

Acute and rehabilitation stroke units more frequently care for those patients having their nutrition managed orally, in other words managing to some degree to eat and drink without enteral support, and often supported by their informal carers and the MDT members caring for them at this time (Foley et al., 2006; Poels et al., 2006; Carlsson et al., 2010; Mosselman et al., 2013). Stroke patients and their informal carers whose participation was sought for the study were more likely to be in acute and particularly rehabilitation stroke units for longer time periods offering greater opportunity for recruitment participants to the study and greater opportunity to collect relevant in-depth data.

Pragmatic considerations were also part of the criteria for case selection. The geographical situation of potential cases was important. As this was a single researcher study with limitations on the researcher's time, potential cases were required within a 30-mile radius of the researcher's base in the north of England. This was important as the study approach incorporating the qualitative data collection methods discussed in sections 3.4.1.1- 3.4.1.4, dictated that the researcher would be required to spend significant time and travel to and from both cases on multiple occasions over a period of up to four months. With further reference to temporal considerations, cases were sought with both acute and rehabilitation stroke units located at one site. Although reduction of researcher bias is not considered in qualitative approaches as the researcher is recognised as an intrinsic part of data collection, cases were sought where the researcher was previously unknown. This minimised potential issues with power relationships between the researcher and participants that may negatively

influence data collection and any future risks to the researcher and participants from study participation (Creswell, 2013). In collective case studies, consideration is required of the type of cases to be included. Although no two cases will be identical, some cases may share some similarities (Simons, 2009). Some case studies explore atypical cases to identify areas overlooked in typical cases (Stake, 1995); others look for typicality, which is thought to enhance the transferability of results (Simons, 2009). Considering potential transferability of the study results the researcher sought two cases with similar attributes, with each case consisting of an acute and a rehabilitation stroke unit. With the previously discussed considerations identified, data published in the Sentinel Stroke National Audit Program [SSNAP] (RCP, 2014), identifying all hospitals in England, Wales and Northern Ireland routinely admitting stroke patients with a stroke unit was used to identify potential sites that could meet the case criteria for this case study.

Approaches for qualitative data collection were required that could identify the relevant data required to answer the research objectives identified in section 3.2. The researcher needed to understand the process of providing support with eating and drinking in practice. Both observation of the process and examination of documents recording the process were identified as data collection methods able to reveal the required data as to how this work is organised in hospital settings. The study objectives also require the exploration of these processes from the perspective of multiple key stakeholders on the support provided for eating and drinking in the hospital setting and interviews were identified as the best data collection method to achieve this data. Gobo and Molle (2008) suggest that the most suitable approaches for qualitative data collection incorporate interviewing, observation, and documentary data. As demonstrated in figure 5 data collected using different methods offers a wider perspective of the phenomena under investigation. As recommended by Simons (2009) interviews, observation and documents were chosen as the three data collection methods in the execution of this case study.

3.4.1.1. Non-participant observations - design

Observation enables the researcher to gain an overall view of the mechanism of the site offering a direct view of people's actions and behaviours in the everyday context of the site. This may include individuals who may not be involved in other data collection methods such as interviews and offering further insight into the complex processes under investigation (Clarke, 2009a). Observations also enable insight into the values of the institution supporting the site and can assist with interpretations of findings from other data sources such as interviews (Spradley, 1980; Simons, 2009).

A variety of observation techniques are described in the qualitative research literature, each with benefits and non-benefits for data collection (Spradley, 1980). These range from the researcher becoming completely immersed as a participant in the field (participant observation) to being a pure observer not seen by those under observation (covert observation) (Clarke, 2009b; Creswell, 2013). A non-participant style of observation was employed in this study. This meant that the researcher was visible in the vicinity of the participants during the observation periods, but the researcher did not take part in activities with the participants. This style of observation technique was chosen to minimise researcher influence on the actions and interactions of participants which would be more likely if the researcher was a full participant in activities. In addition, as a nurse by profession and having worked in this field of practice, the researcher was aware that they could easily be drawn into the nursing role whilst observing and further that the participants under observation could develop this expectation of the researcher. Positioning themselves as a non-participant observer was strategic in helping to maintain the role of researcher. In addition, both Spradley (1980) and Creswell (2013) explain that being present in the setting under observation allows the researcher to collect more authentic observations of activities as they occur in the usual sphere of practice. Therefore, the researcher would gather more authentic data of actions, interactions and processes seen to support eating and drinking. Although the

non-participant style recommended by Creswell (2013) was adopted during observations, it was expected that the researcher would verbally interact with participants enabling the development of rapport with participants and allowing the researcher to explore observations when required.

Two levels of observation were utilised. Spradley (1980) advises general unstructured observations to enable the researcher to get a feel of the setting. This required the researcher to observe and record field notes as advocated by Clarke (2009b) of general stroke unit activities during a planned observation period such as the timing of routine activities including shift handovers, mealtimes, medication administration rounds and doctors ward rounds. It was anticipated that such activities would routinely involve interaction between the MDT, patients, and informal carers. The researcher would observe these activities and identify aspects that appeared to be important and meaningful in respect of support for eating and drinking activity. This would include recording participants' concerns, beliefs and preoccupations when verbalised; description of the conditions under which patients, informal carers and MDT conduct their eating and drinking activities and interactions; perceived barriers and facilitators to eating and drinking; MDT interactions concerning eating and drinking; description of informal unplanned eating and drinking activity appearing to contribute to or reinforce eating and drinking activity.

The second type of observation method is described by Spradley (1980) as focused observation. This enables the researcher to concentrate on specific activities previously identified during the general observation sessions, interview sessions - see discussion of interview methods in section 3.4.1.2 or through document analysis – see section 3.4.1.3 below. During focused observations the researcher planned to record in field notes more fine-grained detail of the specific activities and interactions observed as advocated by Clarke (2009b). The researcher anticipated that such activities and interactions would consist of specific periods of interaction between the MDT, patients, and informal carers at specific times such as observing a patient during mealtimes including being fed; specific MDT activities such as ward rounds, shift handovers and MDT

meetings. Following advice from Spradley (1980) and Creswell (2013), during focused observations the researcher would record the key stakeholders and context of the activity and to achieve the study objectives. The researcher planned to observe the activity of registered nurses [RNs] and HCAs in preparation for mealtimes, during mealtimes, in interaction with patients and ICs at mealtimes. Also, RNs and HCAs interactions with OTs, PTs, SLTs, dieticians, doctors and any other key participants identified if they were present prior to or during mealtimes. As the researcher became more familiar with the day-to-day practice on the stroke units they would remain open to the need to focus on other, sometimes unanticipated data collection opportunities, for example specific therapy sessions, ward rounds and family meetings.

3.4.1.2. Semi-structured interviews - design

To achieve the study objectives, and particularly objective 4. '*To explore how support with eating and drinking is perceived by patients, informal carers and MDT members*', an approach that was capable of eliciting participants thoughts and feelings about the topic was required. King and Horrocks (2010) describe many different approaches to interviewing. These range from those using a very structured question schedule often used in survey data collection, to those in which the participant is given no guidance except for the topic title used in some ethnographic research (Hammersley and Atkinson, 2007). When discussing data collection methods for the Case study approach, Simons (2009) supports the use of in-depth interviews describing four major purposes of this data collection method: to record the interviewees thoughts on the topic; to assist with both interviewer and interviewee's learning about the topic in identifying and analysing issues raised in the interviews; flexibility to manage and pursue issues that may emerge during the interview and discovering feelings and events that cannot be observed.

Examination of the multiple approaches to interviewing described in the qualitative research literature (Hammersley and Atkinson, 2007; King and

Horrocks, 2010), and from those authors advocating interviews as a data collection method in case study research (Simons, 2009; Yin, 2014) the semi-structured interview approach was identified as the most appropriate method to elicit the required data. King and Horrocks (2010) suggest this approach offers flexibility to enable the researcher to explore participants' thoughts, experiences and perceptions of the topic under investigation including areas of interest identified from the narrative synthesis. This approach also allows the researcher to pursue any areas of interest generated from general and focused observations and other issues that participants may bring to the interviews which the researcher felt worthy of further exploration (King and Horrocks, 2010). An unstructured interview approach was rejected as this approach is recognised to produce large quantities of unstructured information which can be difficult to analyse and largely irrelevant due to potential digression from the topic area by the interviewee (Patton, 2004).

Patients, their informal carers and the stroke unit MDT were identified as key stakeholders in supporting stroke patients to eat and drink from the literature identified in the narrative synthesis. Therefore, to achieve an in-depth understanding of how stroke patients are supported to eat and drink and respond to the study objectives and in particular objective 4, the researcher proposed to interview patient, IC and MDT participants. Regarding the stroke unit MDT this would incorporate representatives of all professions making up the MDT on stroke units listed in the National Clinical Guidelines for Stroke (ISWP, 2016) and any other ancillary staff members identified in the observation process seen to impact support with eating and drinking. The researcher proposed an interview guide tailored to each participant group that enabled exploration of participants' thoughts, understanding and experiences of difficulties with eating and drinking following stroke, support provided with eating and drinking and provision of food and drink during the hospital stay. The interview guides acted as a prompt for the researcher to ensure specific topic areas were explored, but also flexible enough to incorporate further exploration of participants responses about aspects not previously identified by the researcher but potentially relevant to the topic area.

3.4.1.3. Documentary data collection - design

Documentary data were collected along with the data from both types of observations and semi structured interviews to answer the study objectives and achieve the research aim. Hammersley and Atkinson (2007) and Simons (2009) suggest in-context, documentary data is used in case study research to add depth to the case and to assist with the understanding of context and issues that are being investigated. Yin (2014) further suggests documentary data can be used to corroborate evidence from other sources. For example, if this contradicts previous evidence gathered during observations then this problem can be pursued in other components of the study such as interviews. The researcher planned to identify documentary evidence that related to patients eating and drinking. It was anticipated that documentary data accessed could respond to all five of the research objectives. The researcher planned to locate relevant documents identified from the narrative synthesis including the patients' MDT records which would assist with identifying which members of the MDT were involved in supporting eating and drinking, what they did and how often. Nutritional and fluid intake charts and Malnutrition Universals Screening Tools (MUSTs) offer data as to how much patients eat and drink and how this is recorded or not, and in the case of MUST how patients' nutritional status is screened. Medication prescription charts could demonstrate evidence of prescribed nutritional supplementation. Such documents could be paper based or electronic. The researcher was aware that further documentary data such as notices and posters located in the stroke units could be relevant to their deeper understanding of the clinical context and culture surrounding the phenomena under investigation, and these would be identified during general and focused observation sessions.

3.4.4 Data analysis - design

To fulfil the five different objectives, it was proposed that data generated from observations, interviews and documents would be thematically analysed using a six-component approach to Thematic Analysis [TA] developed by Braun and

Clarke (2006) see table 9 below. The advantages of TA are its flexibility to analyse and summarise data from multiple data sets, highlight similarities and differences across the data sets, and the ability of the approach to generate unanticipated insights (inductive capabilities) from the data (Braun and Clarke, 2006). Therefore, TA was thought appropriate to analyse observational data supporting the descriptive aspects of the objectives. In addition, data from interviews investigating participants' perceptions of support with eating and drinking, and data from documents supporting or not data from both observations and interviews could be analysed using TA. All TA attributes are relevant to the qualitative collective case study approach and able to respond to the salient elements of the objectives in answering the research question.

To achieve the in-depth understanding of support for eating and drinking, within-case, followed by cross case analysis was proposed. At each site, data from observations would be thematically analysed, then data from semi-structured interviews, followed by documentary data with themes developed from each data set. The themes generated from each data set are compared, then synthesised producing a TA for each case. When completed for both cases, a synthesis to develop common themes from both cases including comparisons of themes and development of further themes produces a cross case analysis to answer the research objectives (Simons, 2009; Yin, 2009).

Table 9. Components of thematic analysis (Braun and Clarke, 2006, p 87)

1. Familiarizing yourself with your data: Transcribing data (if necessary), reading and re-reading the data, noting down initial ideas.
2. Generating initial codes: Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.
3. Searching for themes: Collating codes into potential themes, gathering all data relevant to each potential theme.
4. Reviewing themes: Checking if the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic 'map' of the analysis.

5. Defining and naming themes: Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme.

6. Producing the report: The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis.

Computer- assisted qualitative data analysis software -NVivo 12 (QSR International, 2018) was used to store and manage anonymised data (field notes, interview transcripts, documentary analysis). Although this programme does not analyse data for the researcher - analysis in this approach being an inductive process, it does assist with the management of large amounts of data throughout the process of analysis (Braun and Clarke, 2013). The use of such software is recommended when large amounts of narrative data are to be managed during analysis (Yin, 2009).

3.4.5 Maintaining rigour in the qualitative case study approach

Some criticisms of the qualitative case study approach include lack of rigour; inability to generalise findings; inability to demonstrate cause-effect relationships and researcher subjectivity leading to potential bias in findings (Simons, 2009; Yin, 2009). Rigour or quality in research studies adopting relativist methodology and qualitative methods is approached differently than for those adopting positivist methodology and quantitative methods (Flyvberg 2006; Ritchie et al., 2014). Measures of quality in positivist quantitative approaches such as reliability and objectivity have different value in qualitative research, due to inherent researcher subjectivity in the approaches used, and internal and external validity though relevant, are implemented differently (Simons, 2009).

Qualitative researchers aim for trustworthiness in their research findings, using criteria initially identified by Guba and Lincoln (1989; 1994) which include credibility, transferability, dependability, confirmability, and later authenticity.

The following design elements in this study are suggested to aid credibility. The researcher undertook prolonged periods of engagement and observation in the study sites, data triangulation as previously discussed, and peer debriefing for the research process and preliminary findings and interpretations of the data with study supervisors. Due to time constraints and the transient nature of the participants, it was not possible to check findings and interpretations with the participants (Polit and Beck, 2014).

Transferability relates to the possible application of the study results in other settings (Polit and Beck, 2014). Those wanting to utilise the findings in their own setting decide transferability. To enable this, a thick description of the case and findings was planned to emanate from observational, interview and documentary data (Nowell et al., 2017). Dependability relates to the stability of data over time (Polit and Beck, 2014). To assess dependability, the research process needs to be transparent, allowing the reader to decide if the findings are dependable (Guba and Lincoln, 1989). Dependability in this study will be supported by clear documentation, allowing transparency of the study process in development of the study findings (Polit and Beck, 2014). Guba and Lincoln (1989) suggest that confirmability is accomplished with the achievement of credibility, transferability, and dependability. Ensuring that the study findings have developed from the data, and demonstration of how this was achieved.

Addressing subjectivity, Simons (2009) suggests some subjectivity of the researcher is inevitable in both qualitative and quantitative research but is more closely controlled in quantitative research. In qualitative research when appropriately monitored, subjectivity helps in the understanding and interpretation of data, though too much subjectivity can distort findings. In qualitative research including qualitative case study, subjectivity is acknowledged and managed by the researcher using reflexivity. Reflexivity involves the researcher openly acknowledging and assimilating how their beliefs, values and actions affect the research process, being aware that these could include a combination of positive and negative pre-conceptions (Simons, 2009; Gobo and Molle, 2017). The researcher can then address the effects

these may have on the research process (Guba and Lincoln, 1989). Reflexivity can be managed concurrently or at set points throughout, or at the end of the data collection period (Simons, 2009). The researcher planned to keep a reflective journal throughout the research process. The journal would include memos and notes made throughout data collection, analysis and writing up period. The researcher also planned to critically discuss their reflections and particularly any negative emotions with the supervisory team (Simons, 2009).

3.5. Chapter summary

This chapter has discussed the methodology underpinning the qualitative collective case study approach in research. It has established a rationale for the employment of this method to fulfil the study aim and objectives. The qualitative collective case study approach using two sites each incorporating acute and rehabilitation stroke units allows in-depth exploration of the support with eating and drinking for stroke patients during their stroke unit care. The diagram in figure 6, adapted from Carter and Little (2007) describes the methodology and process of this study.

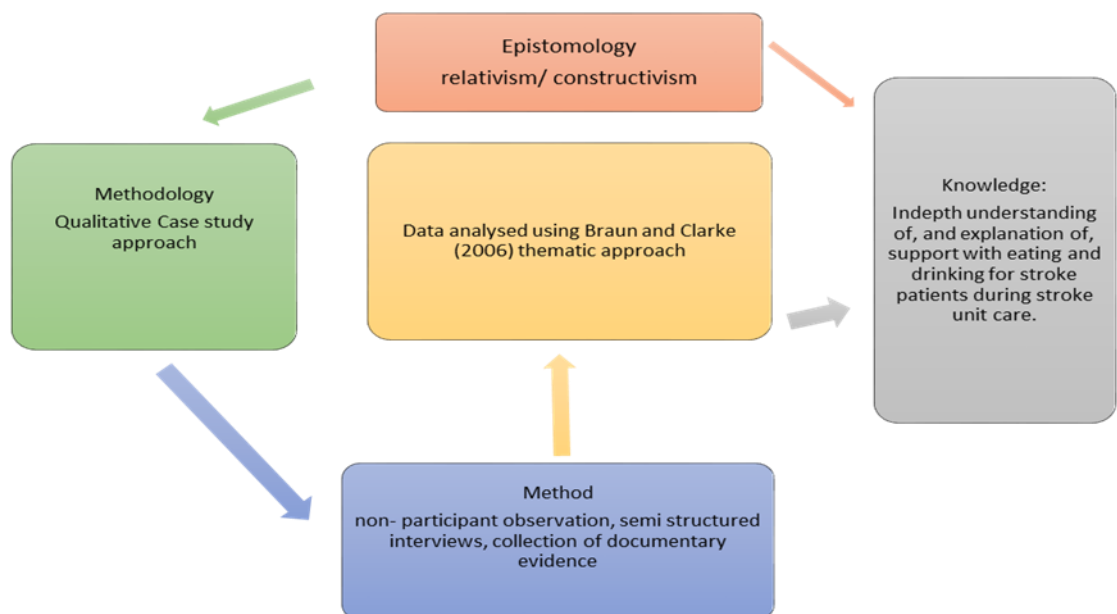


Figure 6. Development of study methods adapted from Carter and Little (2007)

Chapter 4: Methods

4.1. Introduction

This chapter discusses the methods used to develop understanding and explanation of the observed and perceived level of support with eating and drinking for patients during their stroke unit care. It will also examine case selection; ethical approval; ethical considerations; sampling of participants; data collection consisting of general and focused non-participant observations, semi-structured interviews with patients, informal carers [ICs] of patient participants and members of the multidisciplinary team [MDT] and documentary data; also, data analysis employing thematic analysis as developed by Braun and Clarke (2006). The methods employed are advocated for a qualitative case study approach as discussed in chapter 3.

4.2. Identification of cases (sites)

As discussed in chapter 3, the SSNAP data produced by the RCP (2014) was used to source potential sites with the required criteria that would become the cases for this study. Three potential sites were identified that were unknown to the researcher, were within a 30-mile radius of the researcher's base and had both acute and rehabilitation stroke units on one geographical site. Research and Development teams at the three sites were contacted and appointments made with a member of the team to visit the relevant stroke units. In order to gain access to the stroke units, permission was required from the person with the authority to agree to the study-taking place on that stroke unit. Hamersley and Atkinson (2007) refer to these people as 'gatekeepers' and their professional roles within the stroke units varied. At the first potential site visited, the gatekeepers were the ward managers of the acute stroke unit and the rehabilitation stroke unit. Responses to my explanation of the study were

markedly different between these two ward managers. The ward manager of the rehabilitation stroke unit was enthusiastic and gave permission to be a study site immediately. The ward manager of the acute stroke unit was more reserved. After reassurance that the presence of the researcher during observation periods should not interfere with the day-to-day running of the unit, and that the identity of the stroke unit and individual participants would be anonymous, they granted permission. At the second potential site, the gatekeeper was a stroke nurse consultant working across both the acute and rehabilitation stroke units. Having explained the study, they did not appear very enthusiastic. They were unsure whether the stroke units would have capacity to host the study due to other ongoing research studies on the units, and that they would give me a decision in due course. The gatekeeper at the third site visited was a stroke consultant. They were enthusiastic about the study and gave permission for the study to be carried out on the acute and rehabilitation stroke units.

The researcher took the decision to progress with the study at the first and third sites visited that gave immediate permission and had shorter travelling distance than the second site visited. This was a consideration when balancing the study progression with the researcher's other employment commitments (Simons, 2009). The researcher also felt an initial rapport with the gatekeepers at these chosen sites, which developed with further contact on confirmation of the decision to include both sites in the study. Hammersley and Atkinson (2007) suggest that gatekeepers and research participants can view the researcher negatively as an expert or critic. Disclosure of the researcher as a nurse was perceived to ease some of these potential anxieties, with the gatekeepers. This was possibly because they had a preconceived understanding of the nursing profession, which facilitated trust in the researcher, perceived as less threatening than a researcher who had no health professional background (Hammersley and Atkinson, 2007). Building rapport with the gatekeepers also facilitated introductions to other MDT participants working on the stroke units, and introductions to therapy team leaders. At each site, the researcher met with members of the stroke unit MDT at meetings and handover times to explain the study. The researcher disseminated MDT participant information sheets to

those expressing interest in the study at that time, see appendix L. Going forward the two participant sites are referred to as site A and site B.

Reciprocity was discussed with the gatekeepers, about what they would gain from allowing the research to take place in their practice areas. Gobo and Molle (2017) suggest that it is not enough to offer just scientific reasons such as the advancement of knowledge. The researcher had no reciprocal incentive to offer the gatekeepers other than the development of knowledge in supporting patients to eat and drink following stroke in their stroke units. On completion of the study data analysis, initial findings would be shared with the gatekeepers and the wider MDT to support any potential practice developments in this area. The gatekeepers were fully aware of this reciprocity. Patients and ICs participant incentive was the potential development of practice that would benefit future stroke patients and their ICs. This required a degree of altruism from patients and IC participants, who would not receive any immediate benefit from their participation in the study.

4.3. Ethical approval

Any research study led from England and involving the NHS in any way requires Health Research Authority [HRA] approval prior to its commencement (HRA, 2016). HRA approval incorporates the research governance processes of the Integrated Research Application System [IRAS] and Research Ethics Committee Approval. HRA approval for this study was received in mid-December 2016. Site-specific approval from local Research and Innovation Departments for site A and site B was also received at this time.

4.4. Participant population identification and selection

To enable exploration of support with eating and drinking at site A and site B, the study population eligibility criteria was identified as stroke patients, informal carers of stroke patients participating in the study and members of the MDT who met the following inclusion and exclusion criteria in table 10 below.

Table 10. Population identification

Study population	Inclusion criteria	Exclusion criteria
Stroke patients	Stroke patients, aged 18 and over, requiring support with eating and drinking and who had capacity to provide written informed consent or if lacking capacity, a consultee declaration could be obtained.	Stroke patients receiving end of life care. Stroke patients who could not provide written informed consent, and for whom consultee declaration could not be obtained.
Informal carers (ICs) of stroke patients	Informal carers aged 18 and over, of stroke patients participating in the study requiring support with eating and drinking who observed or provided patient support with eating and drinking and were able to provide written informed consent.	None
Members of the MDT	Stroke unit MDT members who may or may not have provided support, assessment and management with eating and drinking for stroke patients. Including medical staff, nurses, physiotherapists (PT), Occupational therapists (OT), Dietitians, Speech and Language Therapist (SLT) and non-professional support staff (domestic, housekeeping and healthcare and therapy assistants)	None

4.5. Sample selection process

Three sampling approaches were utilised for sample selection. Due to the time constraints of the data collection period, and to gather adequate data for

analysis, patients and ICs who met the inclusion criteria on table 8 above were selected using a combination of criterion and convenience sampling approaches. They all met the above criteria but could also be considered a convenience sample (Braun and Clarke, 2013). This was due to patient availability - impacted by the transient nature of care in stroke units, and the frequently fluctuating physiological and psychological condition of stroke patients. As informal carers follow the patients through the stroke pathway, then similar time limitations apply to their availability, often compounded by ICs personal time constraints. ICs could be the stroke patients' immediate family members including spouses and partners, children or grandchildren or other close friends. ICs were not normally expected to have a direct caring role during the stroke patients' hospital stay but, some ICs may choose to provide some support for eating and drinking or were present when activities pertaining to eating and drinking were carried out making it important to include them in the study. Braun and Clarke (2013) suggest that studies investigating participants accounts of practice, understanding and perceptions such as this study, require sample sizes that are large enough to capture a range of them. Despite this, they caution against generating too much data that would be difficult to manage. Therefore, sample sizes were guided by Braun and Clarke (2013) suggesting a minimum twenty semi-structured interviews, focused observations and documentary data sets would be required for the collection of sufficient data to tell an in-depth story about the study topic. Data collection from observation, documents and semi structured interviews was conducted with a minimum of 6-8 patients at each site or until data saturation occurred (Medin et al., 2010; Holst et al., 2011; Polit and Beck, 2014). Semi-structured interviews were proposed for a minimum 6 -8 informal carers at each site or until data saturation occurred (total n=12-16) (Martinsen and Norlyk, 2012).

For the purposes of this study, a definition of data saturation was developed from the work of Braun and Clarke (2013), and Polit and Beck (2014) defined as 'the point at which no new information or ideas are generated from the data'. Although thematic analysis of the data was accomplished after data collection was completed, the researcher was aware when no new information or ideas

were being identified within the data during its collection, for example during participant interviews, and within multidisciplinary team records.

MDT members were selected using purposive sampling with a maximum variation sampling strategy (Polit and Beck, 2014). Following Simons (2009) guidance, this approach ensured that perspectives and dimensions of the concept were explored from all professional groups making up the MDT and including other staff identified during observation sessions whose actions were seen to influence or support patients' eating and drinking in some way for each case. The National Clinical Guideline for Stroke (ISWP, 2016) recommends the MDT members required for stroke units though does not identify ancillary staff such as healthcare and therapy assistants or housekeeping and domestic staff. The MDT participants in this study include medical staff including a stroke specialist consultant, nurses, physiotherapist, occupational therapist, speech and language therapist, dietitian and ancillary staff observed to support stroke patients' eating and drinking and included healthcare and therapy assistants, housekeepers, ward assistants and a volunteer worker. Participants from these staff groups were identified to potentially, directly or indirectly supporting stroke patients with eating and drinking. Semi-structured interviews and focused observations of at least one member of the different identified staff groups for each case were required. All participants met the inclusion and exclusion criteria in table 8.

4.6. Recruitment procedures

To raise awareness of the study to potential participants, posters were displayed at each case site. These included a summary of the study aim and that the researcher would attend the stroke unit at various times between 06.00 and 22.00 hours, for a period of approximately 12 weeks, the period estimated to be required to gather sufficient data. The posters displayed a picture of the researcher which allowed potential participants to recognise the researcher when they were present on the stroke units, see appendix M. Posters were

placed in areas where potential participants were likely to see them and included the researcher's name and contact details. The poster also explained that patients and informal carers, who were eligible to participate in the study, might be approached by stroke unit staff to assess willingness to be contacted by the researcher to discuss potential participation in the study. Recruitment of potential participants continued throughout the researcher's time at each site (Spradley, 1980).

4.6.1. Recruitment of MDT participants

MDT members were identified at the introductory meetings described previously, from general observation sessions, or identified to the researcher by other MDT members. The researcher approached individual members from all professional groups of the MDT at each site to ascertain their willingness to participate in the study. A full explanation of the study was offered using the relevant participant information sheet - see an example of a participant information sheet in appendix L (Braun and Clarke, 2013). All potential participants were reassured that they could withdraw from the study at any point, and any information already collected from them would be used in the data analysis unless they also withdrew consent for their data to be used. That data would then be confidentially destroyed. Potential participants were encouraged to take as much time as required to consider the information and reach a decision regarding participation (Polit and Beck, 2014). MDT participants, having considered the information and agreeing to take part in the study, were consented to the study using the process described in section 4.9.1. - and figure 7. The participants completed a consent form developed specifically for MDT members – see example consent form in appendix X. Ongoing consent was verbally confirmed prior to interviews and each focused observation data collection episode.

4.6.2. Recruitment of patient participants

Potential patient participants were identified by the researcher during general observation sessions or identified and made known to the researcher by MDT members. The researcher approached potential participants only after members of the MDT had initially introduced them to minimise the risk of coercion (Polit and Beck, 2012). The researcher met all potential patient participants, and where required their consultees - who had agreed to initial contact before introducing the study. A full explanation of the study and participant requirements was delivered using the relevant participant information sheet, see an example in appendix L, and answering any questions the participants had. Information sheets for patients were available in an accessible format recommended by the Stroke Association (Stroke Association, 2012). All potential participants were reassured that they could withdraw from the study at any point and any information already collected from them would be used in the data analysis unless they withdrew consent for their data to be used. That data would then be confidentially destroyed. The researcher allowed adequate time for patients or consultees to consider the participant information, the time required at this stage varied for patients and consultees (HRA, 2016). Patient participants, having considered the information and agreeing to take part in the study, were consented to the study using the process described in section 4.9.1. - and figure 7. The participants completed a consent form specifically designed for patients. The same process was followed for consultees with them completing a consultee declaration form if they were willing for their relative to participate in the study. Ongoing consent was verbally confirmed prior to interviews and each focused observation data collection episode.

4.6.3. Recruitment of Informal Carer participants

Informal carers (ICs) fulfilling inclusion criteria for focused observations and interviews were recruited in two ways, though this was not planned. In some instances, ICs were initially approached by members of the MDT as with patients - see 4.6.2. Some ICs directly approached the researcher during

periods of general observation and expressed an interest to participate in the study. The researcher met all potential IC participants who agreed to initial contact and introduced the study. A full explanation of the study was provided using the relevant participant information sheet, see an example in appendix L and answering any questions the ICs had. All potential participants were reassured that they could withdraw from the study at any point, and any information already collected from them would be used in the data analysis unless they also withdrew consent for their data to be used. That data would then be confidentially destroyed. The researcher allowed adequate time for ICs to consider the participant information, the time required at this stage varied between ICs (HRA, 2016). IC participants, having considered the information and agreeing to take part in the study, were consented to the study using the process described in section 4.9.1. - and figure 7. The participants completed a consent form developed specifically for ICs. Ongoing consent was verbally confirmed prior to interviews and each focused observation data collection episode.

4.7. Data collection methods

Data collection was completed at site A, prior to commencement of data collection at site B, as per the rationale discussed in 3.4.1.

4.7.1. Non - participant observation - process

Simons (2009), suggests that observations should take place over a planned period to enable development of appropriate meaning and understanding in any setting. A scheme was developed with pragmatic consideration of the researcher's ability to observe periods in the setting where activities to support eating and drinking were more likely to occur. Following Spradley (1980) observations commenced with general 'grand tour observations' to obtain an appreciation of the routine activity and interactions at both sites. These were

followed by more focused observations of activities and interactions identified as part of the process of patients eating and drinking.

4.7.1.1. General observations

Hammersley and Atkinson (2007) suggest that for some data collection methods employed in a natural setting as with this study, it is impossible to ensure that all participants are fully informed and consented to observation. In this study, individual consent was not obtained for general ward level observations at site A or site B. To attempt to gather consent from all those observed would have been disruptive to the day-to-day running of the stroke units and impossible to manage for observation of unplanned and ad hoc activities. The researcher did not attempt to hide her presence and posters offering information about the study and the presence of the researcher were displayed at the entrance to, and in other highly visible places on the stroke units (Moore and Savage, 2002).

At both sites, to enable observation of variations in participant and organisational behaviours over time (Bryman, 2012), general observations took place on all days of the week between the hours of 06.00 and 22.00 hours. This was accomplished by conducting a minimum of three general observation sessions per week at each site. At both sites, the rate of activity varied throughout the stated time with periods of high activity requiring more observation to capture multiple activities occurring at any one time.

During general observations, the researcher sought to minimise their obtrusiveness in the setting, observing activities from a discrete location though not covertly, but still enabling observation of activities and interactions between participants (Spradley, 1980). General observations concentrated on the researcher familiarising themselves with the setting, including observing interaction between the MDT, patients, and informal carers. The researcher

observed the MDT, patients and informal carers in respect of support for eating and drinking activity, including their concerns, beliefs and preoccupations when verbalised; description of the conditions under which eating and drinking activities were conducted, including perceived barriers and facilitators for planned and unplanned eating and drinking activity (Spradley, 1980).

To capture routine MDT activities and interactions the researcher observed shift handovers, other team meetings and ward rounds placing themselves at the edge of the group. Observation of meal delivery, mainly to the patient's bedsides, was observed by standing at a distance that would not interfere with this process at both sites. To observe interactions with patients and ICs and their interactions with the MDT, the researcher observed patient bed areas comprised of bays of between four and six beds. Observations were not undertaken in single rooms as the researcher felt that this would be too obtrusive to the patients and ICs.

At all observations, the researcher introduced themselves to the participants and explained what they were doing. Participants frequently asked further questions about the study and the researcher's background, allowing an informal rapport to develop between both parties. Rapport building and prolonged periods of observation were thought to help with participants' normalisation of the researcher's presence and encourage the participants' natural behaviours (Hammersley and Atkinson, 2007). Participants' behavioural changes caused by knowledge of being observed is also known as the Hawthorne effect, and possible bias of findings more particularly in research from the positivist paradigm (Polit and Beck, 2014). Hammersley and Atkinson (2007) suggest that qualitative data cannot be valid or invalid, however, the researcher should be constantly aware of how their presence may have affected the data, practising some reflexivity (Simons, 2009).

To guide the collection of data during general observation sessions, an observation guide was developed from work by Spradley (1980). The guide

prompted examination and recording of data from nine areas, an example being space - including the location, the architecture, physical structures, sound, and light. Initially the guide was printed as a proforma to gather fieldnotes, but this was found too unwieldy to use in practice with multiple copies required for each session. A smaller A5 version of the guide was developed that the researcher could refer to. Fieldnotes were made in a small notebook, along with memos to prompt further investigation of areas of interest observed (Spradley, 1980), see appendix N. General observations also helped to identify where subsequent focused observation sessions were required to aid more in-depth understanding of the situations observed.

To assist the researcher with accurate recall, dependent upon the amount of activity, general observation sessions were limited to periods of no more than two hours. Observation of more intense activity resulted in shorter observation periods to enable the researcher to accurately record and consolidate what occurred (Hammersley and Atkinson, 2007). Immediately post observation session, the researcher captured their impressions from the session by audio recording and adding to the written field notes (Spradley, 1980).

4.7.1.2. Focused observations

Activities and behaviours identified from general observations requiring further exploration were the subject of focused observations. Focused observation was perceived to be more intrusive to participants than general observation and was only employed with participants who had fully consented to this part of the study. Some focused observations were pre-planned as with various patient therapy sessions. Other focused observations were opportunistic, as with observing ICs assisting patients to eat. Although all participants had been previously recruited and consented to participation, verbal consent was sought prior to each focused observation session. Despite these, being focused observations, the researcher still attempted to be as unobtrusive as possible, and sensitive to feedback from participants to guide any interactions. In some

observations, the participants actively involved the researcher by initiating conversation. In other sessions, the researcher was more detached, observing from a distance and trying to reduce patient distraction from the job at hand such as in physiotherapy sessions. Although the researcher was a non-participant observer, the different levels of interaction with the focused observations demonstrated that the boundaries between participant and non-participant observer are not always clear (Spradley, 1980; David and Sutton, 2011).

During focused observations, the researcher sought more fine-grained and detailed description of a situation designed to aid understanding of the concept of support with eating and drinking. These included the context of the activity of supporting eating and drinking; who leads and is participating in supporting eating and drinking activity; the nature and purpose of supporting eating and drinking activity as articulated by the MDT; how the participants appear to respond to, participate in, feel about, describe, explain, and make sense of the activity supporting eating and drinking (Spradley, 1980). The researcher's perceptions of the relationship of the activity to the aim of the study concentrated on specific periods of interactions between the MDT, patients, and informal carers; specific MDT interactions such as ward rounds, staff handovers and MDT meetings. The researcher further developed the general observation guide for focused observations to prompt exploration of these areas (Spradley, 1980), see appendix N. The guide was used during focused observations with fieldnotes, and memos made concurrently as with general observations. Following focused observations, the researcher immediately recorded their thoughts and feelings, including reflexive thoughts about the observation, on audio recordings and by updating fieldnotes and memos. Full fieldnotes were written up as soon as possible after each general and focused observation session, see an example in appendix O, anonymised and uploaded to NVivo 12 (QSR International, 2018).

4.7.2. Semi-structured interviews - process

The researcher had previously met the participants who had agreed to interview during focused observation sessions and initiated rapport with them. This is considered important in qualitative interviewing in allowing the participant to trust the researcher and encourage more open and truthful responses to questions (King and Horrocks, 2010).

Interview topic guides assist with the flow of an interview and act as a prompt for the interviewer to ensure that previously identified areas for exploration are addressed in all the interviews (King and Horrocks, 2010). Hammersley and Atkinson (2007) and Ormston et al. (2014) recommend that interview topic guides are developed from the research aims and objectives and are designed to capture the participants' thoughts and experiences, to enable understanding of their perceptions, which in this study are support with eating and drinking. The topic guides included some closed, but mainly open-ended questions recommended by Creswell (2013) to encourage discussion and elicit in-depth responses from participants and designed to answer the study objectives. The questions were developed from the findings of the narrative synthesis - see chapter two, and the wider literature supporting the topic identified in chapter 1, including the National Clinical Guideline for Stroke (ISWP, 2016). Interview guides for all three groups of participants can be seen in appendix P. There was similarity of some questions between participant groups, for example questions around food delivery and availability, though with different emphasis dependant on participant group. For example, patients were asked to discuss their experiences and perceptions of being supported to eat and drink, this being an individual, personal experience that ICs and the MDT could not share. Whereas ICs and the MDT were asked to discuss their experiences when supporting relatives/patients to eat and drink. Utilising the topic guide, the researcher used an active listening approach during the interviews, probing and prompting when required but mainly allowing the patients to talk freely, and allowing time for silences that can further encourage participants to speak (DeWalt and DeWalt, 2002).

All interviews took place during the data collection periods at each site and were completed by the researcher. All interviews were digitally audio recorded and the researcher took additional notes in order to capture paralanguage such as tone of voice, facial expression, body language, and contextual meanings that may permit a deeper understanding of the participants experience than words alone (Creswell, 2013). Following each interview, the researcher maintained the reflexive process discussed in section 4.7.1.2., audio recording their reflections on the interview process including their own thoughts, reactions and responses pre, during and post interview. This promoted the researcher's awareness of their life experiences and nursing roles and the influence of this on the interview process and participant responses (Braun and Clarke, 2013).

4.7.2.1. Interview process - patients

All the patients interviewed had previously been observed at least once during a focused observation session with the process of rapport building with the researcher already initiated (Hammersley and Atkinson, 2007; Braun and Clarke, 2013). Patients were made aware of and given opportunity to ask questions about the interview process. They were asked whether they wanted to be interviewed individually or with a second person. Though the researcher was aware that the presence of others could influence the patients' responses this was offered for support in what may be perceived by some patients as a potentially intimidating experience (Hammersley and Atkinson, 2007). The setting of the interviews was carefully considered. Patients were interviewed whilst still inpatients on the stroke units. The researcher was aware of some potential conflicts caused by interviewing whilst the participant was still in the context under investigation. The benefits being that the thoughts and feelings the patients discussed were less affected by time and distancing from the situation, as may have been the case if interviewed in the weeks or months following discharge from the stroke units. Conversely, patients may have concerns about retribution from other stakeholders in that setting such as MDT members. Therefore, patients were reassured that the interviews and their data

were confidential and would not be shared with any other participants or stroke unit staff (Hammersley and Atkinson, 2007). All interviews took place in a designated area on the stroke units where privacy and confidentiality were maintained. The interview rooms were pre-booked and 'do not disturb' notices posted to minimise the chance of interruption (King and Horrocks, 2010).

Conducting and participating in interviews is considered taxing to both the interviewer and interviewee and this was especially the case with patients as fatigue is a common problem post stroke (Creswell, 2013). Pre - interview the researcher checked that patients had any care needs met, had access to drinks and tissues for personal comfort (King and Horrocks, 2010). To ease patients into the interviews and encourage them to talk, the interviewer opened the interviews by asking patients about their background prior to their stroke. This also helped the interviewer increase rapport and understand more of the patients' context, thought essential to collecting meaningful data (Braun and Clarke, 2013). During the interviews, patients were given the option to end the interview at any time if they felt tired or no longer wished to participate.

Throughout the interviews, the topic guide was used to ensure that all pre-planned areas were addressed, and spontaneous questions asked were relevant to the discussion. As the patient interviews progressed, the researcher modified the topic guide including new questions prompted by interviewee's responses not previously anticipated by the researcher around the topic area (King and Horrocks, 2010). Although the researcher sought to minimise their influence on the patients' responses, the researcher manipulated the delivery of questions and speed of the conversation to suit individual patient's abilities, using interview skills including active listening techniques developed in their role as a clinician and educator (Clarke, 2006; Hammersley and Atkinson, 2007).

4.7.2.2. Interview process - informal carers

All the ICs interviewed had previously been observed at least once during a focused observation session, enabling the development of rapport, which is beneficial in the interviewing process (Braun and Clarke, 2013). The timing and location of the interviews was guided by the ICs. For the same reasons, ICs were offered the opportunity to have another person present at the interview. If the IC requested the interview be held on the stroke units, then a room was organised as described for patient interviews. If the IC requested an interview at their home, this was arranged, and the researcher followed the University of Leeds policy for working alone in this situation. A separate topic guide was designed and used for IC interviews. The same procedure was followed through the IC interviews as previously described with the patient interviews.

4.7.2.3. Interview process - MDT members

MDT members representing the different professional groups of the MDT were interviewed to elicit their views about support with eating and drinking. This included MDT members that had been observed during general or focused observation sessions. The location of the interviews was guided by the MDT member and took place in a pre-arranged room on the hospital site, or for one, at their own home, using the same lone worker policy as used with the ICs. Some MDT members were initially concerned about the length of interviews and taking time away from their work. The researcher negotiated the potential length of the interview with the MDT member prior to the interview, usually one hour, but found that once interviews commenced, some went over the hour, due to the researcher following the interviewees lead at this time. Participants were interviewed individually using an MDT interview topic guide to ensure all anticipated topic areas were discussed. The same process was followed as for patients and ICs. They were reassured about confidentiality and anonymity of study findings, which were more of a concern for some of the MDT than for others and did not appear to be related to seniority within the MDT. To ease the interviewees into the interview questions and help develop rapport, the

researcher commenced the interviews by asking about their professional background. This helped to relax the interviewees and helped increase rapport prior to initiating more topic-focused discussions (Braun and Clarke, 2013). As with patient and IC interviews, the researcher allowed the interviewee to set the pace of the interview. The researcher used questions and prompts as required but was not afraid to allow silences in the conversation, allowing the interviewee to talk further which elicited in-depth discussion about particular areas of interest (Hammersley and Atkinson, 2007; Braun and Clarke, 2013).

4.7.3. Documentary data collection - process

Documentary data were collected to assist with understanding the context of the setting. Such documentary data consisted of signage, posters and notices designed for patients, ICs, and other visitors to the area. Other contextual data were designed specifically for the use of the MDT such as food preparation posters, staff work rotas and timetables of MDT meetings displayed in staff only areas such as the ward kitchen and staff offices. As discussed by Prior (2003), in large institutions such as hospitals such information is integral to working life of the MDT and potentially influences patient care, and therefore relevant to the study question. In medicine and other health professions such as nursing and allied therapies, recording actions, decisions and outcomes of care are fundamental to everyday work and its organisation; they are an important source of data. Awareness of omissions in written records can be as enlightening to the researcher searching for understanding of a context as can written records (Hammersley and Atkinson, 2007).

Documentary data collection was undertaken for consented patients who had been observed at least once during a focused observation session. Data were collected from patient records made by the MDT from both paper and electronic sources. This included documents such as care plans and care summaries, nutritional intake charts, records of carer/family contextual information for example discussions in MDT meetings, records of home visits, assessments of

preparedness for discharge regarding eating and drinking activities. To ensure that relevant data relating to the objectives was collected, a guide was developed to prompt the researcher during the process, see appendix Q.

The researcher collected all documentary data by copying documents by hand and summarising documents. Some documents such as MDT case notes and electronic records were copied insitu, as these could not be removed from the setting. Other documents designed for staff and public consumption, such as information and guidance posters were photographed (Hammersley and Atkinson, 2007). Data were collected using the data collection proforma and anonymised at site. The researcher commenced a new proforma for each document. Some large documents such as sets of medical case notes required additional sheets of the proforma to ensure all the required data were recorded. Images were taken of the completed proforma and other documentary evidence and uploaded to NVivo 12 (QSR International, 2018).

4.8. Data analysis

4.8.2. Data analysis - process

This section presents that analysis of data collected from the three data collection approaches discussed previously.

4.8.2.1. Analysis of observational data

Commencing at site A, field notes including written and audio-recorded memos made during observations were anonymised, transcribed, and written up electronically using a proforma developed by the researcher. This was completed as soon as possible within the 24 hours following the observation, enabling more accurate recall of objective and subjective observations

(Spradley, 1980). Analysis of the fieldnotes commenced during the writing up process. This was an iterative process with the researcher reading field notes and memos, then organising, and categorising before re-reading as more fieldnote data were collected and threads of ideas and concepts running through the data identified (Creswell, 2013). The product was a set of thematically organised fieldnotes (Emerson et al., 2011).

This process was completed for all fieldnotes and memos at site A. The themes were written up into a thematic narrative summary linked by the common topics of the study objectives (Emerson et al., 2011). On completion of the thematic narrative summary for site A, and following discussion and guidance from the supervisory team, the narrative summary produced for site A was thought detailed enough to address the salient issues of the research objectives (Emerson et al., 2011). Furthermore, it was considered that thematic analysis [TA] as described by Braun and Clarke (2006) would not add more to the thematic narrative of what was occurring to support eating and drinking at site A. This compounded with practical constraints for study progression saw TA removed from this stage of analysis. The same process was completed for observational data collected at site B with the development of a thematic narrative summary. Table 11 below, demonstrates the process of theme development from fieldnote transcripts and memos from observations at site B. The final stage generated an overall synthesis of thematic narratives from site A and site B, to answer in part the research objectives.

Table 11. Example of theme development from fieldnotes and memos

Visit no Date/Site/ Time	Activity observed	Fieldnote transcription	Memos- questions, thoughts,	Theme Related to study objective
Visit 2 9.6.17 B1 12.30	Focused Observation Lunch time Patient bay	He then attempts to get the whole bacon rasher to his mouth, it looks precarious, but he manages to do this, and then bites the bacon but cannot bite a piece off, he eventually puts down the fork and removes that bacon that is hung from his mouth with his hand. He manages some of the bacon but leaves some. Not very dignified. There is no staff in the bay currently so no one to help (26).	I do not see any modified cutlery. 26. No staff stay in the bay for the duration of the mealtime – why? No one notices that two of the pts are struggling to eat one handedly and would benefit from the food being cut up or being given adapted cutlery so they could attempt this themselves.	Non-identification of support requirements means patients are often unable to access food and drink in a timely and dignified manner.
Visit 7 19.7.17 B1 17.30	Focused observation Evening meal patient bay	Pt.4 has not attempted to eat his meal. He presses the large nurse call bell that he has been given but no one answers Pt.2 is picking up food he has spilt down himself with his fingers and is eating it. A Health Care Assistant [HCA] walks past but doesn't look into the bay. A Registered Nurse [RN] is outside the bay gathering equipment to do hygiene care for another pt. (87). pt. 6 takes a drink of water from the glass on his table, he has a left sided facial droop / poor lip seal, and the water pours out of the left side of his mouth down his front (89).	87. No supervision once food and drink delivered.	Objective 5.
Visit 21 20.9.17 B2 17.00	Focused observation Evening meal patient bay	He does not have any adapted cutlery currently. (155) Outside the bay I see another visitor approach the staff at the trolley to say that another pt. needs sitting up. A HCA sets off up the ward with the visitor. (156).	155. Missing equipment 156. Patients not positioned to eat prior to food service.	
Visit 22 21.9.17 B2	Focused observation Breakfast Patient bay	2 patients are very low in the bed, at approx. 45 degrees to horizontal. One of the pts is lower than the bed table and can just see the dish on the table, so must reach up and over the edge of the table and dish to get the cereal, this looks very precarious and difficult (158).	158. No one appears to notice this, again I wonder how much training staff have about positioning for eating and drinking.	

4.8.2.2. Analysis of semi-structured interview data

All the semi-structured interviews from site A and site B were analysed using the TA approach developed by Braun and Clarke (2006). Commencing at site A, the first six semi-structured interviews which included a selection from all participant groups, were transcribed by the researcher. This enabled the researcher to become familiarised with the data, developing an initial understanding of topics and issues relevant to the study from the participants' perspective. This initial phase of interview data analysis also assisted the researcher to hone and develop future interview questions to explore issues identified during the transcription process (Hammersley and Atkinson, 2007). Interview transcription is known to be a very time-consuming process and as the study progressed, it became apparent that the researcher would not have enough time to transcribe all the interviews, taking up to eight hours, per hour of interview recording (Hammersley and Atkinson, 2007). The researcher was also engaged in writing up the general and focused observations concurrently making further demands on the researcher's time. In consultation with the study supervisors, the decision was made that all subsequent interviews were professionally transcribed (Hammersley and Atkinson, 2007). All interview transcriptions were read and checked for accuracy against the audio recordings, then anonymised and uploaded to NVivo 12. Following the TA process, transcripts were then read and re-read. The researcher was aiming to become immersed in the data actively searching for meanings and patterns. Braun and Clarke (2013) suggest this should be done at least twice for each interview transcript. In practice finding new ideas in later transcripts triggered re-reading of previous transcripts to check if ideas for codes had occurred previously but been missed. Even at this early stage, the researcher found this an iterative process moving back and forth across the data set, which is not unusual (Braun and Clarke, 2013). Initial analytic ideas for codes, which were recorded along with potential codes, were identified from memos recorded during and immediately following interviews. This data was uploaded to NVivo 12, with these initial code ideas saved in a separate file known as a codebook. Braun and Clarke (2013) describe this as phase one of TA, see an example in appendix R.

Phase two of TA involves the development of codes. Excerpts from interviews were added to initial code ideas identified in phase 1, and more codes generated. Code generation was inductive. Codes identified and described specific features of the data the researcher thought interesting and salient to the research objectives. The researcher completed this process with the whole interview data set using the coding systems on NVivo 12. As the process continued, similarities and patterns were identified across individual codes. These were grouped together under main code headings known as parent codes, described as the initial stages of theming (Braun and Clarke, 2013). To support the researcher and check that relevant data were captured within codes, members of the supervisory team coded a sample of dialogue from the interview transcripts of each participant group at site A. Resulting codes were checked for consistency with the researcher's codes enabling the researcher to develop and hone their coding skills. The researcher repeated the coding process up to five times for each set of participant interviews, refining codes and initial themes (Braun and Clarke, 2013). An example of final generated codes can be seen in Table 12, below.

Table 12. Example of final generated codes

Participant transcript	code ideas Phase 1	Developed codes Phase 2
<p>Patient transcript site A – Alison. “[I have] two adult children, mum and dad, you know, so everybody’s there with the tissues, you know like, and I said, I don’t want this to sound derogatory to anybody else but I said, I keep refusing the pinny because I don’t want a pinny on, but I said, “If it gets to wearing a pinny, shoot me,” you know like, I don’t want to be, you know like... Seems, like, babyish to me, you know like, the pinny, like. You know like the bibs, yeah, and I don’t look at them with it on and think that but to me it does... I’m choosing things that are simple to eat which nothing’s simple to eat I’ve found... I don’t want my food down the side of my face. But I feel as if everyone’s, you know, they’re...[staring]”</p>	<p>Patients discuss how it makes them feel emotionally to require support with eating and drinking. Some patients appear more negatively affected than others. Patients discuss how these feelings affect their eating and drinking behaviours.</p>	<ol style="list-style-type: none"> 1. Feel infantilised. 2. Difficult to ask for and accept support. 3. Embarrassment when eating in front of others 4. Family want to help. 5. Feeling of being watched. 6. Missing mouth with food. 7. Drooling and dribbling. 8. Affects food choices-easy to eat.

Searching for themes describes phase three of the TA process. Following coding of interviews for each participant group, parent codes were read again and grouped into initial themes (Braun and Clarke, 2013). The researcher moved the process from using NVivo12 to work on paper. The 'codebooks', which are the lists of parent nodes from NVivo12, were printed out. Individual codes were cut into paper strips, see an example of a codebook in appendix R. This enabled the researcher to move codes easily to relevant themes as they developed on A1 sheets of paper. Employing this process enabled visualisation of all the themes at the same time, assisting 'flow' of thoughts and ideas, which was not possible working electronically with one screen, see examples in appendix S. All extracts of coded data were worked into initial themes at the end of this phase, see example in table 13 below.

Analysis continued with phase four of TA, which involves the refinement of themes (Braun and Clarke, 2006). Codes within the themes were read again to ascertain their relevance to the themes. This was a lengthy process, with the researcher moving codes to different themes if thought more relevant in supporting other themes. On completion of this process, the researcher was satisfied that the themes captured the coded data. Next, the entire data set was re-read to ensure that themes adequately captured the meaning of the coded data. The researcher repeated the coding process again to ascertain that relevant data had been captured to support the themes. Braun and Clarke (2006) describe this as an iterative process, and some codes and themes were removed or amalgamated with other themes as the analysis progressed. This phase concluded when the researcher thought no further refinement of the coded data would add anything further to the themes.

Table 13. Examples of phase three and four theme development

Phase 2 codes	Initial themes phase 3	Refined theme phase 4	Final theme phase 4
1. Feel infantilised.	Psychological effects of difficulties with eating and drinking.	Patients are demotivated to eat and drink adequately.	Motivation to eat and drink - patients need to want to eat and drink.
2. Difficult to ask for and accept support.			
3. Embarrassment when eating in front of others			
4. Family want to help.			
5. Feeling of being watched.			
6. Missing mouth with food.	Physiological effects of difficulties with eating and drinking.		
7. Drooling and dribbling.			
8. Affects food choices –easy to eat.			

To complete phase five of TA, the researcher organised the codes within each theme to develop a coherent account of the meaning and relevance of that theme with a narrative account of the theme recorded, see examples in table 14 below and in appendix T. As TA is an ongoing iterative process theme titles were modified during the writing up phase of the study. Themes were named to clearly describe the topic of that theme (Braun and Clarke, 2013). Throughout this process, the researcher recorded changes to the themes and the rationale supporting the changes.

Table 14. Example of an initial narrative account of a theme

Phase 5. Initial narrative account of themes
Theme title: Motivation to eat and drink - patients need to want to eat and drink.
<i>This theme emerged from 40 nodes exploring patients' perceptions of what did, and what did not motivate them to eat and drink during their stay on the stroke unit. During the interviews, patients discussed topic areas and issues that motivated, de-motivated or were non-motivators for them to eat and drink whilst on the stroke unit. Further analysis created sub themes of motivators and de- motivators that originated from them as an individual (intrinsic factors) and those generated externally to them (extrinsic factors). This resulted in four sub themes. 1.1 Motivational factors of patient origin (intrinsic), 1.2 Non-motivational factors of patient origin (intrinsic), 1.3 Motivational factors of non-patient origin (extrinsic), 1.4 Non-motivational factors of non-patient origin (extrinsic).</i>

Phase 6 is the final stage of TA analysis. A written report with a supporting diagram explaining the process of eating and drinking supported by the thematic analysis was generated for each participant group, see examples in appendix U. The process described above, including the generated themes were discussed with the researcher's supervisory team to support trustworthiness of findings (Simons, 2009).

4.8.2.3. Analysis of documentary data

Documentary data were anonymised collated and stored in NVivo12. Data were read, in conjunction with the thematic narrative summary of observations and themes generated from TA of interviews at each site. This approach described by Denzin (1978) as data and methodological triangulation, enabled further understanding and verification of issues generated from the narrative analysis and TA at each site and in the synthesis of analysis discussed below (Simons, 2009). For example, during interviews, different members of the MDT at times contradicted data from other MDT members. Some HCAs at both sites reported that Nutritional Intake Charts [NICs] designed to record what patient ate were accurately completed at each mealtime. Analysis of the NICs at both site A and site B found this to be inaccurate, with NICs commonly incomplete when this data set was investigated, and no other accurate measure of patients' intake was found in any patient related documentation.

4.8.2.4. Synthesis of analyses

As stated previously, analysis of data for site A, then site B, generated two distinct case studies. To progress with the qualitative collective case study design, a synthesis of findings from both cases was required to answer the research objectives and questions. Findings from the observational thematic narratives and the TA analyses from interviews for each participant group were compared and contrasted from site A and site B. Working on paper, similarities and differences with findings were noted on 'post-it notes' - see examples in table 15 below and in appendix V. From this process, common issues were

identified, and interconnecting themes developed from both sites - see appendix W, which were discussed and presented in a summary report of findings.

Table 15. Examples of similarities and differences identified from data analysis between the sites

Examples of Differences in activities, behaviours, and perceptions	
site A	Site B
RNs do other work at all mealtimes, usually medication administration.	RNs serve meals and occasionally support patients to eat – but not at breakfast.
Nutritional intake not discussed on Drs ward rounds.	Drs asked patients about nutritional intake on ward round.
Patients found watching others eat and drink difficult.	Not mentioned by any patients at site B.
Some but not all ICs reported they received training from SLT and HCAs to support their relative eating and drinking.	No ICs reported any training from any of the MDT to support relatives to eat and drink.
Examples of Similarities found from site A and B	
Patients perceived staff very busy which made them less likely to ask for support with eating and drinking.	
Patients adapted food choices, so they did not have to ask for support.	
No consistent training programme for MDT for supporting patients eating and drinking.	
All MDT except dietetic teams incorrectly thought basic meals delivered all required calories.	
ICs thought modified diets unappealing and affected how much their relative ate.	

4.8.2.5. Reflexive process

The researcher took the reflexive approach previously described in section 3.4.5., and employed techniques discussed by Simons (2009). The researcher was aware of their own previous experiences from working as a registered nurse with stroke patients on a stroke unit, albeit not in the same geographical area as those stroke units in the study. The researcher accepted that it would be impossible for previous experiences to not influence their own constructs when observing the actions and interactions of the participants, and when working with the collected data. To manage this, reflexive notes and recordings were made during observation sessions and immediately following interviews of the researcher's thoughts and feelings (Simons, 2009). A reflexive log of thoughts, feelings and how they affected the researcher's decisions with the

progress of the study was kept. Any negative emotions and reactions experienced by the researcher were discussed with the supervisory team and managed through critical discussion. This allowed for a clear audit trail of decisions and rationale and was useful to read during data analysis.

4.9. Ethical considerations

4.9.1 Informed consent

If, after consideration of the study information, the MDT member wished to participate, fully informed written consent was obtained for part one (observation) and part two (interview) of the study-see example in appendix X. The MDT consent form was completed and retained by the researcher and the participant given a copy for their records. Fully informed written consent was sought from patients fulfilling inclusion criteria for focused observations, documentary data for example medical notes and care records, and semi-structured interviews. The patients' version of the consent form was completed and retained by the researcher and the participant given a copy of the consent form for their records. A copy of the consent form was added to the patients' medical records. Fully informed written consent was sought from ICs for part one (observation) and part two (interview) of the study. The IC version of the consent form was completed and retained by the researcher and the IC given a copy for their records. All potential participants were assumed to have mental capacity to consent unless it was established that they did not. Mental capacity was assessed using the test of capacity described in the Mental Capacity Act [MCA] (2005). Through informal discussion the researcher assessed whether the potential participant could consider the information provided about the study; could weigh the information and understand what was required of them if they took part in the study; could retain the information for long enough to make a decision to participate or not; could communicate their decision (MCA, 2005). The researcher checked for capacity using the most suitable method of communication - verbal or written. The researcher also sought advice from SLT

regarding patients' communication abilities. To enable potential participation of aphasic patients, a research-based consent support tool for use with those with aphasia developed by Jayes and Palmer (2014) was employed, though in practice this was utilised for only one patient during data collection. For patients assessed to have capacity but unable to sign a consent form due to physical impairment, a carer / family member witnessed the consent procedure.

Consultee declaration was sought for patients who fulfilled inclusion criteria for focused observation and documentary data collection but due to the disabling effects of stroke were unable to participate in interviews (Polit and Beck, 2012). Once agreement to participate was achieved a consultee declaration form was completed following guidance from the HRA, (2016). The researcher retained the consultee declaration form, and a copy was given to the consultee for their records. A copy was also retained in the patients' medical records. Consent forms for patients with communication difficulties were also available in an accessible format recommended by the Stroke Association (Stroke Association, 2012).

In the case of a participant losing capacity to consent during the study, data collection ceased when the researcher became aware of this change. In such a situation a consultee declaration was sought as soon as possible and if this was not achievable the participant was withdrawn from the study. Data collected prior to the participant's loss of capacity was kept in the study as consent had been given. In the case of a patient regaining capacity for which a consultee declaration had previously been obtained, then the researcher sought the participant's written informed consent (HRA, 2016). The researcher assessed the participant's understanding and consent prior to commencing each focused observation session and interview. A flow diagram describing the recruitment and consent process is shown in figure 7 below.

Recruitment and consent flow diagram

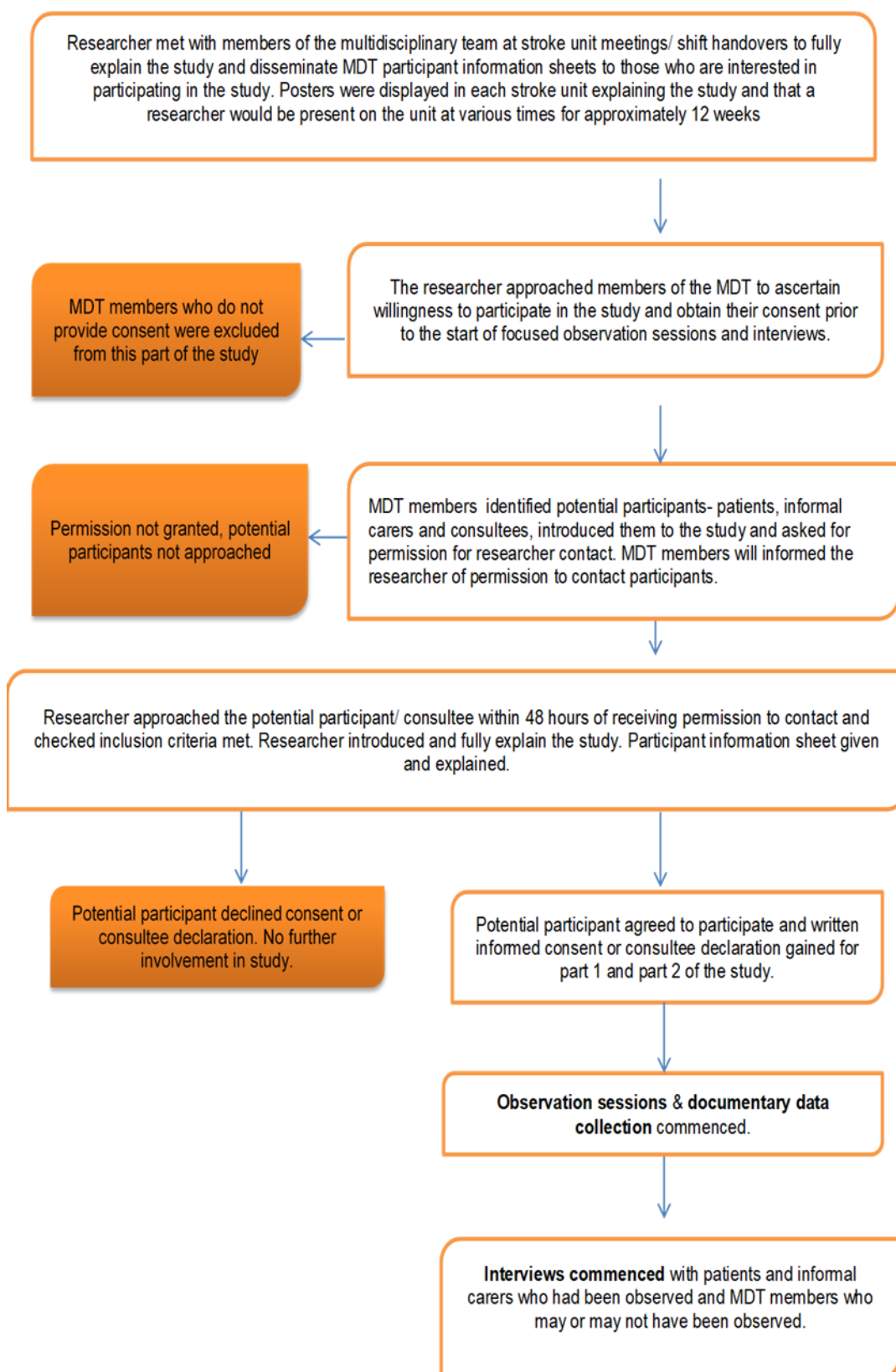


Figure 7. Recruitment and consent diagram

4.9.2. Vulnerable Adults and Safeguarding

Although the approaches to data collection did not involve the potential for physical risk to patients the researcher was aware of the possibility that at some point during focused observation or interview sessions the patient and informal carer participants may become distressed or fatigued. This situation occurred in some patient and IC interviews. The researcher was sensitive to these situations and offered to pause or stop the interview as the participant requested. Patient and informal carer participants were made aware of the Patient Advice and Liaison service at that hospital site for independent advice and support if required.

4.9.3. Managing risk

Observing in clinical practice may result in the observation of malpractice. The researcher was aware of relevant legislation in relation to her own profession and in the role as a researcher in such instances (Nursing and Midwifery Council, 2015; Medical Research Council, 2012). If such a situation had arisen, then the researcher would have immediately reported the incident via the hospital system in place at sites A and B. The researcher was also aware that during interviews, stroke patients and their informal carers might disclose, or the researcher may have concerns that the individual may have experienced abuse or was at risk of abuse. In such instances, the researcher planned to follow the University of Leeds Safeguarding Adults policy as stated on the patient information sheet. The researcher would discuss their concerns immediately with their supervisor(s) and if in agreement, the relevant persons would be contacted as soon as possible. This was likely to be the acute trust, social services, GP or community care team.

4.9.4. Data Protection

Maintaining confidentiality of the geographical site, participant identity and data collected from them is important in preserving trust between the researcher and participants as well as other stakeholders who have given permission for the study (Gobo and Molle, 2017). Personal data were kept strictly confidential - participant consent forms and biographical details were securely stored in a locked filing cabinet in a locked office at the University of Leeds. Electronic data including audio recordings was transferred from the research site using an encrypted password protected laptop. Electronic data and digital audio recordings were uploaded from the laptop as soon as possible to a secure drive at the University of Leeds. Audio recordings were deleted from the recording device once uploaded to the secure laptop.

Hard copy data collected from observations and interviews was anonymised contemporaneously. All participants were given pseudonyms and research sites fictitious names. Interviews were anonymised using the participant ID to maintain confidentiality. Identifiable and non-identifiable data were stored separately but linked using participant identifiers. Identifiable data were accessed by the researcher and shared, when necessary, with supervisors only. All paper-based data were stored in a locked cabinet in a locked office at the University of Leeds. The study complied with the Data Protection Act (1998).

Data will be securely archived at the University of Leeds for a minimum of three years after the study ends. Paper based data will be destroyed by shredding then disposed of by the confidential data destruction systems in place at the University of Leeds.

4.9.5. Serious adverse events

Serious adverse events (SAE's) including life threatening conditions and death were expected in this patient population. The expectation of adverse events related to the research process in this study was extremely low and no such events occurred during the study. However, if in the opinion of the researcher an unexpected and related SAE had occurred to a research participant, this would have been reported to the main Research Ethics Committee (REC).

4.10. Chapter Summary

In this chapter, the methods used to carry out a qualitative collective case study have been presented. Ethical considerations have been described in relation to the participants under scrutiny with consideration of those who are particularly vulnerable in the settings described. Findings that emerged from the data analysis process described are reported in the finding's chapters five, six and seven.

4.11. Explanation of guidelines and policy for stroke care in the UK at the time of data collection.

Prior to presenting the findings of the study, an explanation of the guidelines and policy produced for the management of stroke in the UK is useful, helping to explain the context of some of the findings reported and their relevance to the study objectives.

Prior to the data collection period, the ISWP had published their fifth edition of the National Clinical Guidelines for Stroke (ISWP, 2016) in 2016. These guidelines were developed from the latest research and evidence covering the clinical management of adult patients (aged over 16 years), throughout the

stroke pathway. This includes pre-hospital through to the long-term management of stroke. In previous editions of the National Clinical Guidelines for Stroke, the ISWP mainly matched the NICE CG 68 Clinical Guidelines for Stroke (NICE, 2008). However, with their 5th edition the ISWP guidelines were only aligned with NICE quality standard two - Stroke in Adults published in 2016 (NICE, 2016) due to advances in the management of stroke since the publication of CG 68 in 2008.

Particularly pertinent to this study, are the ISWP National Clinical Guidelines for Stroke recommendations presented for the in-hospital section of the stroke pathway, relevant to supporting patients to eat and drink orally. These recommendations were identified and can be seen in table 16 below. The guidelines form part of the Royal College of Physicians Stroke Programme, which also include a national audit of service provider compliance with the guideline recommendations known as the Sentinel Stroke National Audit Programme [SSNAP] (ISWP, 2016).

Table 16. Recommendations identified relevant to supporting eating and drinking: National Clinical Guideline for Stroke (ISWP, 2016).

<i>Chapter</i>	<i>Recommendation identified as potentially affecting support with eating and drinking</i>
<p><i>Chapter 2:</i> Organisation of stroke services</p>	<p>Resources: Specific MDT skill mix with staffing levels for hyper-acute and acute stroke units (note- only skill mix without working time equivalents is recommended for rehabilitation areas) p.16.</p> <p>Services providers: Services for people with stroke should take responsibility for all aspects of service quality by regularly reviewing service provision against the evidence-based standards set out in relevant national clinical guidelines p.21.</p> <p>Carers: Should be offered an educational programme which teaches them how to provide care and support; gives them opportunities to practise giving care p.21.</p> <p>Intensity of therapy: People with stroke should accumulate at least 45 minutes of each appropriate therapy every day, at a frequency that enables them to meet their rehabilitation goals, and for as long as they are willing and capable of participating and showing measurable benefit from treatment. Multi-disciplinary stroke teams should incorporate the practising of functional skills gained in therapy into the person's daily routine in a consistent manner, and the care environment should support people with stroke to practise their activities as much as possible. Healthcare staff who support people with stroke to practise their activities should do so under the guidance of a qualified therapist p.25.</p>
<p><i>Chapter 3: Acute care</i></p>	<p>Acute stroke care: Patients with acute stroke should have their clinical status monitored closely, including hydration and nutrition. Patients with acute stroke should have their swallowing screened, using a validated screening tool, by a trained healthcare professional within four hours of arrival at hospital and before being given any oral food, fluid or medication. Until a safe swallowing method is established, patients with dysphagia after acute stroke should:</p> <ul style="list-style-type: none"> – be immediately considered for alternative fluids. – have a comprehensive specialist assessment of their swallowing. – be considered for nasogastric tube feeding within 24 hours. – be referred to a dietitian for specialist nutritional assessment, advice and monitoring. – receive adequate hydration, nutrition, and medication by alternative means. <p>Patients with swallowing difficulties after acute stroke should only be given food, fluids and medications in a form that can be swallowed without aspiration p.49.</p>

<p><i>Chapter 4: Recovery and rehabilitation</i></p>	<p>Independence in daily living: People with stroke should be formally assessed for their safety and independence in all relevant personal activities of daily living by a clinician with the appropriate expertise, and the findings should be recorded using a standardised assessment tool. People with limitations of personal activities of daily living after stroke should be referred to an occupational therapist with experience in neurological disability, be assessed within 72 hours of referral, and be offered treatment for identified problems (e.g., feeding, toileting) by the occupational therapist, who should also involve other members of the specialist multidisciplinary team. People with stroke should be offered, as needed, specific treatments that include: –as many opportunities as appropriate to practice self-care. –assessment, provision, and training in the use of equipment and adaptations that increase safe independence. –training of family/carers in how to help the person with stroke p.54.</p> <p>Hydration and nutrition: Patients with acute stroke should be screened for the risk of malnutrition on admission and at least weekly thereafter. Screening should be conducted by trained staff using a structured tool p.70. Patients with acute stroke who are adequately nourished on admission and can meet their nutritional needs orally should not routinely receive oral nutritional supplements p.70. Patients with acute stroke who are at risk of malnutrition or who require tube feeding or dietary modification should be referred to a dietitian for specialist nutritional assessment, advice and monitoring p.71. Patients with stroke who are at risk of malnutrition should be offered nutritional support. This may include oral nutritional supplements, specialist dietary advice and/or tube feeding in accordance with their expressed wishes or, if the patient lacks mental capacity, in their best interests p.71. People with stroke who require food or fluid of a modified consistency should: – be referred to a dietitian for specialist nutritional assessment, advice and monitoring. – have the texture of modified food or fluids prescribed using nationally agreed descriptors p.71. People with difficulties self-feeding after stroke should be assessed and provided with the appropriate equipment and assistance (including physical help and verbal encouragement) to promote independent and safe feeding p.71.</p>
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The SSNAP has gathered stroke data from service providers in England, Wales, and Northern Ireland since 2013. It combines the National Sentinel Stroke Audit programme 1998 - 2010 and Stroke Improvement National Audit Programme 2010-2012. The first annual SSNAP report was published in 2013. Participating teams are measured against 44 key indicators chosen by the ISWP, grouped into 10 domains. Data is gathered three times per year and combined in an annual report. The aims of SSNAP are publication of national and team level results, comparison of results with previous reporting periods, and how pre - existing and future national measures for stroke are calculated (Royal College of Physicians, Clinical Effectiveness and Evaluation Unit on behalf of the Intercollegiate Stroke Working Party, [RCP, CEEU - ISWP] 2017).

One hundred percent of teams that admit patients directly for acute stroke care, and teams that providing acute care following initial admission to a previous team are registered with SSNAP in the UK. Teams are given an overall graded score A to E, calculated from individual patient centred and team centred scores. SSNAP grades are referred to for both sites included in the study in the findings and discussion chapters. Teams are expected to achieve grade A or B perceived to indicate world class stroke care, a score of C or below indicates improvement is required (RCP, CEEU - ISWP, 2017). See table 17 below for grade descriptors.

Table17. SSNAP grade descriptors

A = First class service
B = good or excellent in many aspects
C = reasonable overall - some areas require improvement
D = several areas require improvement
E = substantial improvement required

Chapter 5: Findings site A

5.1. Introduction

This chapter presents a description of the setting and participants recruited at site A. This is followed by findings from the narrative summary of observations supported by documentary data, then findings from the thematic analysis of semi-structured interviews from the three participant groups. A summary of all findings completes the chapter.

5.2 Setting description and participant recruitment

Site A was one of three specialist stroke centres servicing a large city in the north of England. The services at site A were all situated in the same hospital and consisted of an acute stroke unit identified in the study as SA1, and a combined acute and rehabilitation stroke unit identified in the study as SA2. See table 18 below for definitions of stroke unit type as described by the SSNAP annual results portfolio (2017).

Table 18. Definitions of stroke unit type (RCP, CEEU - ISWP, 2017)

Type of stroke unit	Definition
Hyper-acute stroke unit	Stroke unit that treats patients in the first few days of symptom onset (ISWP, 2016)
Acute stroke unit	Acute stroke units which accept patients acutely but discharge early (usually within 7 days). This could include an "intensive" model of care with continuous monitoring and high nurse staffing levels.
Rehabilitation stroke unit	Rehabilitation stroke units which accept patients after a delay of usually, 7 days or more and focus on rehabilitation
Combined acute and rehabilitation	Combined (i.e., no separation between acute and rehabilitation beds) stroke units that accept patients acutely but also provide rehabilitation for at least several weeks if necessary.

Later in the data collection period at site A, a further stroke rehabilitation ward was developed, though no data were collected from that area. SA1 had 17 beds receiving patients directly via the hospital's accident and emergency department, or from the intensive care unit if prior treatment had been required. The unit comprised three single rooms and two larger bays each with six beds, one designated for female and the other for male patients. SA2 comprised 31 beds, 15 designated as acute stroke beds and 16 as rehabilitation stroke beds. Intermittently throughout the data collection period, two extra beds were set up in the patients' dayroom, making 33 beds. Two five-bed bays and five single rooms were designated for acute stroke. Beds designated for rehabilitation comprised two five bedded bays and one six bedded bay. A therapy kitchen and gym were also sited on SA2. Speech and Language Therapy [SLT] and Occupational Therapy [OT] teams had offices based on SA2, the Physiotherapy [PT] team utilised a corner of the therapy gym sited on SA2 as office space.

At site A, lunch and evening meals were delivered to the stroke units already plated on trays in a pre-heated trolley from the hospital kitchens. All food was prepared and cooked on site. The tray was then delivered to the patients. Patients ordered from a menu delivered late afternoon for the following day. Breakfast was managed differently, cereals and toast prepared in the ward kitchen and porridge delivered in a catering tub from the hospital kitchen; these

were served from a trolley pushed around the patient bed areas. Hot and cold drinks were prepared in the ward kitchen then delivered to the patients.

Between December 2016 and March 2017, the main period of data collection at site A, the inpatient stroke services admitted 381 patients and received an overall SSNAP grade A (RCP, CEEU - ISWP, 2017). During this time SA1 and SA2 ran a three shift per 24-hour shift pattern, see table 19 below for observed average Registered Nurse [RN] and Health Care Assistant [HCA] staffing per shift.

Table 19. RN and HCA Staffing complement SA1 and SA2

Stroke unit	Early shift		Late shift		Night shift		Recommended RN and HCA complement (ISWP, 2016; National Stroke Nursing Forum [NSNF], 2016) Hyper acute - 2.9 Whole time equivalents (WTE) per bed (80:20 registered: unregistered) Acute and rehabilitation stroke units -1.35 WTE per bed split (65:35) (registered: unregistered)	Actual RN and HCA complement observed
	RN	HCA	RN	HCA	RN	HCA		
SA1 Acute Average shift staff numbers from observations	4	3	4	3	3	2	Acute staffing formula: Beds (n=17) x 1.35 WTE = 22.95 staff. 22.9 staff x 5 shifts each = 114.75 staff shifts per week. 114.75 / days = 16.39 staff shifts per day. Should be 10.7 RNs: 5.7 HCAs	19 shifts per day, of which: 11 RNs: 8 HCAs Should be: 12.35 RNs: 6.65 HCAs
SA2 Acute and rehabilitation Average shift staff numbers from observations	5	7	5	5	3	4	Beds (n=31) x 1.35 WTE = 41.85 staff. 41.85 x 5 shifts each = 209.25 staff shifts per week. 209.25 / 7 days= 35 staff shifts per day. Should be 22.75 RNs: 12.25 HCAs	29 shifts per day, of which: 13 RNs: 16 HCAs Should be: 18.25 RNs: 10.15 HCAs

Table 20 below presents a summary description of the characteristics of site A.

Table 20. Summary of descriptive characteristics

Location of institution	Urban location situated near a large city in the north of England. One of three specialist stroke centres serving a city population of approx. 800,000.
Stroke unit types	Acute stroke unit at the same geographical site but in a different area of the hospital (SA1). A combined acute and rehabilitation stroke unit (SA2).
Number of beds	SA1- 17 beds. SA2- 31 beds with capacity for two further beds as demand required.
Patient Length of stay	SA1 – Average length of stay 48 hours SA2 - Average 29 days, 60% stay over 21 days
Patient profile	SA1 – Patients were admitted to the unit via a 4-bedded HASU in Accident and Emergency Dept. or via the Medical Assessment Unit. SA2 - Patients were admitted from SA1 or repatriated in from other stroke centres across the area when considered medically stable or for terminal care and usually remain on this stroke unit until discharge or death.

Data collection commenced on the 19th of January 2017 and completed on the 28th of April 2017. The planned data collection period of 12 weeks for site A was extended to 14 weeks to enable the collection of interview data from a sample of all professional groups making up the MDT and informal carers. By this time, the researcher in consultation with the supervisors recognised that no new information was being identified from the data as explained in the Methods - chapter 3. Table 21 below summarises the number and type of participants recruited to the study at site A.

Table 21. Participants consented to study at site A

<i>Patients</i>	<i>Informal carers</i>	<i>MDT members</i>
Male x7	Male x 2	Registered Nurse [RN] x 6 including Ward Manager [WM]
Female x11	Female x 5	Health Care Assistant [HCA] x 8
		Physiotherapist [PT] x 1
		Occupational Therapist [OT] x 3
		Speech and Language Therapist [SLT] x 1
		Dietitian [D] x 2
		Volunteer [V] x 1
		Doctor [Dr] x 1

Observation sessions initially commenced on SA2 as that was the unit to which the researcher had initially been introduced, then continued intermittently between SA2 and SA1. Observations were completed between 06.00 to 22.00 hours across the 7-day week on both SA1 and SA2. Twenty-eight visits totalling 133.75 hours of observation were completed. Peak times of activity relevant to the research objectives were identified, resulting in more observation between 06.00-19.00 hours, with focused observations at mealtimes, MDT meetings and other activities such as patient therapy sessions.

Twenty-three semi-structured interviews were completed at site A, with all but one IC interview completed on site. MDT interviews ranged from 27 to 57 minutes in length, average 43.5 minutes. Patient interviews ranged from 26 to 50 minutes in length, average 33 minutes. IC interviews ranged from 17 to 37 minutes in length, average 28 minutes.

Participants from seven occupations comprising the MDT were interviewed. Table 22 below details their occupation and length of experience working with stroke patients.

Table 22. Participant data - MDT interviews site A

<i>Participants</i>	<i>Abbreviation</i>	<i>Pseudonym</i>	<i>Length of experience working with stroke patients</i>
Health Care Assistant	HCA	Lena	15 years
Health care Assistant	HCA	Jane	10 years
Registered Nurse	RN	Lucy	18 months
Registered Nurse	RN	Rachel	18 months
Ward Manager (also a registered nurse)	WM	Julia	6 years
Occupational Therapist	OT	Sue	6.5 years
Physiotherapist	PT	Cara	6 months
Speech and Language Therapist	SLT	Janice	3 years
Dietitian	D	Alice	1 year
Doctor	Dr	Emma	3 months

Seven of the eighteen patients recruited to the study at site A participated in semi-structured interviews to investigate their experiences and perceptions of eating and drinking on the stroke units. See table 23 below for patient participant details.

Table 23. Participant data - patient interviews site A

<i>Patient participants' pseudonyms</i>	<i>Gender</i>	<i>Age</i>	<i>Length of time support required with eating and drinking</i>	<i>Time since stroke onset to interview</i>
Cynthia	Female	77 years	86 days	86 days
Norma	Female	79 years	49 days	43 days
Beryl	Female	78 years	72 days	72 days
Alison	Female	46 years	28 days	28 days
Moira	Female	85 years	30 days	30 days
Don	Male	68 years	17 days	5 days
Doreen	Female	87 years	20 days	20 days

Six of the seven ICs observed also participated in semi-structured interviews to investigate their experiences of support for their relatives eating and drinking on the stroke units at site A. Five of the ICs relatives were on SA2 at the time of the ICs interview, and one on SA1. See table 24 below for IC participant details.

Table 24. Participant data - Informal carer interviews site A

<i>Informal carer (IC) participants' pseudonyms</i>	<i>Relationship to patient participant</i>	<i>IC gender</i>	<i>Patient participant pseudonym</i>
Jim	Spouse	Male	Cynthia
George	Partner	Male	Beryl
Jackie	Daughter	Female	Moira
Joan	Spouse	Female	Don
Linda	Daughter	Female	Margery
Lynne	Daughter	Female	June

5.3. The management of eating and drinking at Site A

This section presents the findings from the analysis of observation and documentary data at site A for supporting patients' eating and drinking.

5.3.1. Identifying and prescribing support with eating and drinking

5.3.1.1. Formal mechanisms of identifying and prescribing support with eating and drinking

Identified from the MDT records, swallow screening was implemented within 4 hours of the patients' arrival in the emergency department or more usually SA1- by a trained RN or Dr. Patients identified with a specific swallowing problem(s) were referred to SLT or a Dysphagia Trained Nurse [DTN] for a full swallow assessment. Analysis of MDT records and yellow signs at the back of patients' beds found that SLT but less frequently DTNs identified eating and drinking support needs besides those specific to swallowing. Examples of this were for preparation of food such as 'needs food cut up' and moving food from plate to mouth such 'use a teaspoon not a fork'. The SLTs completed all swallowing assessments on SA2. This was a recent change, as previously SLT and some RNs who were DTN trained shared this responsibility. The new system was viewed positively by SLT, Ward Managers [WMs] and DTNs on SA2 as the DTNs had difficulty maintaining competency due to the infrequency of required assessment, and capacity in the RN workload. On SA1, most of the RNs were also DTNs and the WM reported that they undertook up to 90% of the swallowing assessments. Due to safety concerns raised by SLTs, plans were in place for SLT to do all swallow assessments on SA1 as on SA2, but this was not yet in action. This plan was viewed negatively by the WM on SA1, who suggested that 'management' were trying to de-skill the RNs who were DTNs, and concerns about SLTs capacity to meet demand for swallow assessments due to the patients requiring frequent re-assessment.

Dietitians assessed the nutritional status of patients who potentially required their expertise. These patients were identified at daily whiteboard (digital screen patient information systems (NHS England, no date)) meetings, MDT meetings and referrals from RNs, but were more commonly patients who had been systematically referred to them, as they required enteral feeding. MDT records identified that dietitians continued to monitor these patients as they progressed from enteral feeding to oral diet.

OTs suggested that they assessed patients eating and drinking ability, but this was observed on only one occasion and thought by the researcher to be prompted by their presence. Some patients had kitchen assessments with OT assessing their functional ability for food preparation and eating prior to their discharge home, with the results recorded in the MDT record. MDT records revealed that often this was their first OT eating assessment since hospital admission. MDT records identified that only patients seen by SLT had regular planned, structured assessment of eating and drinking ability as part of their therapy prompted by swallowing problems.

Following swallow assessments, analysis of MDT records and signage at the back of patients' beds identified that SLT and on SA1, DTNs prescribed modified diet and fluids to support patients to eat and drink safely. Recommendations as to how patients should be supported was also recorded for example 'use a teaspoon', 'rest between teaspoons'. Dietitians prescribed specialist dietary requirements, food supplements such as full fat milk, requested doctors to prescribe commercially prepared feed supplements and requested the recording of patients' nutritional and fluid intake, all documented in the MDT record. Feed supplements were prescribed on electronic medication charts. Doctors, physiotherapists and therapy assistants were not observed prescribing any support for eating and drinking, a finding supported by no evidence of these activities recorded in the MDT record.

5.3.1.2. Informal mechanisms of identifying and prescribing support with eating and drinking

RNs, ICs and the patients were observed at various times identifying support needs for eating and drinking. More often, the HCAs identified these needs due to having the greatest patient contact and delivering all the patient meals. However, they were unable to observe all patients at the same time. HCAs were observed verbally prescribing support to patients, ICs, their peers and at times RNs. RNs were observed to prescribe the recording of nutritional and fluid intake if they identified any concern about patients' dietary intake. This was usually identified by the HCAs and implemented by commencing NICs for patients. These prescriptions were inconsistently recorded in the MDT records.

5.3.2. Providing support

5.3.2.1. Therapy supporting eating and drinking

SLT offered the main therapy supporting eating and drinking for those patients under their care on the stroke unit. PT and OT were observed delivering therapy, which benefitted patients' ability to eat and drink such as hand and upper limb rehabilitation but reported this was not specifically aimed at enhancing this ability. PTs, OTs and dietitians were infrequently observed in the patient areas at mealtimes.

5.3.2.2. Supplements

RNs in part delivered prescribed feed supplements during medication rounds. Despite being signed as administered on the electronic prescriptions these supplements were frequently left unopened at the patient's bedside, as were the food supplements such as full fat milk and the 'build up pots' which were supplied to all patients alongside all meals. Frequently uneaten, these

supplements were observed to mount up on the patients' tables throughout the day before being removed untouched.

5.3.2.3. Practical support with eating and drinking

Patient support with eating and drinking was observed to be largely reliant on HCAs, who delivered all routine nutritional care at mealtimes without direct supervision from any professional group in the MDT. Lunch and evening meals were delivered in the heated trolleys and handed out by the HCAs. HCAs also served breakfasts and drinks. The volunteer also completed some drink rounds, on the days they worked. HCAs were observed verbally prompting patients to eat and drink, position patients to better enable eating and drinking, place cutlery within reach and in the correct position in the hand, manipulating patients' hold on a cup, manipulating food on the plate and transferring food from the plate to the mouth. Some RNs and HCAs did not support patients when observed having difficulty reaching food and drink. The WM on SA2 was not observed delivering any direct support with eating and drinking. RNs were usually administering medication during mealtimes, though occasionally identified patients' support requirements with eating and drinking as they were in the patients' vicinity. The WM on SA1 was observed to feed a patient on one occasion possibly prompted by the researcher's presence.

Some ICs encouraged by SLT, RNs and HCAs were observed to support their relative to eat and drink though this was for a small number of patients. Verbal advice and support for ICs was offered by RNs, but mainly HCAs (not recorded in any documentation) and SLT (recorded in MDT notes), regarding the texture of foods that were acceptable, size and speed of delivery of food and patient positioning. RNs, Dietitians, DRs, PTs and OTs prioritised other work over mealtime support and supervision. Dietitians, DRs, PTs and OTs were rarely observed on the ward at mealtimes.

5.3.3. Monitoring support

5.3.3.1. Record keeping

Three tools were observed that could be used in monitoring and recording patients' nutritional intake and nutritional status, these were supplied as pre-printed documents ready for staff to make recordings. They were the Nutritional Intake Chart (NIC), Fluid Balance Chart (FBC) and the Malnutrition Universal Screening Tool (MUST). Document analysis identified that RNs recorded daily, frequently brief, superficial and inaccurate information regarding patients eating and drinking activity, for example 'eating and drinking well' recorded in the nursing and MDT records, though analysis of NICs frequently revealed contradictory information. RNs were observed to glean this information verbally from HCAs rather than checking the NICs themselves. Observation and document analysis identified that NICs were completed exclusively by HCAs and often at the end of a shift rather than at mealtimes. HCAs were observed completing NICs for patients they had not observed or supported, with information that was frequently omitted or inaccurate.

Document analysis revealed that HCAs exclusively completed MUSTs, which required the patients' weight. During observations, both HCAs and the dietitian questioned the accuracy of these recordings with the researcher, due to difficulty using and the accuracy of weighing hoists. Analysis of the MDT records and MUST charts identified that some patients lost weight over several weeks before a referral to the dietitian was made. The dietitian then reviewed the patient's MUSTs and NICs, but these were often of limited use, due to incompleteness and inaccuracies. The dietitian became aware of this issue during the observation period and instigated an audit of MUST completion weekly, though reported that time constraints made this difficult to complete. HCAs did not record information in the MDT notes, though made occasional notes in separate care notes located in a folder kept in the bed bays along with the NIC and MUST charts. These notes were brief and lacked detail, for example 'assisted to eat'.

5.3.3.2. Communication

SLT communicated prescribed instructions on yellow signs positioned on the wall at the back of patients' beds and recorded in the MDT notes. However, signage was inconsistently updated with changes to the patients support requirements. This potentially caused errors in provision of the correct support for patients with eating and drinking. Frequent verbal communication of prescribed changes to patients' dietary requirements was observed between the SLT, dietitian, nurses and catering staff for extra meals and modifications to meal requests, which were usually fulfilled. Other special diet requirements were listed at the nurses' station then ordered from the kitchen by the ward clerks. Dietitians prescribed dietary changes and recorded them in the MDT notes.

Occasionally RNs were observed verbally communicating support requirements to HCAs at shift handovers, and during the shift as patients' support requirements were identified, though these were not specific and unrecorded for example, patient X needs some help. Analysis of shift handover sheets identified that they contained minimal information about patients eating and drinking, and this was usually about the stage (texture) of diet and fluids required and broad comments such as 'needs support'. HCAs were not observed at any time to read the MDT notes stored at the main nurses' station.

Communication among MDT members regarding eating and drinking ability and nutritional intake other than for swallowing was limited with no defined communication process for patients' nutritional status identified. Analysis of observations and documents established that nutritional intake was not a 'standing item' on handover sheets, MDT goal planning proforma, or at safety huddle. It was not discussed on any doctor's rounds and observed very occasionally at whiteboard meetings and MDT meetings where all professional groups were usually represented. Patients were observed trying to request

support. This was usually from HCAs however, due to communication difficulties such requests often went unacknowledged, leaving patients' unable to consume food or drink provided.

5.4. Findings of semi-structured interviews at site A

This section reports the findings of the thematic analysis of the semi-structured interviews from the three participant groups at site A. The analysis examines participants understanding of the management of eating and drinking and their experiences of identifying, providing, receiving and monitoring support with this activity and adds further insight into the findings reported in section 5.2. Table 25 below lists the themes identified from semi-structured interviews and discussed in this chapter.

Table 25. Themes identified at site A

	<i>Main theme, number and title</i>	<i>Related sub themes, number and title</i>	
MDT themes	1. I know what support should be like.	1.1.	I know what ideal support looks like.
		1.2.	When I do it well it feels good, when I can't it's frustrating.
	2. Mechanisms for identifying a need for support are inconsistently implemented and communicated.	2.1	Identifying a support need is often an ad hoc process.
		2.2.	Communication systems for support needs are used ineffectively.
	3. The provision of essential components to support eating and drinking is inconsistent.	3.1.	Food quality and availability is variable, and equipment is missing.
		3.2.	I know whose job this is, but there is not enough of them?
4. We think we offer effective support, but how do we know?	4.1.	It's my responsibility but others do the work.	
	4.2.	The presumption is that the work is done, but we don't always check.	
5.	I picked up how to support patients as I went along.		
Patient themes	1. I know I should eat, but I don't always want to - perceptions of facilitators, motivators and barriers to eating and drinking.	1.1.	This is what makes me want to eat and drink.
		1.2.	Sometimes, something puts me off eating and drinking.
	2.	I didn't really think I had a problem with eating and drinking.	
IC themes	1.	The inconsistent provision of nutritious and appealing food is not supportive to my relative's eating and drinking.	
	2. Mechanisms to support eating and drinking benefit from IC intervention.	2.1.	Inconsistent support mechanisms require ICs to enhance patient experience
		2.2.	Inconsistent support mechanisms reduce confidence and provoke anxiety for some patients' wellbeing.

5.4.1. Findings from Multi-Disciplinary Team (MDT) interviews site A

Thematic analysis of the MDT interview data identified five main themes with sub themes. The themes were inductively developed from an initial identification of 75 codes and revised and refined over three iterations prior to finalisation.

5.4.1.1. Theme 1. I know what support should be like.

This theme consists of two subthemes, subtheme 1.1 explores what the MDT perceive to be support with eating and drinking and what they think support with this activity looks like. As the analysis progressed, subtheme 1.2 was identified as participants discussed their emotional responses to what they considered

sufficient and insufficient support and consequently the effect on the patient experience.

Subtheme 1.1. I know what ideal support looks like

When exploring what constituted supporting eating and drinking, all MDT members initially identified direct physical support, such as feeding patients and preparing patients to eat:

“The word support, well sort of making sure that the patient’s aware that the food’s there, making sure they’re in the correct position to be able to eat the food, if they’re in bed that they’re sat up appropriately, making sure that they’re physically able to get the food to the mouth with whatever, you know.” (Sue, OT)

Following discussion around physical support, all MDT members moved to discuss psychological support with eating and drinking, but this received most emphasis from SLT, RNs and HCAs who talked at length about their approach to patients and the importance of tailoring support both physically and psychologically to individual patients:

“We tend to go for the main meal first, to let the soup cool down a bit, try and engage a little bit with the patient while you’re with them but not too much where you’re expecting them to talk and choke on the food. Yeah, just try and make it a relaxing, a relaxing time, nothing too stressful” (Jane, HCA)

Building a positive relationship with patients assisted RNs and HCAs in understanding patients’ food tastes. This enabled support with food choices, and being able to advocate for the patient, at times replacing food that was less acceptable to the patients:

“...so, some things are just, seem to be harder to eat than others but we do try and like you know, say if they don’t want tough foods or if they don’t you know, want, they can’t have certain things we’re quite good at helping them not order certain things if we think they’re not going to manage it” (Rachel, RN)

Subtheme 1.2. When I do it well it feels good, when I can't it's frustrating

RNs, but more so HCAs, experienced positive thoughts and feelings when they perceived they had supported patients to eat and drink what they, and the patients considered adequate amounts:

"...it gives you satisfaction knowing that if they're happy after a meal you know, because food's important to so many people, if they're happy after having a nice meal or happy after having something nice to drink or something that they really like to eat you know, it makes, it makes you feel happy, so." (Rachel, RN)

Conversely, RNs but particularly HCAs, reported negative emotions when they considered they had provided inadequate support with eating and drinking. This was reported to be due to increased workload. On such occasions, mealtimes were emotionally stressful particularly for the HCAs, who were aware that this could reduce patients' intake of food and fluid:

"...you sometimes feel like you're rushing it because you know you've got several patients to do in a certain amount of time and you do, you don't feel like you're engaging properly with someone sometimes, purely on time constraints, so that's a bit of a downer" (Jane, HCA)

In summary, MDT members thought patients required both physical and psychological support with eating and drinking. MDT attitude and approach to patients when delivering support was considered important. The ability to offer perceived adequate support gave MDT members satisfaction in their work, feeling that they had done their best for the patients. Conversely, feeling that they had not offered support to the best standard was emotionally difficult and stress inducing for RNs and HCAs.

5.4.1.2. Theme 2. Mechanisms for identifying a need for support are inconsistently implement and communicated.

This theme explores MDT members understanding of the processes of identifying and communicating the patients' needs for support with eating and

drinking, their individual role within the processes and the barriers to effectiveness.

Subtheme 2.1. Identifying a support need is often an ad hoc process

The findings discussed in this subtheme suggest that the MDT were aware of the objective methods of screening for malnutrition recommended by national guidelines (ISWP, 2016). However as described previously MUSTs were inconsistently completed. Responsibility for completing the MUSTs was reported by the wider MDT to be with the RNs and HCAs, though the HCAs usually were delegated this task:

“...because we [HCAs] do the MUST screening every week” (Lena, HCA)

The RNs and HCAs reported that the intention was to complete MUSTs weekly. Lack of time due to workload and for some HCAs, inadequate knowledge of MUST score completion were acknowledged reasons for omission, inaccurate or untimely completion. This was a barrier, which often led to patients' support requirements remaining unidentified, or referral to dietitians for further assessment not made within an appropriate timeframe:

“...so, weight is a big one that's not done straight away and can get added in later but then if you haven't got the weight how can you assess pretty much the whole rest of the score [MUST]?” (Alice, Dietitian)

If completed accurately, the MUST would identify patients who were at risk of or were malnourished but not the cause of their malnourishment. Some physiological and cognitive deficits following stroke affecting manipulation of food and drink in the mouth and swallowing, were identified by SLT and DTNs at initial screening and swallowing assessments. Specific support requirements were then prescribed with reassessment in ongoing SLT therapy sessions:

“...it’s like well they need to learn to use the spoon, so do hand-over-hand and then let go of them, see if they can do it themselves, that kind of thing. So, we try and be specific about that.” (Janice, SLT)

Although different professional groups identified other physiological and cognitive deficits within the MDT, these did not specifically address patients eating and drinking abilities and support required. As an example, PT may have diagnosed an upper limb weakness, but would not prescribe required support to cut up food because of that weakness:

“I’ve also come from the point where I’ve done exercises with the upper limb rather than making it functional. So, we’ve had maybe like some weights, doing a bit of weights and then movements with like poles and things like that, rather than actually, you know, eating, grabbing a fork.” (Cara, PT)

Only one HCA and one RN stated that patients might occasionally request support unprompted by a member of the MDT. No rationale was offered for this. Possible reasons are the MDT identified most support requirements and fulfilled these, or patients did not realise they had a support need or if they did, preferred not to communicate this to the MDT. The ICs role in identifying support needs was acknowledged by one RN and the doctor. Despite ICs alerting staff to these support needs, they were unable to specifying what specific support should be delivered:

“From my personal experiences, it’s been relatives that have been concerned about the weight, weight loss, and that, and then when you actually have a look, they have lost weight...” (Emma, Dr)

All MDT members suggested that direct visual observation was the most frequently used method of identifying patients’ support requirements with eating and drinking. All the MDT thought the RNs and the HCAs employed this

method, as they had most direct contact with patients, and other than SLT, the only MDT members present on the ward at mealtimes:

“It’s usually the healthcare [identifying support needs], because they give out, predominantly give out the meals.” (Julia, WM)

HCAAs and RNs reported confidence in using observational skills to identify support requirements. Other MDT members suggested that observational skills were inconsistent within the RN and HCA staff groups, resulting in unidentified and unmet patient support requirements:

“I think sometimes if people aren’t aware, that staff aren’t aware of some of the issues that we’ve talked about, where people do need support, things can be misinterpreted, so like as a sort of straightforward refusal to eat or, you know, declining to eat when it’s not really that, it’s just it’s not being offered in the correct way, or it’s not being offered at the right time...” (Sue, OT)

All MDT members varied in their knowledge of the process of provision of specialist equipment to support eating and drinking, particularly RNs and HCAs who provided most support. Some thought that OT or SLT would identify and provide equipment if required, though others thought not:

“...speech therapists tend to advise on the cups and drinking and occupational therapists tend to have quite a big involvement in things like using plate guards and things, they supply them, but I don’t know for sure to be honest, if we saw that they needed something then we could follow that up, but I don’t know.” (Rachel, RN)

These findings suggest that identification of patients’ support requirements was inconsistent. There was lack of clarity for different MDT members’ roles and responsibilities for this activity. This meant that some patients were not adequately supported to eat and drink, potentially not meeting their full nutritional requirements, precipitating malnutrition and dehydration.

Sub theme 2.2. Communication systems for support needs are used ineffectively

The findings discussed in this subtheme suggest that verbal and written methods of communicating a requirement for support once identified varied in consistency leading to errors in practice. MDT case notes were only mentioned briefly by the SLT as a method of communication. Although all MDT members except HCAs made some record of their activities with patients in the MDT records, they did not identify written care plans as a method of communication. It was acknowledged that shift handover sheets mainly used by RNs, HCAs and the dietitian lacked sufficient, up to date detail about the patients support requirements:

“There’s not that information on, well there’s some information on the handover but not detailed about how, you know, needs assistance with eating unless it’s a real concern for various reasons.” (Alice, Dietitian).

Yellow signage situated at the back of the patients’ bed for those under SLT care was thought to be more accurate and practically useful:

“...then they’ll put a formal assessment in the nursing notes but also behind the patient’s bed there’ll be clear precise instructions as to what that particular patient’s needs.” (Jane, HCA)

RNs and HCAs cited the shift handover as the main method of receiving information regarding patients support requirements with eating and drinking. Information on the shift handover sheets was transferred from the digital whiteboard and reported to be often inaccurate and too brief to be of practical use:

“That the handovers aren’t always the same as the [whiteboard], and the handovers are supposed to be updated as a result of the whiteboard meetings.” (Sue, OT).

RNs, SLT, Dr and the dietitian reported verbally communicating changes to patients' support requirements and nutritional status to the wider MDT at weekly MDT and to a lesser extent at daily whiteboard meetings and at other ad hoc times:

"I've worked there a while, and I know the dietitian that works on this ward, I just mention it [concern with eating and drinking]. Like, in the instance today, I just mentioned it, because I don't know how to refer to the Dietitian" (Emma, Dr).

Participants discussed how reliant they were on the channels of communication described above for continuity of patient support. Shift patterns, rotation of staff from other areas and the use of agency staff were cited as barriers to effective communication:

"Because with the staff changing all the time, obviously different nurses are looking after different patients and it's hard for them, they've got so many patients; it's hard for them to know, it's better for them if we kind of say... so we tend to write on the boards" (Janice, SLT).

Errors with the implementation of support delivery were acknowledged despite the communication processes described above, and suggested to be the responsibility of the individual who administered the incorrect support:

"They were just a bit confused why he had normal fluids on his table. I was like "well I didn't put it there; it was on the table so don't know where it came from". So obviously someone has accidentally not read charts above beds" (Cara, PT).

To summarise the findings in 2.1 and 2.2, the MDT discussed two methods of identifying patients support requirements with eating and drinking but no formal specific assessment of a patient's ability to eat and drink. They acknowledged communication pathways exist but are not consistently utilised to fully communicate support needs with eating and drinking when identified.

5.4.1.3. Theme 3. The provision of essential resources to support eating and drinking is inconsistent

This theme explores the MDTs perceptions of the resources required to support patients eating and drinking, and barriers to patients eating and drinking adequately caused by inconsistent provision of these resources. As the theme developed two sub-themes were identified. Sub theme 3.1 identified inconsistent provision of food and equipment and the effect on eating and drinking. Sub theme 3.2 examines who provides support with eating and drinking.

Sub theme 3.1. Food quality and availability is variable, and equipment is missing

The findings discussed in this subtheme suggest that the availability of food and drink were seen as restrictive for some patients, particularly those prescribed modified diet and fluids:

“Especially on the staged menus [modified diets], [choice] it’s quite limited... you only get a choice of two for the main meals... but we do try and accommodate as best we can, although sometimes we, with all our best efforts, it’s difficult” (Lena, HCA).

The appearance of meals provided for patients and especially those on modified diets was criticised and thought to be a major contributing factor to some patients not eating adequate amounts of diet or drinking enough fluid:

“Well, I don’t know, just if I was a patient and I saw that in front of me I just would think, “no, I’d rather not eat that”, because it doesn’t look nice because it’s just a load of gloop on the plate” (Rachel, RN)

The nutritional quality of meals, particularly modified diets was of concern to MDT members with specialist knowledge in this area. The SLTs and Dietitians thought some of the meals, particularly the modified meals produced by the kitchens to be nutritionally incomplete. Despite no supporting scientific evidence

for their perceptions, the provision of food supplements for every patient suggested this was so:

“There is some development needed for some of the menus really from an energy and protein point of view. So, the Dietitians currently are working with the catering department to kind of look at the menus and the content and trying to get it a bit better.” (Alice, Dietitian)

HCA's who support patients to make meal choices were unaware of this issue potentially encouraging patients to make fewer nutritional choices, and did not recognise the importance of the food supplements supplied:

“I kind of figure that nutritionally, as a balanced meal, that everything would be there, so I kind of entrust that as a Trust, they've already addressed that issue and that, yeah, that the meals that we provide are already nutritionally balanced.” (Jane, HCA)

Sub theme 3.2. I know whose job this is, but there is not enough of them?

All MDT members acknowledged a collective responsibility for ensuring patients adequate nutrition and hydration, and that supporting stroke patients with eating and drinking was an important though complex and time-consuming process. RNs but predominantly HCA's were identified as providing most direct support with eating and drinking:

“SLT or OT wouldn't, like, come at mealtimes to help feed them, only if they're doing assessments. So yeah, it's mostly, it's mostly down to the nursing staff” (Lena, HCA).

RNs, HCA's and some other MDT members recognised that support was often compromised due to RN and HCA excessive workload:

“But if you've got a bunch of people all who need actual feeding, or hand-over-hand, I think it can be quite hard, because I've sat with patients for 45 minutes to an hour and it's like, they don't have 45 minutes to an hour, and they've got 31 patients on the ward, and I don't know however many... not that many staff to manage it” (Janice, SLT)

Although acknowledging RN and HCA difficulties with provision of support particularly at mealtimes, other MDT members did not feel they could offer

support. Their rationale for this included limitations on their capacity caused in part by recommendations for timed therapy targets from national guidelines (ISWP, 2016):

“It was felt that feeding patients didn’t class as part of the 45-minute therapy... it was felt that feeding didn’t contribute to that 45-minute therapy target” (Julia, WM)

Other rationale for being unavailable to offer support at mealtimes was that it was not within the remit of their role to offer direct support with eating and drinking. Despite voicing a collective MDT responsibility for ensuring patients were adequately nourished and hydrated, concerns were voiced about the maintenance of role boundaries:

“And then sometimes you sort of feel like you’re stepping on the boundaries of other people’s roles and it’s, as a student it’s something that you get marked on.” (Cara, PT)

ICs supporting eating and drinking was thought to improve the patient experience and decrease the RN and HCA workload, and viewed positively:

“...we ask relatives if, just sometimes just because I think they eat better for them sometimes and it just helps out as well, so they get their meal on time, you know.” (Lena, HCA)

In summary, the findings from subthemes 3.1 and 3.2 suggest that food and drink, important resources for supporting eating and drinking were not of consistently good quality and had limited availability. Supporting eating and drinking was acknowledged as important by the MDT, but on a regular basis thought to be the remit of RNs and HCAs role only, who in turn were perceived to be inconsistent in fulfilling this responsibility.

5.4.1.4. Theme 4. We think we offer effective support, but how do we know?

This theme explores the MDTs perceptions of how they know that they are offering effective support with eating and drinking. As the theme developed, two

subthemes were identified from the data. Subthemes 4.1 discusses delegation of support work and supervision of delegated work. Subtheme 4.2 reports MDT perceptions of how support with eating and drinking are formally monitored.

Subtheme 4.1. It's my responsibility, but others do the work

The wider MDT agreed that supporting patients to eat and drink was important work and that ongoing daily support with this was the responsibility of the nursing team WM and RNs. They in turn delegated what they perceived as important work the HCAs:

"...it would be up to the healthcares predominantly to deliver drinks throughout the day and then the staff nurses to be reviewing the fluid balance to make sure they're getting the food and drink, or asking the healthcares, but it tends to be the healthcares that deliver that element of hydration" (Julia, WM).

RNs trusted the HCAs do this work and considered the HCAs abilities for delivering support to be as developed, if not more so than their own ability.

There was no concern that the required support was not offered:

"...some of the healthcare assistants have been here 25 years, they've a lot more experience than I have, they might not, I don't like this trained and untrained because there are, they've got a lot more experience than me." (Lucy, RN)

Subtheme 4.2. The presumption is that the work is done, but we don't always check

There was inconsistency between HCAs the WM and RNs as to who recorded nutritional intake. HCAs reported that they gathered and recorded some objective information about nutritional intake on NICs and completed the MUSTs. There was concern from some RNs as to the completeness, accuracy and timeliness of the information recorded. Unless a HCA reported concerns to a RN in a timely way, the RN failed to identify a patient with reduced intake of diet or fluid until much later in the day, and sometimes not until the end of a shift when the RN were completing care records:

“...sometimes you have to rely on other people telling so, so like the healthcare assistants, how much they’ve eaten and drank or you know, rely on them to fill out food charts, rely on them to fill our fluid balances, rely on them to you know, to do all that” (Rachel, RN).

SLT occasionally asked for verbal feedback on patients’ eating and drinking abilities at mealtimes from the RNs but more so HCAs. Dietitians and Doctors relied on objective measurements such as blood results and the MUST score to monitor the nutritional status of patients:

“Yeah, but then sometimes it [malnutrition] might be picked up on the ward round, as well.... obviously if the patient’s losing weight and things like that, or if their renal function is going up, and we’ve seen on the bloods, yeah”. (Emma, Dr)

Though the weekly requirement for MUST completion was inconsistent, if a patient had lost weight and the MUST score increased, the MDT used this information as part of the process to evaluate if the support was effective. It prompted reassessment and or an investigation as to whether prescribed support had been implemented and if not why:

“...when we’re auditing a MUST score... we’ve got poor compliance really.” (Alice, Dietitian)

Implications for patient care were those patients not eating and drinking or losing weight were not always identified in a timely fashion. This delayed referral to others, such as dietitians and lack of awareness across the MDT that the patient was potentially malnourished or not progressing in their recovery.

In summary day-to-day support with eating and drinking was delegated to HCAs, usually unsupervised by RNs. It was recognised that objective monitoring of nutritional intake and status was inconsistent. Only the SLT asked patients, RNs and HCAs directly about the level of support patients required with eating and drinking and its effectiveness. Inconsistent completion of the MUST delayed referral to dietitians.

5.4.1.5. Theme 5. I picked up how to support patients as I went along

This theme explores the specialist knowledge and skills required to support eating and drinking and their acquisition from the MDT perspective. All MDT members identified that supporting stroke patients to eat and drink was specialist work and required some knowledge and training:

“Feeding a patient sounds really basic but I think people worry that they’re going to do something wrong, particularly on a stroke ward, there’s a risk of aspiration or giving the wrong thing to the wrong patient, you know, it’s quite important that we do feed people correctly. So as long as someone’s trained it doesn’t matter who it is really.” (Alice, Dietitian)

All MDT members reported the potential risks of aspiration and malnutrition and perceived the SLTs and dietitians to have expert knowledge in these fields. Other MDT members had varying degrees of knowledge and skill in supporting eating and drinking. They reported that some knowledge and skills were gained prior to commencing work on the stroke unit during pre-registration courses, and some from previous work and life roles, but it was not stroke specific:

“I didn’t ever have any specific training about eating and drinking, we discussed it at university,” (Lucy, RN)

There was an assumption that all MDT members received some education and training including skills to support patients to eat and drink when they initially came to work on the stroke unit, however, some MDT members had received no training:

“I’ve never had any training on like feeding a patient or eating and drinking, you know, helping a stroke to eat and drink, no” (Rachel, RN).

Some had received initial training, but this had not been updated for many years. RNs and HCAs reported that they learned from experience, often peer to

peer. They occasionally sought expert advice from the SLT if they were present on the unit, thereby developing their knowledge and skills, though not always from a validated source of expertise:

“I don’t know, probably just years of doing it; it’s, you know, experience I suppose. It’s like somebody that’s new into the job, I mean, it’s these things that they learn isn’t it over time.... I don’t know who’s been on (the training) and who hasn’t, to be honest, especially like the new ones, new starters and things, probably do go on it but I’m not sure.” (Lena, HCA)

The MDT, particularly RNs and HCAs were not always aware of each other’s capabilities and limitations in supporting eating and drinking. RNs and HCAs participated in this work from their first shift on the stroke units:

“But it’s a skill that we use really, really quickly, so a healthcare on day one will be involved in eating and drinking.” (Julia, WM)

This potentially meant that patients were not given the required support to eat and drink, increasing the risks of aspiration and malnutrition described above.

In summary, specialist knowledge and skills are required to ensure that stroke patients are supported to eat and drinking effectively and safely. Pre-registration nurse education cannot be relied upon to impart these skills. RNs and HCAs learned their skills from ad hoc, on the job learning, with no assessment of ability or competency.

5.4.1.6. Conclusion

All the MDT members interviewed acknowledged that supporting patients to eat and drink was important for their patients’ wellbeing and recovery from stroke. In addition, most thought that the patients were adequately supported with this

activity. However, other than for patients directly managed by SLT, there was no structured assessment of patients eating and drinking abilities and the identification of support requirements with eating and drinking was inconsistent. Compounded with variable communication of identified support requirements, some patients did not receive effective and timely support to eat and drink. The provision of modified food was unappealing; the nutritional content of the food provided was also a concern, potentially affecting patients' intake of adequate nutrition. At times, constraints on RN and HCA time and fluctuating patient acuity affected the level and quality of support offered at mealtimes, HCAs felt rushed as did the patients, leading to reduced food intake. Objective measures of food and fluid intake and MUSTs were often incomplete, resulting in delayed referral to the dietitian. RNs and HCAs received variable education and training for managing eating and drinking with stroke patients, mainly relying on experiential learning. At times, this negatively affected the identification of patients' support requirements and their communication to the wider MDT, the acquisition and use of specialist equipment, and the monitoring of patients progress and performance with eating and drinking.

5.4.2. Findings from patient interviews site A

Thematic analysis of the patient interview data identified two main themes with subthemes. These were developed from 47 initial codes, inductively themed over four theming attempts prior to finalisation.

5.4.2.1. Theme 1. I know I should eat but I don't always want to, perceptions of facilitators, motivators and barriers to eating and drinking

Patients discussed factors that they perceived to facilitate and motivate them to eat and drink and barriers to this activity during their stroke unit experience. Two subthemes developed - subtheme 1.1 explores what patients perceived as facilitating or motivating eating and drinking. Subtheme 1.2 investigates what patients perceived as barriers to eating and drinking.

Subtheme 1.1. This is what makes me want to eat and drink

All the patients had been independent with eating and drinking pre-stroke. For some but not all patients, motivation to eat and drink came from awareness of their physiological requirements - to stay alive, they must eat and drink and experiencing hunger and thirst. Some patients acknowledging this soon after their stroke onset (within forty-eight hours) for others this was after an initial period of enteral feeding:

Int: "Are you saying it's just a task that you've got to do [eating], as in, "I need to eat to stay alive?"

"Yeah, it's a bit of that. I've got to eat... During the night, [I get] very, very thirsty". (Cynthia, patient)

Positive ideas about eating and drinking post hospital stay were motivational, and fuelled a desire to be independent with eating and drinking and have food and drinks they enjoyed prior to their stroke:

"I'm looking forward to the day when I can eat food, properly cooked with veg". (Cynthia, patient)

These motivational thoughts prompted acceptance of their current eating and drinking situation. Often viewed as part of their rehabilitation programme, the more they practiced the better at it they became:

"But then again you've got to get used to it [modified diet] if you want to get better. And I know myself it's not going to last forever, the eating problems ... a couple of months on, hopefully." (Norma, patient)

All the patients interviewed had received verbal encouragement as well as physical support such as cutting up food, thought to facilitate eating and drinking:

Int: "And encouraged you to do it yourself, did they?"

"Yes... eventually. I'm tempted to say a whip [laughs]". (Cynthia, patient)

Mainly the HCAs and informal carers provided this support, though doctors and a volunteer helper were mentioned:

"I had low blood pressure which they (doctor) say, "You need to drink more, you need to drink more," so I had to get through, you know, quite a lot of fluids." (Alison, patient)

Eating in the dining area was perceived as more normal, physically and psychologically more comfortable than when situated in bed or at the bedside both motivating and facilitating eating and drinking:

"But recently I've been eating down in the residents' lounge, is it, and found out there's more space, big table, and you're not, people are not looking at you, yeah. Because that's when it gets a bit embarrassing, when you're fumbling about, you're missing your mouth and that." (Don, patient)

Subtheme 1.2. Sometimes, something puts me off eating and drinking

Not experiencing hunger or thirst was a barrier to eating and drinking and at these times eating and drinking was perceived as a chore:

"I don't think so, I don't feel hungry, very hungry some of the time, just sort of forcing something down, you know." (Doreen, patient)

Some patients could not explain why they did not experience these physical drives, whilst others thought lack of physical exercise or involvement in food preparation reduced appetite:

"...when my meals come, I'm not ready for them. I'm like, you know at home you, like, fancy something and you prepare it, you know like, and then you sit and eat it, you get some satisfaction then. But I think maybe because I'm not preparing, I've not worked for it, you know like, I get this meal and then I feel as if I've just had lunch and then tea's here and everything's about food, hmm." (Alison, patient)

The physical effects of stroke were perceived barriers to eating and drinking. Patients identified upper limb and hand weakness, swallowing difficulties and problems with proprioception [awareness of body position], resulting in spilling food and drink, varying degrees of coughing with expelling food and drink from the mouth, drooling and fatigue:

“Well, I'd had quite enough, as I say I had this coughing do...like at this mincey thing ...with a bit of this mince with it if you know what I mean, but I thought oh I don't want anymore.” (Moir, patient)

The relationship between physical disabilities and emotional response was complex. Most patients experienced embarrassment when eating and drinking due to their disabilities, which affected their behaviour – often declining food and drink or not completing meals:

“I was just, didn't want anything because I felt very, you know like, on show, you know, so you know, it was like very obvious my failings [dribbling], you know... so I'd rather not eat than be in that situation.” (Alison, patient)

At some point, all the patients had required support from the MDT or their ICs. Some patients described pragmatic acceptance of support. Others experienced negative emotions when receiving support (frustration, embarrassment, uselessness, infantilisation, loss of pride) which stopped them seeking support, and sometimes meant they could not fully complete meals and drinks:

“They'd help me, I think, if you asked. Yeah, but I found it embarrassing.”

Int: “What bit was embarrassing to you?”

“Well, asking the nurse to help you to eat. No, no. I'm too proud to, no”. (Don, patient)

Some patients' experienced feelings of disgust when exposed to other patients drooling and coughing, and guilt when observed by other patients who could not eat. These were perceived barriers to eating and drinking:

“I feel as if...I feel greedy because, you know like, I'm not struggling but they've got worse problems in eating and drinking than I have...they're desperate to get off the NG tubes and I'm there having toast and it's a big part of our [patients] conversation as well” (Alison, patient)

Patients' perceptions of the 'nurses' busyness were barriers to asking for support, and often attempted the process themselves with difficulty or left food uneaten:

"I think the girls [nurses] are really busy. They're very busy, they do a good job, and I wouldn't mither, no, I wouldn't bother them, I'll manage on my own [cutting up food]." (Don, patient)

At some point, the patients had been prescribed modified diet or fluids. These were viewed negatively for texture, appearance and lack of variety. Normal diet and fluids were thought to be more palatable, though did not particularly motivated them to eat and drink:

"It just looked the same every meal colour wise. It was either brown I realised that was like the stew, I can't eat stew, but everything is the same ...And the one that I have now [soft diet] yeah, it's set out better, but it just looks the same, it doesn't look, it's not appetising... Everything tastes the same, whether it's me I don't know. I wouldn't know what was chicken or what was beef, put it that way, very, no". (Norma, patient)

In summary, not all patients experienced a physical drive to eat and drink and emotional responses to eating and drinking post stroke were overwhelmingly negative. Eating and drinking was perceived to be hard work and fatiguing. Though patients acknowledged that they required the support they received, this often triggered negative emotions with some patients preferring to struggle rather than instigate support, resulting in them eating and drinking less.

5.4.2.2. Theme 2. I didn't really think I had a problem with eating and drinking

This theme explores the patients' perceptions of identifying and then adapting to the process of to eating and drinking following stroke.

When initially asked if they required support with eating and drinking, half of the patients interviewed stated that that they did not. These patients all had some physical deficit such as upper limb weakness, reduced dexterity and facial

weakness, which affected the process, but they had not identified this as a problem. Instead, they had adapted to the stroke deficit:

“Difficult. I tend to cut my food up to pieces, use my right hand, then to eat off one hand. I don’t use my knife and fork like I used to do. Yeah, I cut my food up and then eat it in small pieces.” (Don, patient)

For other patients adaptations had been identified by RNs, HCAs, SLTs and for one patient an OT during a therapy session.

Patients independently adapted to their altered state of eating and drinking following stroke in different ways, dependent upon their stroke deficit. They mainly selected foods that were easier to eat, thereby removing the need to ask for support, and perceived as achieving some level of independence. Avoiding foods that required support to eat, was acknowledged to reduce food choices, but this was outweighed by the perceived gain in independence. These patients did not receive any support from the MDT as they were seen to be eating adequately, thereby perpetuating the issue of limited food choice:

Int: “So, so has nobody offered you any equipment like that (plate guard), Alison?”

“No, no. I think a guard would be good but like I say, I’m managing my main meal quite easily now”.

Int: “But only because you’re choosing food that you know you’re not going to have to chase about on your plate”.

“Yeah, yeah, I’m not even choosing a dessert, you know, because I know, I tend to choose the yoghurts, but I can’t eat the yoghurts, you know. Is there anything that holds, you know like, pots?” (Alison, patient)

In summary, all the patients adapted their approach to eating and drinking to a greater or lesser degree dependent on the effects of their stroke. Some patients found methods to manage this process independently, others with support from ICs and the MDT.

5.4.2.3. Conclusion

Both physical and psychological factors affect motivation to eat and drink following stroke. Some patients independently adapt to their changed abilities with eating and drinking, though restricting their food choices making eating and drinking a less pleasurable experience. Patients who are unmotivated and are unable to adapt to eat and drink require unsolicited support from the MDT as patients experience difficulty in asking for support.

5.4.3. Findings from Informal Carer interviews at site A

Two themes, one with subthemes were developed from the analysis of IC interviews. Eighty initial codes were themed inductively with three iterations of the themes prior to finalisation.

5.4.3.1. Theme 1. The inconsistent provision of nutritious and appealing food is not supportive to my relative's eating and drinking

At some point since stroke onset all the ICs' relatives had required modified diet and fluids. All the ICs understood why the modifications to diet were necessary, but they viewed their appearance, in particular pureed diets to be unappealing and perceived this negatively affected how much their patient ate:

"...they could actually make the food look a lot nicer than it is, you know, it just looks like slop on a plate. I mean, visually, mum just said, "It looks like crap, it looks like rubbish" ... Yeah, it's just like, "Please, just don't give that to me". (Lyne, IC to June)

Food choices for modified diets were perceived as limited and monotonous compared to those for normal diet. Thickening agent added to drinks affected the taste, which at times negatively affected relatives' mood and in turn their fluid intake:

“He hated that, he hated, hated, hated it, because they put it in everything don’t they [thickener]. And he was really quite low with that”. (Joan, IC to Don)

As their relatives had progressed from a pureed diet towards a normal diet or thickened drinks to unthickened drinks, ICs opinion of the food and drink in taste, texture and appearance improved:

“There’s not been one day. Since he came off the thickener there’s not been one day when he’s said, “Lunch was horrible,” or, “Evening meal was horrible,” (Joan, IC to Don).

All ICs supplemented their relatives’ diet and felt encouraged to do so by MDT members. ICs felt this increased the variety of food and drink available, relieving the monotony of modified diets, and benefited their relatives’ nutritionally:

“They’re probably only getting a thousand calories a day...so, I’ve brought yoghurt in.” (Lyne, IC to June).

In summary ICs perceived that the taste, texture, appearance and lack of food choice for modified diets negatively affected their relatives’ mood and discouraged them from eating and drinking adequately. All ICs supplemented the dietary provision delivered by the institution.

5.4.3.2. Theme 2. Mechanisms to support eating and drinking benefit from IC intervention

This theme and subthemes developed as ICs discussed actions and processes perceived as supporting their relatives to eat and drink and those that did not. Subtheme 2.1 Explores ICs perceptions of their role in supporting their relatives’ eating and drinking. Subtheme 2.2 Explores ICs perceptions of the role of others in supporting their relatives to eat and drink.

Subtheme 2.1. Inconsistent support mechanisms require ICs to enhance patient experience

ICs discussed times when they identified and delivered support and when on other occasions, support needs had been identified by the MDT but then delivered by the ICs. ICs identified that the post stroke deficits experienced by their relative made eating and drinking difficult. Their relatives were often not hungry, easily overfaced by the size of meals and fatigued, causing them to eat and drink inadequate amounts and requiring support to overcome these issues:

“She couldn’t eat...she was close to tears, not because she couldn’t eat, just because she felt tired,” (Jim, IC to Cynthia)

All the ICs considered they provided both physical and psychological support. Physical support included cutting up food, removing food coverings, positioning equipment, thickening drinks, supporting hand to mouth actions, feeding and facial cleansing with some ICs identifying their support as part of the rehabilitation process:

“I think it's correct for me to let her do as much as she can, rather than keep butting in and say, "Oh, let me do that", from a therapy point of view I think it's better if she can do everything herself, really.” (Jim, IC to Cynthia)

ICs discussed providing foods they knew their relative liked, encouraging their relatives to eat more. This was perceived to be supportive both physically - increasing calorific intake and psychologically - lifting mood:

“...so, we brought her in a chocolatey-yogurt things... to have after her meals and that was obviously very popular.” (Jackie, IC to Moira)

ICs offered psychological support in the form of encouragement and discussed being patient in their approach and choosing their words carefully as they perceived how difficult eating and drinking was and how demoralising for their relative:

"I will say "let me help you eat", not, "Let me feed you", I'm trying to use more words that I'm aware of that won't make her feel like she's an invalid." (Lynne, IC to June)

Other ICs acknowledged they had been coercive, though justified their behaviour, as it was perceived to benefit their relative:

"I kept saying, sort of waving the tube at her, you know, if you don't eat this is going to go back up and you won't be able to come out of hospital and you won't be able to come home." (Linda, IC to Margery)

Some, but not all ICs felt supported by the MDT enabling them to support their relative more effectively and viewing open visiting at mealtimes positively:

"...the hospital would always say, would you like to feed her, yeah, especially in SA1 ...but I think after a couple of times they just took it for granted that we would because we were just there. And discouraged? Never. Never." (Linda, IC to Margery)

Education and training from the MDT for ICs with supporting eating and drinking was variable. Some ICs had direct intervention from SLT, others referred to SLT yellow signs at the back of their relatives' bed, and others felt left to work out what to do themselves, increasing their anxiety as to whether the support they administered was correct:

"that's lacking here, even though they're very nice people, and I think they're very good at their job, I think if they had like maybe a protocol to show all the new people how to feed their parents or their loved ones." (Lyne, IC to June)

Subtheme 2.2. Inconsistent support mechanisms reduce confidence and provoke anxiety for some patients' wellbeing

ICs identified RNs, HCAs, SLTs and a volunteer as supporting patients to eat and drink. ICs had experienced the HCAs delivering food and the volunteer delivering drinks to their relatives. HCAs offered encouragement and directly assisted them to eat and drink, with the volunteer verbally advising and encouraging eating and drinking:

"...the staff would encourage her to, you know, 'you really should try and have, to eat this because it's got all the vitamins and all the rest, it's going to be good for you'." (Jackie, IC to Moira)

ICs identified MDT behaviours they thought non-supportive to eating and drinking. They described occasions when HCAs were observed not giving the correct prescribed support to their relative. This required the IC or their relative to intervene:

"...there has been the odd occasion when one of the nurses, who isn't a regular on the ward, has offered her a cup, and Cynthia has had the good sense to say, "No, I can't do that". But I don't know what would happen if she did take it and try to take a drink, it would probably be a disastrous thing." (Jim, IC to Cynthia)

ICs perceived that some care was omitted; particularly oral hygiene, which they thought negatively affected their relative's eating and drinking experience. ICs identified that this often happened if the staff member was not a regular member of the stroke unit MDT, and often in conjunction with increased workload when nurses were busy. This increased ICs anxiety about how their relatives were supported when they were absent:

“So, I know they're getting fed, but sometimes it might be, by the time it gets to them it might be cold. I noticed that our neighbour didn't get fed until they were almost clearing them away and they kind of had to quickly feed her.” (Lyne, IC to June)

Three of the ICs were aware that their relatives should be weighed regularly. Two ICs were aware that their relative had gained weight, which to them inferred they had taken adequate amounts of food and drink and received appropriate support to enable this. Another IC was aware their relative had lost weight and was not eating and drinking adequately. Some ICs were aware of other objective measures of food and fluid intake describing NIC and FBCs but were not convinced that these were completed accurately or used correctly by the MDT. Three ICs perceived that at times their relatives did not eat and drink enough. Only one of the ICs had sought communication specifically about their relative's food and fluid intake and received a superficial response causing the IC some concern:

“I've even asked the Dietitian (about nutritional values of food) ... she didn't know, she should know that, especially since she's estimating how much she's eating, I don't know how she estimates the protein and calories and how much, but that chart that they do (food chart), it's very, in this age it's very archaic.” (Lyne, IC to June)

All ICs acquired some information subjectively, for example they had seen their relative eat some of the food delivered from the hospital kitchen at some mealtimes or thought their relative looked to have lost or gained weight. Two ICs trusted that the hospital would provide all the food and nutrition that their relative required:

“So, I was quite pleased that the hospital thought that was the right amount for her because it was a very small portion and it was a 'her' size portion.” (Linda, IC to Margery)

In summary, ICs physically and psychologically supported their relatives to eat and drink, understanding that this was an important part of their relatives'

rehabilitation and recovery. ICs perceived that support from the MDT was inconsistent, whilst some received education and encouragement, others were left to work things out for themselves. MDT communication with ICs about their relatives' nutritional status and eating and drinking abilities was inconsistent in content and availability. Some ICs perceived their relatives received inconsistent direct support with eating and drinking from the MDT, particularly agency workers. Some ICs experienced increased anxiety due to concerns with safety and the standard of support their relatives received when they were absent.

5.4.3.4. Conclusion

ICs considered the taste, texture and appearance of modified diet and fluids were barriers to eating and drinking adequate amounts. ICs recognised that their relatives required support to eat and drink which was delivered in part by the ICs. Support with eating and drinking from the MDT was inconsistent with occasional errors perceived hazardous increasing ICs anxiety for their relatives' safety. ICs received inconsistent information about their relatives' nutritional status. Some ICs implicitly trusted the MDT to ensure their relative was eating and drinking adequately and receiving adequate nutrition. These suppositions were often based on minimal subjective information.

5.5. Summary of findings from observations, interviews and documentary evidence at site A.

The MDT, patients and ICs identified physical and psychological factors influencing patients eating and drinking abilities following stroke, acknowledged to impact patients' nutritional status and wellbeing. Despite all MDT members stating that supporting patients to eat and drink was important in post stroke recovery and rehabilitation, their actions did not always reflect this. HCAs were delegated all mealtime work and provided most of the direct support with eating

and drinking at site A. Except for those patients under the management of the SLT, identification of support requirements and delivery of support was completed by the HCAs and a small number of ICs. HCAs were delegated to record MUSTs. These activities were approached and executed with variable levels of effectiveness. Discussion and communication of patients support requirements across the MDT and with ICs was limited despite formal communication mechanisms being in place. At times, this inconsistent communication incurred time wasting and led to errors and omissions with support for eating and drinking with potentially hazardous outcomes.

Lack of education and training with minimal professional leadership and supervision contributed to inconsistent support with eating and drinking for patients on the stroke units. Patients frequently did not receive the support to eat and drink the food and fluid, which they required to support their recovery at site A.

Chapter 6: Findings site B

6.1. Introduction

This chapter introduces the setting and participants recruited at site B. The findings from the analysis of observations, supported by analysis of documentary data, then semi-structured interviews from the three participant groups. A summary of findings from site B completes this chapter.

6.2 Setting description and participant recruitment

Site B was the specialist stroke centre servicing a large city in the north of England. The services at site B were situated in the same hospital and consisted of a hyper-acute stroke unit, an acute stroke unit identified in the study as SB1 and a rehabilitation stroke unit identified as SB2. See table 16 in chapter 5 for definitions of stroke unit types.

Permission was not obtained for inclusion of the hyper-acute stroke unit in the study so no data were collected from that area. SB1 had 28 beds receiving patients from the hyper-acute stroke unit, or those patients designated as requiring terminal care. The unit comprised four single rooms and six - four bedded bays, designated for female or male patients as the patient profile required. Another four-bed bay had been converted to a therapy space, sited on SB1. Speech and Language Therapy [SLT], Occupational Therapy [OT] the Physiotherapy [PT] teams had offices on SB1. SB2 comprised 28 beds, with the same bed formation as SB1. Another 4-bed bay had been converted into a patients' dayroom on SB2. Stroke consultants had their offices on SB2.

The lunch and evening meal delivery system at site B required bulk meal orders submitted to the catering department two weeks in advance. Meals were ordered with reference to the patient profile of the unit at the time of ordering. Prepared raw food was delivered to the stroke units prior to midday and evening mealtimes and cooked in specially designed heated trolleys. Once ready, the trolley was wheeled to a central point on the ward area where meals were plated and delivered to the patients. On the day of delivery, the patients ordered from the menu for that day. Breakfast consisted of a selection of cereals and toast prepared on the stroke unit and porridge delivered from the catering department. Hot and cold drinks were prepared in the stroke unit kitchens.

Between April 2017 and November 2017, which incorporated the period of data collection at site B, the inpatient stroke services admitted 604 patients and scored an overall SSNAP grade C April to July 2017, increased to a grade B August to November 2017 (RCP, CEEU - ISWP, 2017; 2018). During this time SB1 and SB2 ran a three shift per 24-hour shift pattern, see table 26, below for observed average RN and HCA staffing per shift.

Table 26. RN and HCA Staffing complement per shift SB1 and SB2

Stroke unit	Early shift		Late shift		Night shift		Recommended RN and HCA complement (ISWP, 2016; National Stroke Nursing Forum [NSNF], 2016) Acute and rehabilitation stroke units -1.35 Whole time equivalents (WTE) per bed split (65:35) (registered: unregistered)	Actual RN and HCA complement observed
	RN	HCA	RN	HCA	RN	HCA		
SB1 Acute Average shift staff numbers from observations	4	5	3	4	2	3	Beds (n=28) x 1.35 = 37.8 staff. 37.8 staff x 5 shifts each = 189 staff shifts. 189 staff shifts / 7 days = 27 staff shifts per day. Should be 17.5 RNs:9.45 HCAs per day	21 staff shifts per day, of which: 9 RNs :12 HCAs Should be: 13.65 RNs: 7.35 HCAs
SB2 Rehabilitation Average shift staff numbers from observations	4	5	4	4	2	3	Beds (n=28) x 1.35 = 37.8 staff. 37.8 staff x 5 shifts each = 189 staff shifts. 189 staff shifts / 7 days = 27 staff shifts per day. Should be 17.5 RNs:9.45 HCAs per day	22 staff shifts per day, of which: 10 RNs: 12 HCAs Should be: 14.3 RNs: 7.7 HCAs

A summary description of the characteristics of site B are presented in table 27 below.

Table 27. Summary description of characteristics at site B

Location of institution	Urban location situated in a large city in the north of England. Serving a population of approx. 565,000.
Stroke unit types	Acute stroke unit (SB1) geographically adjacent to and linked to SB2 same hospital site. Stroke rehabilitation unit (SB2).
Number of beds	SB1- 28 beds. SB2- 28 beds.
Patient Length of stay	SB1 – Average 7 days. SB2 - Average 30.2 days.
Patient profile	SB1 – Patients were admitted to the unit via a separate Hyper Acute Stroke Unit (HASU) based in the same hospital or admitted for terminal care. Patients remain on the unit until transfer to SB1, discharge to the community or death. SB2 - Patients were admitted from SB1 or repatriated from other stroke centres across the area when considered medically stable and usually remain on this stroke unit until discharge or death.

Data collection at site B commenced on the 6th of June 2017 and completed on the 30th of October 2017. The planned data collection period of 12 weeks for site B was extended to 21 weeks due to the researcher's other work commitments during this time. The extended data collection period enabled collection of interview data from a sample of all participant groups. The end of data collection was agreed when the researcher in consultation with their supervisors, agreed that no new information was being generated from the data, as discussed in the Methods - chapter four. Table 28 below summarises the number and type of participants recruited to the study at site B.

Table 28. Participants consented to the study at site B

<i>Patients</i>	<i>Informal carers</i>	<i>MDT members</i>
Male x 9	Male x 1	Ward Manager (WM) x2
Female x 4	Female x 5	Ward sister (SR) x1
		Registered nurse (RN) x 4
		Trainee Associate Practitioner (TAP) x1
		Health Care Assistant (HCA) x4
		Physiotherapist (PT) x 1
		Occupational therapist (OT) x 2
		Speech and Language Therapist (SLT) x1
		Dietitian x1
		Dietetic Assistant x1
		Consultant x2
		Therapy Assistant (TA) x1
		Ward Assistant (WA) x1
		Housekeeper (HK) x1

Observation sessions initially commenced on SB2 as the researcher was initially introduced to this area by the principal investigator, then alternated between SB2 and SB1. Observations on SB1 and SB2 took place between 06.00 to 22.00 hours across the 7-day week. Twenty-nine visits totalling 194.5 hours of observation were completed. Peak times of activity relevant to the research objectives were identified, resulting in more observation between 06.00-19.00 hours, with focused observations at mealtimes, MDT meetings and other activities such as patient therapy sessions.

Thirty semi-structured interviews were completed on site at site B, with one interview completed at an MDT member's home. MDT interviews ranged from 20 to 77 minutes in length, average 57 minutes. Patient interviews ranged from 14 to 64 minutes in length, average 43 minutes. IC interviews ranged from 21 to 38 minutes in length and averaged 32 minutes.

Participants from thirteen occupations comprising the MDT were interviewed. Table 29 below details their occupation and length of experience working with stroke patients.

Table 29. Participant data - MDT interviews site B

<i>Participants</i>	<i>Abbreviations</i>	<i>Pseudonym</i>	<i>Length of experience working with stroke patients</i>
Health care assistant	HCA	Edith	9 years
Health care assistant	HCA	Shaun	26 years
Ward manager	WM	Chris	7.5 years
Ward manager	WM	Katie	1 year
Sister	SR	Liz	12 years
Registered Nurse	RN	Sally	4.5 years
Registered Nurse	RN	Kirsty	1 year
Registered Nurse	RN	Pat	12 years
Speech and Language Therapist	SLT	Naomi	20 years
Ward Assistant	WA	Elaine	25 years
Housekeeper	HK	Molly	2 years
Dietetic Assistant	DA	Corinne	3 years
Dietitian	D	Diana	5 months
Consultant	Con	Steve	6 years
Consultant	Con	Jack	7 years
Physiotherapist	PT	Joanna	6 months
Occupational therapist	OT	Harriet	8 years
Occupational therapist	OT	Adele	16 years
Trainee Assistant Practitioner	TAP	Rosie	10 years

Six of the thirteen patients recruited to the study at site B participated in semi-structured interviews to investigate their experiences of eating and drinking on the stroke units. See table 30 below for patient participant details.

Table 30. Participant data - patient interviews site B

<i>Patient participants' pseudonyms</i>	<i>Gender</i>	<i>Age</i>	<i>Length of time support required with eating and drinking</i>	<i>Time since stroke onset to interview</i>
Eric	Male	82 years	91 days	91 days
Jeremy	Male	56 years	123 days	123 days
Sylvia	Female	69 years	108 days	108 days
Paddy	Male	51 years	101 days	101 days
Andrew	Male	87 years	105 days	105 days
Douglas	Male	77 years	34 days	77 days

Five of the six recruited ICs observed also participated in semi-structured interviews to investigate their experiences of support for their relatives eating and drinking on the stroke units at site B. All the ICs' relatives were on SB2 at the time of their interviews. See table 3128 below for IC participant details.

Table 31. Participant data - Informal carer interviews site A

<i>Informal carer (IC) participants' pseudonyms</i>	<i>Relationship to patient participant</i>	<i>IC gender</i>	<i>Patient participant pseudonym</i>
Valerie	Daughter	Female	Rita
Maureen	Spouse	Female	Joe
Betty	Spouse	Female	Tommy
Donna	Daughter	Female	Tommy
Marie	Spouse	Female	Geoff

6.3. The management of eating and drinking at Site B

This section presents findings from the analysis of data collected from observations and documents at site B. These findings assist with setting the scene as to how patients are supported to eat and drink at site B.

6.3.1. Identifying and prescribing support with eating and drinking

6.3.1.1. Formal mechanisms of identifying and prescribing support with eating and drinking

Analysis of MDT records revealed that potential swallowing problems were initially identified during a swallow screen usually completed by trained RNs within 4 hours of the patients' arrival in HASU. This process usually, but not always, occurred prior to transfer to SB1 or SB2 with one patient on SB1 identified to not have been swallow screened. MDT records revealed that patients identified with a swallowing problem(s) at screening were referred to SLT and received a full swallow assessment usually but not always within 24 hours of admission. During swallow assessment, SLT often identified other support needs for preparation of food such as cutting up and moving food from plate to mouth.

An OT was observed assessing a patient's eating and drinking ability and identifying a support requirement during only one of six observed joint OT and PT therapy sessions. In this instance, the researcher thought this to be prompted by their presence. The dietitian and dietetic assistant mainly identified support requirements for patients who had progressed to oral diet from enteral feeding, having received referrals due to need for enteral feeding identified in HASU, SB1 or infrequently SB2. MDT records indicated that RNs referred patients on oral diet to the dietitian or dietetic assistant infrequently prompted by a reduction in MUST scores.

Analysis of MDT records revealed that SLTs prescribed the stage of modified diet and fluids and some support requirements for those patients identified as able to manage oral diet and fluid. The SLT also communicated these prescriptions on yellow signs at the back of patients' beds, though this information did not always match the most up to date information in the MDT records. OT was observed to prescribe specialist cutlery for one patient, verbally communicated to an RN and added to a yellow sign at the back of the patients' bed 48 hours later. OTs and PTs attended the whiteboard round and MDT meetings but were not observed to prescribe support with eating and drinking at these times. Analysis of the MDT notes revealed no entries from OT or PT pertaining to the prescription of support with eating and drinking. The doctors and dietitian prescribed commercially prepared feed supplements on the electronic medication prescription charts. The dietetic assistant also requested the Drs to do this and documented the prescription in the MDT records. Consultants were observed to request the recording of NICs, FBCs and MUSTs for specific patients on ward rounds and at MDT meetings, which was recorded in the MDT records. The SLT, Dietitian and the Dietetic Assistant also prescribed food additional to the standard menu such as cooked breakfasts, recorded in the MDT notes. The Dietitian and Dietetic Assistant recorded prescribed care in the MDT notes but did not attend whiteboard rounds or MDT meetings and never observed verbally prescribing care to other members of the MDT.

6.3.1.2. Informal mechanisms of identifying and prescribing support with eating and drinking

RNs were occasionally observed verbally prescribing patient support with eating and drinking to other RNs and HCAs at shift handover and rarely, during the rest of the shift including observed mealtimes. The support they prescribed was rarely detailed for example 'patient in bed 2 needs a hand' and infrequently entered into the nursing care record or MDT records.

Those patients not referred to SLT did not have a specific structured assessment for any part of the eating and drinking process observed or recorded in the MDT records. Patients, ICs or other members of the MDT, but most frequently the HCAs were observed to identify a need for support. Patients were frequently observed having difficulty preparing food (cutting and separating), manoeuvring food on the plate, reaching food and drink, transferring food from their plate to their mouth but did not request support from RNs or HCAs.

6.3.2. Providing support

6.3.2.1. Therapy supporting eating and drinking

SLT therapy sessions were observed to sometimes incorporate mealtimes, and SLT supported patients to eat and drink during these times. SLT accurately recorded patients' progress with eating and drinking in the MDT record. OT and PT were not usually present on the stroke units at mealtimes, though very occasionally were observed to pass through the stroke units. They were observed to use patient mealtimes to take their scheduled breaks, record the patients' therapy sessions and occasionally hold therapy team meetings.

6.3.2.2. Supplements

RNs dispensed prescribed commercially prepared feed supplements during medication rounds though rarely observed the patient taking them despite signing them as administered. These feed supplements were placed on patients' tables and lockers and frequently unconsumed by the patients. If consumed, this was rarely recorded on NICs or FBCs. Patients were often observed with numerous opened and unopened feed supplements by the end of the day, which were eventually discarded.

6.3.2.3. Practical support with eating and drinking

Patients were frequently observed not receiving their menu choice as it had run out. HCAs and RNs perceived that this was due to a change in patient profile in the two weeks since the bulk order was placed to the catering department. This particularly affected patients on staged diets who had more limited food choices. They were often observed receiving jacket potatoes with butter, the only remaining food suitable for them over consecutive mealtimes. A limited choice of snacks was available, but not all were appropriate for patients on

modified diets. During observations, RNs, HCAs and the dietetic assistant commented that the menus did not cater to the patients' food tastes, who were perceived to prefer non-spicy more traditional British foods. ICs often voiced negative opinions about the quality and presentation of the food provided by the institution expressing disgust and were distressed as they thought this reduced the amount their relatives ate.

The WM on SB1 was observed to supervise some mealtimes but the WM on SB2 was not observed at any mealtimes. SRs and RNs did not serve breakfast, as they were otherwise employed administering medication or completing patient related administration tasks. HCAs were often involved with other patient care at this time but also assisted with breakfasts, mainly the Ward Assistants [WAs] and Housekeepers [HKs] completed breakfast delivery with no RN supervision. No ICs visited at breakfast. Provision of some foods such as porridge was often inadequate, observed to prompt HCAs to limit portion sizes. At lunchtime and evening meal, SRs and RNs usually plated the meals at the heated trolley with HCAs, HKs and some RNs delivering the meal to the patients. Supervision of patients at mealtimes was ad hoc. HCAs were observed to return to support some patients after meals were delivered for the whole ward. During this time, meals had gone cold and some patients to decline to eat them. One SR and one RN were observed on multiple occasions asking staff to check that all patients had received meals and were being supported to eat. Patients were observed receiving the incorrect diet type or no meal on several occasions.

The SR and some but not all RNs were observed occasionally to provide direct support to patients with cutting up food, positioning patients to eat, feeding patients and on one occasion providing specialist cutlery and crockery. HCAs were most frequently seen to support patients with eating and drinking, both physically and verbally though this varied between HCAs. Some were observed to be more knowledgeable of patients dietary and support needs and infrequently received direction from the RNs. Patients were frequently observed to have eating and drinking difficulties, but left unsupported, despite RNs and

HCA's being in the patient vicinity. Some patients appeared indifferent to this, whilst others reacted with frustration, disengaging from the process by eating none or part of their meal. In between mealtimes and drink rounds, no support with eating and drinking was observed.

ICs were observed cutting up food, feeding, offering verbal and physical prompts to eat and drink, requesting food and drink, and specialised crockery and cutlery from ward staff at mealtimes. More ICs attended the evening mealtime to support with eating and drinking than at lunchtime, reporting during observations that this was due to other life commitments such as work. ICs were observed to advocate with the MDT for their relative regarding food and drink issues at mealtimes and expressed anxiety that their relative would not be supported to eat and drink adequately if they were not present.

6.3.3. Monitoring support

6.3.3.1. Record keeping

The Dietitian and Dietetic Assistant requested verbally to RNs and in the MDT record the completion of NICs and MUSTs to assist with monitoring food intake and nutritional status. Analysis of NICs and MUSTs revealed that they were inconsistently completed with some patients not weighed over several weeks. During observations, the dietetic assistant and consultants supported these findings, explaining that they had to use evidence that was more subjective in the prescription of support. Consultants occasionally recorded brief notes about patients' nutritional status in the MDT notes at MDT meetings, but never recorded detailed support requirements. RNs recorded some entries on nutrition care plans found on the patients' electronic nursing record and in the MDT notes. These were usually entered once per shift, were brief and lacked detail for example 'eaten adequate amount'. HCA's did not make entries in the electronic nursing or MDT records.

Observations and analysis of NICs identified that recordings were occasionally made by RNs but more usually by HCAs. The WA cleared away used crockery after meals but was not observed to inform RNs or HCAs when patients' left food. Often HCAs and RNs were observed to complete the NIC though they had no accurate account of what food a patient had eaten. ICs did not complete NICs when they had supported their relatives, RNs and HCAs discussed patients' intake with ICs, but did not record this information contemporaneously on the patients' NIC.

6.3.3.2. Communication

Medical staff including consultants frequently enquired about patients' eating and drinking abilities at ward rounds and MDT meetings, and less frequently at daily whiteboard rounds. At such times consultants relied on verbal feedback from the SRs unless the patient was under the care of SLT. Often the SRs were observed to have minimal knowledge of patients' eating and drinking abilities and support needs. Dietitians infrequently attended MDT meetings or daily whiteboard rounds.

HCAs were observed verbally communicating patients' support needs to each other at mealtimes, though these were often nonspecific. RNs and HCAs received a printed handover sheet at the start of the shift. When analysed, these communicated a prescription of the patients' diet and fluid type and rarely non-specific support needs such as 'needs assistance'. If HCAs occasionally identified a potential swallowing problem this was verbally reported to a RN who then referred the patient to SLT.

SLTs usually attended daily whiteboard rounds where most professional groups of the MDT were represented to receive updates on patients' progress. They attended weekly MDT meetings where they clearly verbalised patient support

requirements that were recorded in the MDT records. SLT also communicated the prescribed support on a yellow laminated sign above the patients' bed, visible to all. This information was usually, but not always accurate when compared to the latest SLT entries in the MDT notes.

Conversations commonly occurred with participants during observation sessions, which were useful in guiding the interview topic areas and questions. For example, ICs responses to the delivery and appearance of food provided by the institution at mealtimes.

6.4. Findings of semi-structured interviews at site B

This section reports the findings of the thematic analysis of the semi-structured interviews from the three participant groups at site B. The analysis examines participants understanding of the management of eating and drinking and their experiences of identifying, providing and monitoring support with this activity and adds further insight into the findings reported in section 5.2. Table 32 below lists the themes identified and discussed in this section.

Table 32 Identified themes and subthemes site B

	<i>Main theme, number and title</i>		<i>Related sub themes, number and title</i>	
MDT themes	1.	The identification and communication support requirements is unpredictable.	1.1.	Bespoke systems for identifying a need for support with eating and drinking are inexistent.
			1.2.	Systems for communicating a support need are ineffectively implemented.
	2.	Essential components to support eating and drinking are inconsistently provided.	2.1.	We think food should be consistently appealing and adequately nutritious, but we know it's not.
			2.2.	Factors influencing individuals' approaches to supporting eating and drinking and the continuity of support delivery.
3.	Mechanisms for monitoring the effectiveness of support have limited use.			
4.	You pick up a little knowledge here and a little there, that's how you learn to support patients to eat and drink.			
Patient themes	1.	Exploring patients' motivation to eat and drink - You need to want to do it.	1.1.	Factors motivating or demotivating eating and drinking of patient origin.
			1.2.	Factors motivating or demotivating eating and drinking of non-patient origin.
	2.	Patients' respond differently to eating and drinking after stroke.	2.1.	Patients' developing recognition of a need to need to adapt.
			2.2.	Patients' development of adaptations assisting eating and drinking.
IC themes	1.	I feel that I need to help - Informal Carers motivation to support relatives to eat and drink.	1.1.	I'm not convinced that the support is always there for them.
			1.2.	Supporting eating and drinking is difficult.
			1.3.	Mechanisms for supporting eating and drinking can be enhanced by ICs pre-existing knowledge.
			1.4.	The establishment of IC support is ad hoc and unsupported.
2.	ICs identify inconsistencies in essential components to support eating and drinking.			

6.4.1. Findings from Multi-Disciplinary Team (MDT) interviews site B

Thematic analysis of the MDT interview data resulted in four main themes with subthemes. Themes developed from 103 initial codes, the themes were revised and refined over three iterations and are presented below.

6.4.1.1. Theme 1. The identification and communication support requirements are unpredictable.

This theme explores how the MDT identify then communicate what support stroke patients require to eat and drink. As the theme developed two subthemes were identified and are presented below.

Subtheme 1.1. Bespoke systems for identifying a need for support with eating and drinking are inexistent.

When discussing the identification of support requirements with eating and drinking, all MDT members including SLT, were confident that SLT did this for those patients in their care. For those patients not under SLT care, no MDT members could describe a systematic approach to the identification of support requirements:

“I don’t know how that information comes about, that they need support, I’m not sure who’s identifying it, literally, I can’t pinpoint anybody and say this is what I want you to do, I think it just evolves.” (Chris, WM)

SRs, RNs, HCAs, HKs and WAs were acknowledged by themselves and the wider MDT to have most direct patient contact at mealtimes. This was usually when support needs were identified, mainly by HCAs:

“Sometimes you observe, yeah, how they, you know, get on. If you see them like having difficulty, then you go and help.” (Edith, HCA)

Other MDT members reported multiple occasions when they had by chance identified previously unidentified support requirements inferring that although

SRs, RNs, HCAs, HKs and WAs were mainly in direct contact, they did not consistently identify patients support requirements:

“Well, a part of me thinks, oh thank goodness I’ve discovered that about them. Another part of me thinks, if I’ve discovered that about them, what’s going on with the other people on the ward that haven’t just happened to walk past at that time and see they’re not eating?” (Harriet, OT)

Subtheme 1.2. Systems for communicating a support need are ineffectively implemented.

MDT participants directly and indirectly discussed multiple communication systems throughout their interviews including shift handovers, daily whiteboard rounds and MDT meetings. Verbal communication was alluded to regarding shift handovers by SRs, RNs and HCAs. Handovers were not received for the whole ward only the patient bay to which staff were allocated for that shift and not received on late shifts. During handovers, discussion of support requirements was generalistic in content:

“In the afternoon, no (no handover). There's the occasions when I haven't had handover as luck had it, I'd been on quite a few days so you know most of the patients. Like this week, I've come back and two thirds of the ward I don't even know, so I have to ask other staff who's, who needs assistance and who don't, I mean, it gets passed down that way. So, you have to ask.” (Shaun, HCA)

Those staff attending shift handovers received a printed handover sheet, but acknowledged that these were ineffectively employed:

“...we have handover sheets, as far as I'm concerned ...they're not always updated, you've got contradictory information on them that aren't always changed... if you've got that happening with special diets, you can see there there's going to be problems,” (Rosie, TAP)

Participants revealed that verbal communication at daily board meetings and the twice-weekly MDT meetings rarely included patients support requirements for eating and drinking.

It was acknowledged that apart from the SLT signage situated at the back of patients' beds, written communication in MDT notes, nursing notes, on MUSTs and NICs was often inaccurate and incomplete, affecting continuity of support with eating and drinking, and perceived by some to be difficult to access:

"I personally I'm not very good at reading notes and... kind of migrating around the electronic system, I don't really know how to navigate it very well, so I have to say so far I'm not looking at the electronic system, I'm relying on my nursing staff having filled in the food charts." (Jack, Cons)

It was acknowledged that poor communication of patient support requirements was detrimental and potentially hazardous to the patients' wellbeing:

"Because there have been mistakes, you know, people, like I think I know a patient and then I find out that, because there was a patient on here, I know I probably can't say who, whose just gone down to puree again, who was fork mash for ages, so we all thought we knew, and then he's gone back to puree ... it was lucky someone just grabbed that on its way to him because he would have eaten a fork mash when he can't." (Kirsty, RN)

In summary for theme one, the identification of patients' support requirements with eating and drinking for those patients not supported by SLT was inconsistent. Communication systems were in place, but inconsistently employed often leaving MDT members particularly HCAs delivering most of the direct support with eating and drinking with inadequate information, perceived at to affect patient safety and wellbeing.

6.4.1.2 Theme 2. Essential components to support eating and drinking are inconsistently provided

This theme explores the MDTs' perceptions of the systems and practices of food and drink provision and their impact on supporting patients to eat and drink. As the theme developed, two subthemes were identified and are discussed below.

Subtheme 2.1. We think food should be consistently appealing and adequately nutritious, we know it's not

All MDT participants acknowledged the importance of the patients' consumption of food and drink for adequate nutrition, required to aid their rehabilitation and recovery from stroke. All participants commented about the provision, taste, texture, appearance and presentation of food and reported frequent issues with all aspects, contributing to patients declining or not completing meals:

"I think it's alright, it's not a hotel is it at the end of the day, but it's got to be enjoyable enough that people do eat otherwise we can't treat them." (Adele, OT)

Participants perceived the food provided to be often inappropriate for the patient demographic with 'foreign foods' receiving most negative comments. Alternative food choices provided were acknowledged limited and repetitive, not stimulating patients to eat and received frequent complaints from patients and ICs about the food provided:

"It's not like it's not planned for ...say like if the whole ward is eating, they can still just to bring up 3 portions... and we kept on saying to them, there is not enough food, there is not enough food to go around and that's not fair, and they said, well they are just going to have to have sandwiches, and you're thinking, what if they don't want sandwiches, how is that fair that half the people are going to have a hot meal and the rest just have to have sandwiches, and they said, basically it's not our [catering] problem."(Molly, HK)

The dietitian and the dietetic assistant acknowledged that normal diet provision without any extra snacks or supplements contained 1700 calories, whereas modified diets provided 12-1400 calories daily. This was significantly less calories than the dietitian's recommendation for patients following stroke. The Consultants, WMs, SR, and RNs along with HCAs who provided the most support with eating and drinking were unaware of the nutritional value of the food provided. Potentially they did not realise the critical importance of prescribed snacks and feed supplements to achieve the required nutritional intake:

"They should be having their proper intake because it's calculated how many calories, I should imagine it's between the dietitians and the people who are cooking for nutrition-wise." (Shaun, HCA)

The MDT unanimously described the appearance of modified foods as unappealing and perceived this negatively affected patients' consumption:

"I mean your pureed meat, I would retch if somebody gave me that, I really would, so I can't, I can't get too upset when patients say, 'I don't want, I've had enough of that, I don't want any more', because I would be saying, I would be doing the same" (Liz, SR).

SRs, RNs, HCAs and HKs discussed how service was organised at mealtimes. They thought the system worked, but described numerous occasions when patients had no meal or an incorrect diet was delivered. It was acknowledged that food was often badly plated and perceived to be unappealing, particularly when compounded with the appearance of some foods. This had led to complaints from patients and ICs:

"They've even had complaints from relatives. Again, that one with gravy on fish, why would you do that!" (Corinne, DA)

Subtheme 2.2. Factors influencing individuals' approaches to supporting eating and drinking and the continuity of support delivery.

The consultants had on limited occasions supported patients to eat and drink when they perceived the nursing staff overwhelmed and unable to adequately support the patients. OT, PT, Dietitian and Consultants were rarely in the patients' vicinity at mealtimes reportedly due to the Protected Mealtimes Initiative and perception that supporting eating and drinking was not part of their role. SLTs occasionally incorporated individual patient therapy sessions into mealtimes. All participants had observed situations where support was not delivered, principally thought due to insufficient staffing at these times:

"...there's something [food] just sat there waiting for the patient to eat, and nobody there and seemingly nobody in the near future coming to give that food. And it's more like frustration on my part, like, "Blinking heck!", you know, this patient's waiting for their lunch, we know there's a problem and yet there's nobody here, and the food's there and it's going cold." (Steve, Cons)

SRs, RNs, HCA, and HKs perceived that the effectiveness of support with eating and drinking often depended on the individual MDT member's style of support delivery. They acknowledged that some were more able to individualise their approach to the patient:

"Some people are just like, "They're not eating," and not try a different way or a different knack to it or [pauses] I think yeah, I think sometimes people are a bit like, "Oh they're not eating," just move on, do you know what I mean? Rather than thinking, actually, "Come on, let's try it, let's try it," or thinking they may not be keen on the main, let's try the pudding, because some people prefer puds don't they?" (Sally, RN)

Supporting patients to eat and drink was perceived by SRs, RNs and some HCAs as part of the patients' rehabilitation, with those who ate enough

recovering more quickly. It was also thought to improve the patient experience and perceived to increase the work satisfaction for these staff members:

“Oh goodness, yeah, you know when your patients eat well and... I get encouraged by that, I think, you know, it's nice to see a patient eat well,” (Liz, SR)

RNs, HCAs and HKs described mealtimes as often pressurised inducing stress, associated with dissonance between patients' support requirements and staff availability to meet those requirements and managing patients' and ICs' expectations of the food:

“...you get people tutting at you, complaining at you [about food]. I had one person shouting at me and chucked their knife and fork at me, and I was thinking, I don't like this,” (Molly, HK)

RNs and HCAs suggested that some of their peers avoided mealtimes and the associated patient support by finding other work to do instead. Sometimes this work was legitimate but at other times, it was not. Some perceived supporting eating and drinking at mealtimes a boring and unpleasant task, and some patients did not require the support they requested:

“...a lot of people find it a mundane, boring job, sat feeding...” (Rosie, TAP)

A minority of senior nurses acknowledged that some RNs and HCAs required supervision during meal delivery to ensure required support was administered. This engendered frustration as they thought these staff should not require supervision, but frequently identified situations where patients had not received the appropriate support with eating and drinking. Supervision was dependent on who was on shift, leaving some senior nurses concerned about unsupervised staff practices:

“I am so cross when I walk into a bay and there's somebody lying flat on their back and they're spoon-feeding off of their table, and it happens.... I despair, I really, really do, I'm being totally honest now... I can't be observing every day, every minute while they're eating and drinking... everybody knows how important it is...if somebody did choke, they'd be mortified... it's such an upsetting thing to see.” (Liz, SR)

In summary of theme two, food provided for the patients was thought lacking in terms of suitability to the patient demographic, choice, amount, nutritional value and appearance, and perceived to negatively affect patients eating and drinking experience. SR, RNs and HCAs, accepted responsibility for the delivery of food and supporting patients to eat and drink the required amounts. Senior nurse supervision of mealtimes was acknowledged inconsistent, and patients often did not receive the required food, or the support required to eat and drink.

6.4.1.3. Theme 3. Mechanisms for monitoring the effectiveness of support have limited use

This theme explores how the MDT monitored the effectiveness of support with eating and drinking. A minority of the MDT perceived that the patients did eat enough to meet their nutritional needs. They stated that they developed these perceptions from their direct observations of patients who appeared well nourished and a lack of official complaints about patients being hungry or malnourished. The rest of the MDT participants did not share these perceptions:

“... despite what I think are probably best efforts, then, yeah, I think, often patients don't get enough [food and drink], yeah. I mean, we've prescribed a lot of supplements, a lot of supplements for patients, so the dieticians must think they're not as well,” (Steve, Cons)

RNs and HCAs thought completion of NICs and MUSTs the main method of monitoring patients' food intake and nutritional status. They acknowledged

responsibility for their completion, but were aware this was inconsistently implemented with other work often prioritised:

“We do weekly weights, well, we're supposed to do weekly weights, to see how patients are going.” (Shaun, HCA)

The Consultant, Dietitian and Dietetic Assistant confirmed that NICs and MUSTs were frequently incomplete. The missing data meant they had to rely on the subjective observations of RNs and HCAs and occasionally ICs to judge patients' weight maintenance. They were aware of and concerned about delays and omissions in referrals to dietetic services:

“...the MUST score is the key part of the screening process because they don't, they can't always weigh a patient. So, it's hit-and-miss really, so the risk there is because we don't know if they're doing everybody properly in terms of screening, is that there's probably lots of other patients that may have been at risk that we totally miss because they don't always weigh all the patients.” (Diana, Dietitian)

These concerns had been reported to senior nursing staff in writing and verbally with no effect, initially resulting in frustration, followed by acceptance that the situation was the status quo. Consultants and the Dietitian suggested that a shortage of qualified nursing staff was the main contributing factor, an issue they perceived to be outside their control. This was supported by comments from all levels of the nursing team:

“I think there's also kind of a culture of they've almost accepted that there's never going to be the information that they require when they require it because certain things like weights etc., have gone out the window, [due to nursing staff shortages] ...” (Katie, WM)

Multiple methods of record keeping within the MDT compounded these issues. Requests for patient weights were recorded in MDT notes that HCAs reportedly

did not read, relying on RNs for this information. HCAs were reticent to use the electronic system supporting nursing records, again relying on the RNs. If completed, RNs recorded weights and MUST scores on the electronic system that most of the other MDT members stated they did not read:

“They [NICs] are rarely complete and that shouldn't come as a surprise, so I think for the dietitians it's really hard to know what's going on!” (Naomi, SLT)

In summary to theme three, it was reported that there was no consistently implemented objective assessment and monitoring of patients' eating and drinking abilities and resulting nutritional status. Inadequate monitoring of patients' food intake meant the Consultants, Dietitian and Dietetic Assistant did not receive information about patients declining nutritional status. Identification and prescription of support requirements was frequently delayed. Consultants reported unsuccessful attempts to remedy this situation. They had asked the WMs to on numerous occasions to ensure NIC and MUST completion, which did not occur, with shortage of nursing staff offered as a rationale. The situation had become the status quo. They thought this often contributed to greater use of expensive and for some invasive feeding methods with resulting delayed recovery and discharge from hospital.

6.4.1.4. Theme 4. You pick up a little knowledge here and a little there, that's how you learn to support patients to eat and drink

This theme developed as MDT members discussed how they had acquired their knowledge to support the patients to eat and drink after stroke. Some MDT members could not recall any training. SRs, RNs and HCAs who delivered the most support with eating and drinking acknowledged that they had received some training whilst in this employment, but reported wide variation in specificity, regularity and the source of training:

“We had a training session on, when I was still on here the SLT team gave us a training session, about an hour, that’s all, and they explained about different textures and different coating methods and how to mix it together correctly...Ooh, it’s got to be about, what, eight, nine year [ago].” (Shaun, HCA)

RNs and HCAs reported that they had develop their knowledge experientially - ‘on the job’, but others questioned the efficacy of this method knowledge acquisition:

“I think there needs to be more education within that respect [identifying and supporting eating and drinking issues after stroke], at the beginning of employment as opposed to progressively picking it up throughout their employment”. (Chris, WM)

It was acknowledged that staff training was not monitored or mandatory, and that the knowledge of some staff was out-dated:

“There’s none of that, no. I think what’s happening at the moment as part of this, I think there’s a gap analysis in Stroke training for nursing happening at the moment, and it’s looking at that, because we have been in conversations with the Consultant Nurse for Stroke, and I’ve sort of said you know, ‘how can we get a sign-up to this’, our nurses have done this for a long, long time and feel that they know everything.” (Naomi, SLT)

Concerns were acknowledged about the frequent employment of locum staff, as no one knew if they had received any training, but were still expected to support eating and drinking:

“I think staffing is an issue and... what can come together is low staffing numbers and agency workers or, you know, nurses who come to just cover and they don’t have the training.” (Naomi, SLT)

Lack of organisation and leadership of staff training was acknowledged by senior members of the MDT. Thought in part due to lack of prioritisation of

patients eating, drinking and nutritional support from senior members of the nursing team:

“So, unless you make [training for eating and drinking] relevant and explain the importance of it ... emphasise and re-emphasise why it's important, then training's not worth anything, really... if it did occur... then you get into a stage...where the ethos of the environment on the ward changes...you reach a tipping point where people start to prioritise it. And if the ethos of the Unit changed, then actually, this stuff [eating and drinking support] should be a lot better than it is.” (Steve, Consultant).

In summary, this theme identifies that training regimes for supporting eating and drinking were chaotic in delivery and inconsistent in content, acknowledged to affect the consistency of support received by patients. This was purported as partly due to a lack of prioritisation of support for patients eating and drinking and ultimately their nutritional support by senior members of the nursing team.

6.4.1.5. Conclusion

It was determined that stroke patients at site B did not receive consistently effective support with eating and drinking from the MDT. Identification of support requirements was unreliable due to variable levels of direct observation of patients at mealtimes and inconsistent communication between the MDT. This was compounded by inaccurate recording and monitoring of patients support requirements and food and fluid intake. Day to day responsibility for supervising, monitoring and recording support was acknowledged the WMs, Srs and RNs who delegated most of this work to the HCAs - often inexperienced agency HCAs. Despondency and lack of leadership from senior MDT members resulted in inconsistent support with eating and drinking becoming the status quo. They reported the use of more expensive and at times invasive nutritional management methods and delaying patient recovery and discharge from hospital.

6.4.2 Findings from patient interviews at site B

Two main themes and subthemes were developed from the thematic analysis of the patient interview data. Seventy-five initial codes were identified and inductively developed into the themes, which are presented below.

6.4.2.1. Theme 1. Exploring patients' motivation to eat and drink - You need to want to do it

All the patients interviewed discussed aspects of their eating and drinking experience on the stroke units that motivated (motivators) or demotivated (demotivators) them to eat and drink. Further analysis identified motivational and demotivational factors to eating and drinking originated from the patient (intrinsic) or from sources external to the patient (extrinsic). This resulted in two subthemes discussed below.

Subtheme 1.1. Factors motivating or demotivating eating and drinking of patient origin

Motivation to eat and drink for some patients was prompted by physiological responses. For some but not all patients, satiation of hunger and thirst motivated them to eat and drink:

“Well, I have felt hungry when me meals, like I said, are not a big enough portion, I think I could eat more, I could eat double that, yeah.” (Jeremy, patient)

All patients interviewed thought they had lost weight at some point since their stroke and perceived this negatively affected their wellbeing and recovery. This knowledge motivated their eating and drinking in order to regain weight:

“And when I first came in, I were losing it but I put some weight on as you can probably see the front sides of me now... [and] keep myself hydrated.” (Paddy, patient)

Physical changes such as upper limb weakness caused pragmatic issues with eating and drinking such as cutting food and transferring food from plate to mouth making eating and drinking more difficult:

“No, I can't cut it up because I can't use me left arm for me fork, so I have to get the nurses to cut it up.” (Jeremy, patient)

Requiring support to eat and drink from others, engendered negative emotions including frustration, helplessness, being a burden to others and infantilisation. Low mood was frequently described secondary to such emotions and perceived to affect their eating and drinking:

“I mean it only takes a minute to cut someone's food up and then but sometimes you think to yourself, oh bugger it, I'll not have any, whatever it is, and then you sort of think to yourself I can't be arsed to mess with it...and you feel as though you're a burden to everybody, and or other people, because you can't do these things... you feel such a failure, such a nuisance to people..” (Sylvia, patient)

Low mood was also a primary effect of the stroke for some patients, and recognised as demotivating them to eat and drink:

“I was, I mean how can I put it, I was just not wanting to do anything and you know I was just kind of just wanted to lay down and not do anything [eating]... and so I came in I think I was 66.3 kilo I went down to 63.” (Andrew, patient)

For some patients the conflict between understanding the need to eat more to aid recovery, and not physically wanting to eat the food provided, was stressful

and thought to incur low mood. This cyclical pattern was acknowledged, but difficult to break:

“Me eating’s not been very good, and it’s very stressful at times, you know, yeah, you get a little bit down and all.” (Eric, patient)

Subtheme 1.2. Factors motivating or demotivating eating and drinking of non-patient origin

Patients perceived that RNs and HCAs referred to collectively as nurses, delivered the most support to enable eating and drinking along with ICs for some patients. The timeliness of, and perceived attitude to the delivery of support both motivated but at times demotivated patients to eat and drink:

“I mean there are certain little nurses are often saying, “You are not drinking enough, come on,” and, “Yes ma’am,” (laughs) ... “and you think to yourself, I only want something cutting up, and then you sort of think, well you’re not, they’re not very cooperative sometimes ...they sort of seem to, not like you asking them to do things for you.” (Sylvia, patient)

The food and drink provided both motivated and demotivated patients to eat and drink. All patients found some foods acceptable some of the time, though none stated that it particularly motivated them to eat, described as repetitive, boring and unattractive:

“I looked at it and thought, no I can’t eat that. It’s not looked right to eat.” (Douglas, patient)

All the patients thought the regular delivery of hot drinks motivated patients to drink:

“Yeah, Elaine who brings the drinks round, she’s a lovely, lovely lady, yeah. The drinks were nice, yeah, nice and hot, not cold.” (Paddy, patient)

In summary, some patients were motivated to eat and drink by intrinsic factors generated from the physiological responses of hunger and thirst. Low mood caused primarily by their stroke, and secondary to other deficits caused by their stroke affected motivation to eat and drink. Extrinsic factors including the taste, appearance and choice of food, identification of support requirements and timeliness of delivery, and the attitude of staff offering support both motivated and demotivated patients to eat and drink.

6.4.2.2. Theme 2. Patients’ respond differently to eating and drinking after stroke

All the patients had been independent with the process of eating and drinking prior to their stroke, but this changed post stroke. Further analysis identified two subthemes exploring patients’ adaptation to their situation post stroke.

Subtheme 2.1. Patients’ developing recognition of a need to adapt

Stroke affected the patients’ individual ability to eat and drink in different ways, including swallowing deficits, upper limb weakness, difficulty maintaining posture and visual problems. All patients described times when they had requested support with eating and drinking from the nurses suggesting they identified a requirement for support independently:

“They won’t see you struggle. I’ve only got to shout across to one of them and they will come straight away and help me.” (Douglas, patient)

However, when asked at interview if they required support to eat and drink, three of six patients stated that they did not. They did not recognise actions

such as cutting up food as support or had adapted to their new situation. For two patients the need to adapt their eating and drinking method was identified by SLT. They were aware that failure to adapt how they ate and drank could be detrimental to their recovery:

“Well, I thought, “This could kill me if it goes on, if I don't swallow it properly”, so they were right, I was eating too fast. It could be very serious if you don't do it right.” (Jeremy, patient)

Two patients were prompted to adapt the amount they ate and drank when informed of their weight loss:

“I've lost well over two and a half stone while I've been in, since March...I mean me doctor asked me these sort of questions when they found out, they know what you're eating with them charts that they do, and they found out that I were missing meals, and they wanted to know why and I would have to try harder.” (Eric, patient)

Other than SLT assessment, none of the patients acknowledged receiving any MDT assessment that identified or prescribed adaptations with eating and drinking. However, all the patients frequently described how they had adapted their method of eating and drinking. This suggests that some patients independently identified a need to adapt.

Subtheme 2.2. Patients' development of adaptations assisting eating and drinking

All the patients interviewed had adapted different methods to eat and drink post stroke. Patients modified their choice of food to make eating easier, managing food on the plate and transferring it to their mouth, or easier to chew and swallow enabling them to increase their food intake:

“I’ll pick what’s easiest to eat, you know, like you know, oh yesterday I had fishcakes, fishcakes and potato mash...No, easier because I know I’m going to make an effort to eat it, not because there’s nowt wrong with it, but it’s just because I’ve got to make an effort to eat as much as I can” (Eric, patient)

Patients used cutlery in an adapted style to cut food, enabling some maintenance of independence:

“I’m one handed. The helpers, care workers, place it on a tray as they serve a meal, put it in front of me and the first, I always use a spoon or a fork because it is, it’s difficult to cut and you know use the knife in the conventional way so I’m, I’ve used the side of a spoon or a fork in the main to cut things up.” (Andrew, patient)

Some patients adapted their food provision by acquiring other food from ICs or other providers from outside the hospital such as take-aways or had adapted their taste to the food provided:

“I didn’t used to eat very much vegetables, but I’ve started eating a bit more, more from necessity than anything because they give you these meals and I didn’t particularly like them, you know, but I thought to myself, you’ve got to have something, you’ve got to have something to eat Sylvia.” (Sylvia, patient)

Patients discussed psychological adaptations to their altered eating and drinking process, such as becoming more patient with themselves and those supporting them:

“But I realise that it’s not just me [requiring support] so I’ve just had to be patient and you know, they come to you eventually.” (Paddy, patient)

Other patients suggesting it was not a case of adapting, but more enduring the situation:

“If they see you struggling [with food] then they're soon there but there aren't enough of them... but you just get on with it... but having that said that it's endurable it really is” (Andrew, patient)

In summary to theme 2, all patients had identified changes to their eating and drinking abilities post stroke, some independently and others prompted by SLT. Patients described adapting to these changes both physical and psychologically to enable them to eat and drink.

6.4.2.3. Conclusion

Two themes with subthemes developed from analysis of the patient interviews at site B. All patients acknowledged physical and psychological changes post stroke affecting their ability to eat and drink. They described independently identifying a need to adapt to these changes to enable them to eat and drink. None of the patients was aware of having a specific assessment of their eating and drinking ability other than with SLT, with some support requirements potentially unidentified. Patients requested support with eating and drinking exclusively from nursing staff, with inconsistent responses perceived as demotivational.

6.4.3 Findings from Informal Carer (IC) interviews at site B

Two main themes and subthemes were inductively developed from 56 initial codes identified during the thematic analysis of IC interview data. Four attempts were made prior to the finalisation of the themes presented below.

6.4.3.1. Theme 1: I feel that I need to help - Informal Carers motivation to support their relatives to eat and drink.

All the ICs' relatives were patients on SB2 at the time of the interviews and had previously been cared for on HASU and SB1. ICs discussed what motivated them to support their relatives to eat and drink during this time with further analysis of their interview data identifying four subthemes.

Subtheme 1.1. I'm not convinced that the support is always there for them

ICs lacked confidence in the ability of the MDT to consistently support their relative to eat and drink to what they perceived as an acceptable standard. ICs thought this due to insufficient numbers of RNs and HCAs collectively referred to as nurses, other MDT members were not referred to in this context:

"I said, 'I'm coming in to feed her' so she said, 'oh we'd feed her' and I just thought no you wouldn't. I'm not saying, the nurse is lovely, lovely girl and I thought yeah she's saying that because at this instant she probably would but I know for a fact she wouldn't get fed they haven't got the time," (Valerie, IC to Rita)

Some ICs reported multiple occasions when the nurses had not attempted to support their relative to eat and drink:

"Because I mean the meal would be there in front of him and nobody about, so obviously there were nobody about to do it, I mean I know they're busy, very busy and pretty short staffed at times but I did felt as though if I don't feed him, like I saw other people [not fed] ... he wasn't able to feed himself." (Maureen, IC to Joe)

They had found their relatives dishevelled and covered in spilled food after mealtimes, perceiving that the nurses were unavailable to support or did not care about their relatives' dignity:

"As you know we had one of them days where everything was all over, potatoes and the lot in bed, and we had quite a few of them days... but not to be left in the mess. And that's when I was mad." (Betty, IC to Tommy)

ICs described mistakes made by the 'nurses' delivering the wrong food to their relative at mealtimes causing particular concern where the relative was prescribed a modified diet:

"Because one lady came and she says, "oh I brought him his dinner" and I took one look and I went that's not his, and she goes "oh it is", I says, pointed at notice above his bed [SLT instructions about diet]. "Oh, oh somebody's told me it's this one" and it weren't. I don't know who it were for but it were wrong room. Oh dear." (Marie, IC to Geoff)

ICs had seen some positive interactions between the nurses and patients at mealtimes, but their confidence was undermined by witnessing what they perceived as sub-standard support with eating and drinking:

"You know, it were, because I know they don't, they have, they are, they won't have a lot of staff on anyway and, you know what I mean, it's hard work... and they were all trying to get meals out and feed them in-between, you know, and I thought "no, I don't like our meals cold." (Marie, IC to Geoff)

Subtheme 1.2. Supporting eating and drinking is difficult

ICs discussed emotional responses to their relatives' eating and drinking ability. They reported experiencing negative emotions, describing frustration when their relatives were perceived to respond inappropriately to ICs support, guilt and anxiety if unavailable to support, and anger at what they perceived as inappropriate or substandard support by the nurses:

"When he's angry, we're trying to get him to eat and then he can't be bothered and it's like "Come on dad, you've got to do this" and you feel like walking away... like it frustrates me." (Donna, IC to Tommy)

Three of the ICs felt compelled to support their relatives at both lunch and evening mealtimes. This induced stress from conflict with other commitments and fatigue:

“...and it’s having an effect on, you know, us lives really... [Crying] Yeah because my sister even, even my brother-in-law’s been coming, he’s just got a new job and my sisters got two jobs and it’s hard. You know, but we don’t feel as though we can’t not come and feed her...” (Valerie, IC to Rita)

When relatives were perceived to take adequate amounts of food and drink, ICs reported experiencing satisfaction and other positive emotions such as joy and relief:

“[I feel] really good like Michelle brought her the soup in yesterday for the first time and she said she had every bit.” (Valerie, IC to Rita)

Both positive and negative emotions motivated ICs to continue supporting their relatives to eat and drink but all reported experiencing intermittent carer strain.

Subtheme 1.3. Mechanisms for supporting eating and drinking can be enhanced by ICs pre-existing knowledge

All the ICs had prior knowledge of their relatives’ preferences with food and drink. ICs imparted this knowledge to the MDT and when acted upon, viewed positively:

“And he loves his rice pudding, can’t get enough of it... because we asked for a small portion of main meal and then they knew to bring him a large portion of rice pudding.” (Donna, IC to Tommy)

Alternatively, ICs were frustrated when such information was ignored. ICs thought these issues should be easily remedied, but this was not their experience:

"In fact, I've told two or three people that there's too much on the plate and they've actually said yeah we know it can put them off but..." (Valerie, IC to Rita)

ICs were attuned to the fluctuating responses of their relatives towards eating and drinking, discussing the techniques they practised in differing situations, including verbal encouragement, bribery and direct action:

"Mind you I bribed him. He liked chocolate and I just took this block of chocolate and he said, "I'm not having that", I says, "what is it?" and it was stew and dumplings", I said "eat it". "Oh, I'm not having it". I says, "well you want this then". [Whispers] Chocolate. I says, "you'll have to eat that first". It worked." (Marie, IC to Geoff)

ICs thought they were more tenacious and assertive with their relatives when supporting them to eat and drink than the MDT. Their relatives ate more perceived as a better result.

Subtheme 1.4. The establishment of IC support is ad hoc and unsupported

The establishment of ICs in supporting their relative to eat and drink was inconsistent. SRs or RNs directly approached some ICs, or ICs approached them, some ICs commenced support autonomously without referral to any MDT members:

"Well, I said "do you want me to come and feed him?" I didn't say "I'll come", I just said, you know, did they want me to come and feed him. And it were "oh yeah"." (Marie, IC to Geoff)

Three ICs did not recall receiving guidance from the SLT about how to support their relative to eat and drink. Another referred to the SLT chart at the back of the patient's bed, the remaining IC explained that they worked out what to do themselves without any instruction:

IC: "I just left it so long between his spoonful's, to give him because to chew on anything it would take longer so I can't remember, I don't know why but I did yer."

Int: "So you just realised yourself you'd got to do it slowly so he had time?"

IC: "Yes." (Maureen, IC to Joe)

Four of the five ICs' relatives had swallowing difficulties at some point post-stroke; only two ICs could recall any form of guidance given by the MDT for supporting their relative with this. None of the ICs acknowledged any ongoing support from the MDT whilst supporting their relative to eat and drink.

In summary, ICs motivation to support their relatives to eat and drink was instigated by lack of confidence in MDT support and a desire to ensure their relative was adequately nourished. They had concerns about incorrect food delivery, and the potentially serious consequences for their relative's health and wellbeing. At times ICs found the constraints of supporting their relatives' emotionally and practically difficult to manage, reporting minimal support from the MDT with these issues. ICs knowledge of their relative was valuable in ascertaining preferences with food and approaches to support, though felt this was frequently unacknowledged by the MDT. They perceived their relationship with their relative allowed them to be more assertive when supporting eating and drinking, achieving better results than the nurses did. By supporting their relatives, ICs thought they reduced the nurses' workload and improved the patient experience with eating and drinking.

6.4.3.2. Theme 2: ICs identify inconsistencies in essential components to support eating and drinking

This theme developed as ICs highlighted issues with the provision of the food and staff required to support their relatives to eat and drink adequately. ICs reported concerns with the presentation of the food provided by the hospital, and perceived to affect how much their relatives ate:

“He’s like “Hmm, not bothered about this”, some’s ... a bit to be desired, I don’t blame him for not wanting it... Yeah, it’s disgusting.” (Donna, IC to Tommy)

ICs inferred that the purchase of poor-quality food, compounded by the cooking methods at times made the food inedible:

“...all I know is when they got that beef, that was horrible and they come in and they’re [ward sister] telling me that he wasn’t eating. I said, well he can’t eat it... they said well the food used to be cooked outside and brought in but now it’s cooked on here or something... I said, the National Health is always short of money so buying cheap meat is making it worse because he’s not eating... and there’s a poor old chap in there, he says even the Yorkshire puddings were a joke” (Maureen, IC to Joe)

Although patients had requested foods from the available menu, in practice these had often run out, leaving patients with inappropriate choices they did not eat:

“...they kept bringing the wrong food, they kept bringing him a baked potato, which Joe can’t stand baked potatoes... so he wasn’t eating and then they kept turning to me, the nurse, he’s not eating, he’ll have to eat something... they’ll come in and ask him what he wants and by the time to get around to coming to Joe they haven’t got any left,” (Maureen, IC to Joe)

SLTs and nurses had encouraged the ICs to supplement their relatives’ diet, acknowledging inadequate hospital provision of some foods:

*"I says, "well he likes banana" and one of them says "well if you bring one", she says "we only get six for' ward". Hope they don't all want a banana then."
(Marie, IC to Geoff)*

SLT had arranged provision of an individual diet for one relative. This was initially viewed positively, but when the same meal was received every mealtime for an extended period, it was perceived by the IC to be monotonous and discouraged their relative to eat it:

*"...with the potato and the corned beef pie as though, you know, and her face sometimes, it's as if you're trying to poison her...I'm worrying now about what she's going to eat at home because I don't think she'll eat corned beef again."
(Valerie, IC to Rita)*

All the ICs thought there were insufficient numbers of nursing staff to support patients to eat and drink adequately. They developed these perceptions from their observations and experiences at mealtimes:

"They're always too busy to see to you. They're busy wards...And at weekends worse when there's hardly any staff on. And when you ring a bell, you know, the buzzer and they don't come for a long time, I always say to him "well" ... (Betty, IC to Tommy)

The physio and doctor had offered one IC advice and information about their relatives' nutrition and eating abilities during therapy sessions and consultations, but were not present at mealtimes suggesting that the ICs request specialist equipment to support their relatives eating and drinking:

"...and we've been told there's a, well exercise people, physio, one of them said that it's, ask for a ridge plate so that he can put his fork in and food don't come out at other side..." (Betty, IC to Tommy)

6.4.3.3. Conclusion

Two themes with subthemes developed from the analysis of IC interviews at site B. ICs were motivated to support their relatives by personal commitment, and lack of confidence in the ability of the MDT to adequately support their relatives to eat and drink. At times, they found supporting their relatives physically and emotionally challenging, and did not receive support with this from the MDT. ICs perceived their support resulted in their relatives' eating and drinking more and reduced the nurse's workload at mealtimes.

Institutional food provision was inconsistent and perceived to affect how much their relatives ate and drank. ICs identified that other than themselves, the nurses provided support with eating and drinking, but perceived there were insufficient nurses to deliver this support adequately. Furthermore, ICs felt that the nurses did not consistently recognise when support was required.

6.5. Summary of findings from observations, interviews and documentary evidence at site B

There is consistent screening of patients swallow following stroke at site B, with appropriate referral to SLT. For those patients without swallowing deficits, but whose stroke has affected their ability to eat and drink, the MDT, patients and ICs acknowledged that the identification, delivery and monitoring of support was inconsistent. This led some patients to consume inadequate amounts of food, detrimentally affecting their nutritional status and wellbeing. Of the thirteen patients recruited to the study at site B, documentary analysis revealed that six of the thirteen had lost weight between admission and discharge or close of the study. Another three patients had lost weight initially during their stay, though identification was delayed resulting in delayed management of the situation.

Chapter 7: Synthesis of findings from site A and site B

7.1. Introduction

This chapter presents a synthesis of findings from site A presented in chapter 5 and site B presented in chapter 6. The findings are presented to respond to the study objectives. A total of 46 multidisciplinary team (MDT) participants, 31 patients and 13 informal carers (ICs) were recruited across site A and site B.

7.1.1. Objective 1: To determine how and by whom a requirement for support with eating and drinking is identified.

Despite SLT and dietitians employing several different mechanisms to assess the support required by individual stroke patients for eating and drinking, such assessments did not result in the provision of appropriate individual support for all patients at either site. This was due to several related factors. These were that the wider MDT did not employ any formal assessment of eating and drinking ability for those patients not assessed by SLT or the dietitians at either site. MDT members with specific expertise in supporting eating and drinking (SLT, Dietitian and OT) were not involved with the provision or supervision of support for eating and drinking at either site.

Across both sites, there was inconsistent patient supervision at mealtimes caused by: the prioritisation of other work across the MDT including those staff groups usually present at mealtimes; lack of senior leadership at mealtimes on SA2 and though observed, was limited on SA1 and across site B; inconsistent education for stroke unit staff for the identification of patient support requirements with eating and drinking at both sites. Specific tools employed to

enable the identification of patients not meeting their nutritional requirements and requiring intervention were inconsistently completed due to lack of prioritisation, inadequately educated staff and lack of senior leadership across both sites. The consequences for stroke patients at both sites were that they often did not receive the required direct physical assistance to eat their food or to drink. Patients were not provided with adaptive devices to enable independence with eating drinking such as modified cutlery and non-slip mats at site A, with limited provision at site B. Food and drinks were often left out of reach and were inedible by the time delayed assistance was provided across both sites. Referral of some patients to those members of the MDT specialised in dietary and eating and drinking support was delayed across SA2, SB1 and SB2. There follows an explanation of the issues identified in the above summary, illustrated with evidential examples.

Assessment related to supporting eating and drinking at both sites included a recommended swallow screen (ISWP, 2016). Patients with recognised swallowing problems were referred to SLT for a swallow assessment and identification of their support requirements:

“So, then we see them [for specialist swallow assessment], all new strokes within 24 hours.” (Janice, SLT, site A)

At both sites, these patients remained under the management of the SLT as recommended for as long as their condition required (ISWP, 2016). Apart from some therapy sessions, SLT did not directly support patients, or supervise patients or the wider MDT with delivery of prescribed recommendations, such as thickening drinks; hand over hand feeding and ensuring the correct stage of diet was delivered.

In keeping with national guidelines (ISWP, 2016) the nutritional screening tool employed was the Malnutrition Universal Screening Tool (MUST) (BAPEN, 2012). This tool does not identify or assess specific patient support

requirements, but does identify those who are already malnourished, or are at risk of malnourishment. Such identification should result in referral to the dietitian for further assessment and prescription of nutritional support requirements. At both sites, the nursing team (WM, SR, RN, and HCA) were identified by the wider MDT to be responsible for weekly MUST completion. Despite the nursing teams at both sites acknowledging awareness of and responsibility for the completion of MUSTs, this was often omitted or inaccurate. These findings were contradicted by some of the nursing team at both sites, but corroborated by the dietitians at both sites and medical staff at site B:

“...so, weight is a big one that’s not done straightaway and can get added in later but then if you haven’t got the weight how can you assess pretty much the whole rest of the score (MUST)?” (Alice, Dietitian, Site A)

There was a lack of accountable leadership regarding MUST completion. At SA2, the dietitian acknowledged this and had commenced an audit that had achieved some, but not total compliance with MUST completion. At site B, frequent requests to senior nurses from consultants and dietitians for improvement in MUST completion had been ineffective, with the omission of MUST completion becoming the status quo:

“I think there’s also kind of a culture of they’ve almost accepted that there’s never going to be the information that they require when they require it because certain things like weights etc., have gone out the window...” (Katie, WM, site B)

At both sites, RNs delegated MUST completion to the HCAs, though no specific direct instruction was observed and inconsistent training for MUST completion encouraged errors and omissions. The nursing teams at both sites, but more so at site B acknowledged that other work was prioritised over MUST completion. At both sites but more so at site B, this was precipitated by understaffing of the nursing teams in actual numbers of staff, but also in the ratio of RNs to HCAs. At both sites, the staffing establishment of RNs and HCAs did not meet the recommendations identified in the National Clinical Guidelines for Stroke for

hyper-acute and acute services (ISWP, 2016) or recommendations from the National Stroke Nurses Forum [NSNF] (2016) for stroke rehabilitation services. At both sites, but more so at B there was back filling of RN shifts with HCAs and HCA shifts with agency staff, who were unaware of the requirement for MUST completion.

Patients' support requirements during mealtimes were inconsistently identified, leaving some patients unable to access and consume the delivered food and drink. Multiple factors precipitating this situation were identified at both sites. Patients and ICs observed that there was often no one unavailable to identify or recognise patient support requirements:

"Because I mean the meal would be there in front of him and nobody about, so obviously there were nobody about to do it," (Maureen, IC, site B)

Direct observation of patients at mealtimes was the most common method of identifying patient support requirements by nursing staff. Nursing staff to patient ratio at both sites meant that not all patients could be continually observed throughout mealtimes, often leaving their support needs unidentified:

"...with regards to cutting, that's never, like, progressed...they see me on a daily basis and they will help me, you know, as they see me struggling. But I'm not, like.... I suppose it's my fault as well because I'm not, you know like, saying that I'm struggling...I don't think I'm observed as much, you know, because I'm young and perceived to be coping, you know... I don't think they think that I'm going to have many problems." (Alison, patient, site A)

Other than SLT delivering some therapy sessions at mealtimes, the MDT at both sites considered mealtime management the remit of the nursing teams' only, the lack of the wider MDT presence limiting observation opportunities:

Int: "Have you ever, like the occupational therapist or the physiotherapist, anybody like that ever helped you to cut up food or with your eating?"

Patient: ... "Oh no, no, no, they're never there, you know?" (Eric, patient, site B)

The nursing team at both sites identified that OT with expertise in functional rehabilitation following stroke had historically assessed patients' eating and drinking abilities, though this had not regularly occurred for several years. OTs at site B cited protected mealtimes, an emphasis on discharge planning and meeting national guideline recommendations for therapy hours (supporting eating and drinking was not recognised as therapy) (ISWP, 2016), as rationale for no longer undertaking this assessment:

"It is something we should be doing an assessment of definitely, and we do in the community, that's why it's so strange to when I think about it that here, I think we just assume it's taken care of by somebody else, and because we're sort of quite removed from mealtimes," (Harriet, OT, site B)

OTs at site A reported that they occasionally undertook such assessments, but were limited by time citing the same rationale as the OTs at site B. Only one such assessment was identified across the data set at site A:

"The fact that, to do a lunchtime assessment, I don't get a lunchtime because there'll be something else that I need to do immediately... and if I didn't have all these stats to do". (Sue, OT, site A)

7.1.2. Objective 2: To identify how and by whom support is prescribed once identified

Despite the employment of multiple communication devices, there was frequent omissions in, and miscommunication of patients' support requirements for eating and drinking. This was a consequence of multiple factors including perceived role boundaries, behaviours, responsibilities and accountability

across the MDT, patients and ICs; limited access across the patient record set for all the MDT but particularly those delivering direct support; lack of prioritisation of eating and drinking support across the MDT. The consequences for the patients in the stroke units were that they often did not receive their prescribed: modified food and fluid, supervision or direct physical assistance and adaptive devices such as specialist crockery and cutlery that would enable them to eat and drink safely and adequately and encourage independence. These findings are explored in more detail below.

Those identifying a support requirement did not always prescribe the support, as this was often dependent on their role. Patients at both sites frequently identified their own support requirements with eating and drinking but inconsistently communicated them to the MDT. Some patients felt able to ask for support, other patients found it difficult and avoided doing so, this finding was consistent across both sites and is discussed in more depth in objective 4:

“Well, I usually ask, but sometimes they notice, so I usually ask, “Can you cut this up?” (Jeremy, patient, site B)

ICs identified support requirements and communicated these mainly to HCAs at site A and to RNs and HCAs at site B, and very occasionally to SLT at both sites. At site B, ICs perceived that the responses they received were inconsistent and at times contradictory from all but the SLT, provoking frustration and anxiety with the level of service their relatives received with eating and drinking. ICs at both sites thought these issues were mainly due to the busyness of the nurses (RNs and HCAs), which ICs blamed on perceived understaffing. Although they communicated their relatives support needs, ICs found this often precipitated feeling guilty, as they perceived they were adding to the nurses' workload.

At both sites, SLTs consistently prescribed and communicated patient support. This was done verbally to RNs and via yellow signs at the back of patients' beds

and in the MDT record, though at both sites the yellow signs did not always advertise the most up to date support prescription. At both sites, the doctors and dietitians prescribed feed supplements on medication administration charts and recorded this in the MDT records. At both sites, the dietitians prescribed dietary supplementation such as extra food in the MDT records and verbally communicated this to the RNs.

The RNs at site B, occasionally verbally prescribed support requirements for eating and drinking to each other and HCAs during a shift instead of at shift handover. This did not occur at site A. At both sites, HCAs verbally prescribed patient support requirements to each other, to patients but infrequently to ICs. They were inconsistent in reporting identified support requirements to RNs and did not directly report to any other members of the MDT. This often resulted in a delay of appropriate targeted patient support. HCAs did not access or contribute to MDT or nursing records at either site, so did not use information recorded there about prescribed support requirements. At site B, the move of nursing records from the joint MDT paper record to an electronic system was perceived to reduce access by other MDT members limiting communication of support requirements.

At site A, nursing staff received a verbal handover from the RN on the previous shift, reporting patients' progress and care requirements at the start of all shifts. At site B, shift handover was reported for all shifts except the late shift. This required those starting a late shift to request information from colleagues who had been on the early shift. The information was not always accurate due to changes in the patients' condition and revised prescriptions of care since the early shift handover. At both sites, the handover was supplemented with a paper report. Information about the patients' diet type was usually included on the paper report, but often inaccurate, and specific detailed support requirements for eating and drinking rarely reported precipitating errors in support delivery. At SA2 and SB2, RNs and HCAs only received verbal handover for their specific patient allocation (6 to 12 patients dependent on staffing). They then served meals for the whole unit, including patients they had

not received a handover for, which accounted for some errors and omissions with food and support delivery. HCAs reported that they mainly relied on their peers verbally communicating support requirements on an ad hoc basis. Inadequate staffing disrupted continuity of communication, with inconsistent shift patterns and more particularly at site B the use of agency RNs and HCAs to meet staffing requirements.

At both sites, some but not all patients had notice boards communicating some care prescriptions at the back of their beds, beside those used by the SLT. The intention being to ensure staff approaching the patient had some basic information about patient support requirements and occasionally included support for eating and drinking. The RNs at both sites acknowledged it was their responsibility to complete and update these notice boards. Any prescribed support for eating and drinking was for those patients not under the management of SLT and was more limited and less detailed than SLT prescriptions. The notice boards were more consistently completed and updated across site A and much less so across site B, at both sites there were patients with no visible direction for support with eating and drinking. At both sites, it was acknowledged that this had caused errors compromising patient safety with the supply of prescribed food and drink and the support required to consume it, by both staff and ICs.

At both sites electronic wall mounted whiteboards displayed information taken directly from the patient's electronic record, designed to give the MDT easy access to this information. The screens were situated near the nurses' station across site B, and at SA1. On SA2, they were situated in a meeting room purported to promote patient confidentiality but making the board less accessible to the MDT. At both sites, all members of the MDT except the HCAs could add information to the system. Display information included symbols representing various care requirements such as a knife and fork if patients required assistance with eating and drinking, but no further detail. Patients had multiple symbols making immediate, 'at a glance' identification of care and support requirements difficult. At both sites, the information was often outdated,

with support requirements for eating and drinking limited to diet type and occasional instruction to encourage diet and fluid:

“...the handovers aren’t always the same as the [whiteboard], and the handovers are supposed to be updated as a result of the whiteboard meetings” (Sue, OT site A).

At both sites, daily whiteboard meetings - duration between thirty and forty-five minutes, offered the opportunity for communication about patient progress between the wider MDT. MDT attendance at site A whiteboard meetings was more consistent, including PT, OT, SLT, dietitians, senior and junior doctors but rarely consultants and was nurse led by the WM, SR or a senior RN. Information was offered about patients’ nutritional intake and required diet type by the SR and the dietitian, but no information about any support required to enable patients to eat and drink. Any other members of the MDT present did not query this information including the medical team. SLT informed the team of which patients they were assessing that day, but not patient support requirements for eating and drinking.

At site B, whiteboard meetings were usually led by senior medical staff and always attended by a PT and OT. SR and SLT attendance was inconsistent, and the dietitian did not attend. If a SR was not available, there was no representation at these meetings from the unit nursing team. One consultant requested information about the patients’ nutritional intake, though this was less consistent with other consultants and junior medical staff. The SR or SLT if present would respond with the patients’ modified diet requirements, but never with the support that patients required to eat and drink. Communicating detailed and accurate support requirements with eating and drinking to the wider MDT was not prioritised. The timing of these meetings at both sites meant that RNs and HCAs who delivered most of the support with eating and drinking, were engaged in other work, such as medication administration, and direct patient care. HCAs did not attend these meetings perceived as outside the HCA role

remit by the HCAs and rest of the MDT, despite the HCAs frequently holding the most knowledge of patients eating and drinking abilities.

Weekly MDT meetings were held additionally to daily whiteboard meetings at both sites to discuss patients' progress and forward goal planning for rehabilitation in accordance with national clinical guideline recommendations (ISWP, 2016). Occasionally at SA2 and more frequently at SB2 there were no SRs or RNs available to attend these meetings, HCAs did not attend the meetings that were medically led. At SB2, the SR and RNs were often unable to update the rest of the MDT of any patients' nutritional intake, possibly due to not receiving a handover for the full ward and the nurses not being adequately prepared for the meeting. Both sites had a MDT proforma completed for each patient with individual sections for PT, OT and SLT goal setting. PT and OT did not set goals for, or report on patients eating and drinking ability at either site. SLT set goals for patients swallowing ability, but not functional eating drinking ability at both sites. At both sites, the MDT proforma had no specific section for the dietitian. At site A, dietetic comments were written in a section marked 'other' on the proforma and at site B, there was a section headed 'nutrition' which as it was inconsistently and minimally completed suggested that dietetic input was not considered a priority for stroke patients at either site. At site B, the dietitian attended one of eleven observed MDT meetings. This was reportedly due to lack of capacity within the dietetic team. As the dietitians at site B relied upon referrals from other MDT members outside the formal MDT communication mechanisms, they were concerned that the tardiness of these referrals posed a risk for those patients at risk of malnourishment and those patients already malnourished. At site A, dietitians attended all MDT meetings. Other than nutritional intake, dietitians rarely discussed other direct support requirements such as assistance to eat and drink, despite recommendations for dietetic input with assessment and the prescription of direct support (BAPEN, 2018). Support with eating and drinking was rarely discussed or recorded at any of the MDT meetings at either site,

Despite the availability of multiple communication mechanisms at both sites, these were not consistently employed to communicate support requirements and progress with patients' eating and drinking. This suggests that supporting eating and drinking was not a MDT priority despite all individual MDT members stating that it was.

7.1.3. Objective 3: To investigate how and by whom prescribed and unprescribed support is delivered and monitored

Despite MDT acknowledgement that adequate nutrition is necessary for recovery and rehabilitation following stroke, and employing several mechanisms to monitor this, patients did not consistently receive appropriate individualised support with eating and drinking at both sites. This was a result of multiple related factors identified at 7.1.1. The consequences for stroke patients at both sites were that they often did not receive direct physical assistance to eat and drink; support to develop independence with eating and drinking; access to food and drink and ingest enough food and drink to meet their dietary requirements. These factors are explored in more depth below.

Across both sites, prioritisation of other work at mealtimes meant OT, PT and SLT who had specific expertise, such as body positioning, provision of specialist equipment and feeding techniques that could support patients to eat and drink were not present at mealtimes. Their rationale has been explained in 7.1.1. Across both sites this meant that most direct and indirect support with eating and drinking was delivered by the HCAs and less so by the RNs with no expert supervision. At site B, food delivery was augmented by WAs and HKs whose role specified delivering breakfast and drinks with and between meals, though role boundaries precluded them delivering direct support with eating and drinking. At SA2, the delivery of between meal drinks was inconsistent, relying on a part-time volunteer despite acknowledged by the WM as this situation being less than ideal. Neither the WA nor HK role existed across site A, with no other staff roles perceiving responsibility for the delivery of between meal

drinks. This suggests lack of leadership in ensuring staff have clearly defined jobs within their roles, and supervision to ensure the work is done:

“...drinks can be a little bit more ad-hoc, so we know for definite that we do one with breakfast, and then we rely on our volunteers to do the hot drinks, so depends on ward acuity and then the volunteers, what time they arrive to do mid-morning,” (Julia, WM, site A)

At both sites, HCAs were observed to prioritise other care work at mealtimes meaning they were not available to support with eating and drinking. At both sites, RNs and HCAs justified this, offering patients' toileting and associated hygiene needs as examples of care needs that were prioritised over support at mealtimes. At site B, reduced numbers of HCAs and RNs augmented this situation. All the MDT acknowledged that mealtimes were periods of peak patient activity requiring more staff, implying more HCAs and RNs, other professions remained unavailable prioritising other work at mealtimes, offering national guideline therapy targets as one justification (ISWP, 2016). At both sites, HCAs were aware that some aspects of care work were audited. They felt pressured to prioritise this work over supporting eating and drinking, naming Intentional Roundings and pressure area care as examples:

“...it's like they always look at all your things like your statistics, that they look at to equate whether we're a good ward or a bad ward, the little things like feeding someone, ensuring they get what meals they've ordered, that they get it hot, are perhaps low in priority compared to, like falls” (Rosie, TAP, site B)

These comments were supported by one of the WMs at site B, inferring that they were pressured from a higher level in the organisation to meet nationally audited targets (NHS Improvement, 2013). This in turn meant that the completion of other work, including support with eating and drinking (not on the audit list) was less of a priority:

“I’m thinking in terms of our compliance with various audits, I get a lot more hassle about things like falls and pressure sores than I do about food, from a management point of view.” (Katie, WM, site B)

Senior nurse leadership at mealtimes was inconsistent across both sites. WMs across site B and at SA2, were confident in their delegation of this work to RNs and HCAs and did not think their leadership was required at these times. They prioritised other managerial activities over mealtime work:

Int: “Do you assist?” [Assist with mealtimes]

Katie: “Sometimes, not always, not very often, but yeah, sometimes.” (Katie, WM, site B)

The lack of WM leadership or involvement at mealtimes across both sites suggests WMs did not perceive this work as a role priority, contradicting their expressed views that supporting eating and drinking was of paramount importance in patients’ recovery and rehabilitation following stroke. This potentially influenced the actions of more junior members of the nursing team, who were observed prioritising other work during mealtimes at both sites.

At site A, there was no leadership of mealtime work. Despite delivering all the meals, no HCA took a lead role during mealtimes and HCAs did not always stay with or return to the patient to monitor their progress with the meal. No patients at site A were given adaptive devices such as non-slip mats, plate guards or modified cutlery, despite most HCAs and RNs acknowledging their utility to assist patients to eat and were unsure of how to access these. An OT and dietitian alluded to a ‘red tray’ system being in place which should identify those patients requiring support to eat and drink, though no red trays were observed across site A, and HCAs and RNs were unaware of this system. RNs stated they supervised mealtimes, whilst administering medication and rarely identified patients’ support requirements or directed HCAs with support. The RNs justification for prioritising medication administration at mealtimes was due to

timings on prescription charts coinciding with all mealtimes. When challenged about medication administration conflicting with mealtimes, RNs agreed this was not ideal, but thought it would be too difficult to change, involving multiple agencies including the pharmacists and wider medical team. Patients were regularly observed to have unmet support requirements which resulted in many struggling to consume their delivered meals and drinks across site A.

At site B leadership at mealtimes was inconsistent, with the delivery and provision of direct support dependent on which individual SRs, RNs and HCAs were on duty that day. When on shift the SRs at site B were observed to ask RNs and HCAs to check that all patients had received meals, and were receiving required support, though this was inconsistently implemented. Patients were often missed out during meal delivery. Often, by the time the error was identified there was no hot food left and they were offered cold sandwiches, which they often declined. Some RNs supervised mealtimes for their daily allocation of patients, others did not. One SR and two RNs were observed to directly support patients with feeding, cutting food, physical positioning, providing modified crockery (lipped and different coloured plates), and gave verbal direction to HCAs and patients. Some HCAs offered direct support whilst others failed to identify or acknowledge patients' difficulties with eating and drinking and did not offer appropriate advice or provide essential support or devices to assist with eating when patients were observed to require support.

At site B, there was no visual system such as red trays to identify patients requiring assistance with eating and drinking. The use of non-slip mats was not observed at site B. OT had assessed two patients at site B as requiring modified cutlery, though was inconsistently provided, as this had not been communicated to the relevant staff. Patient support requirements with eating and drinking were frequently not met at site B, with patients often not completing meals and drinks they had been served and not ingesting their nutritional requirements. Across site B, some RNs commenced medication administration once meals were served, changes having been previously made to the timings of administration on prescription charts, the only medication

administration/ mealtime clash being breakfast. This was purported to free RNs to support at lunchtime and evening mealtimes. Despite these changes, some RNs at site B were observed administering medication at mealtimes. The rationale being that medication administration was a lengthy task and therefore started early to ensure the patients received medication at a reasonable time. Both sites used digital medication prescription systems, which RNs at both sites considered substantially lengthened the medication administration process when compared to previously used paper prescription charts, adding to their pressure of work.

At both sites, ICs supplemented some patients' support. This was a small number, with no more than five patients observed to receive IC support at any one mealtime at either site. The experience of ICs varied from site A to site B. At SA2 (acute and rehabilitation), the Protected Mealtime Initiative [PMI] (designed to prevent patients being interrupted during mealtimes for non-urgent treatment (Hospital Caterers Association, 2004)), was lifted to enable ICs to support their relative with eating and drinking. This had not been communicated to all MDT members resulting in some ICs initially being told they were not allowed on the unit at mealtimes. SA1 still practiced the PMI and ICs had to request permission from the nurse in charge to attend at mealtimes. This was granted if it was thought appropriate for them to support their relative to eat and drink and caused some frustration for ICs. Site B practised PMI across both units, but its application was inconsistent causing some frustration and confusion for ICs. Some ICs requested permission to visit at mealtimes and assist their relative; others were already present and decided to remain on the unit at mealtimes unchallenged, whilst others had been asked to stay to support their relatives by the SR. At SA2, most ICs felt encouraged to support their relatives, some having received verbal direction from the SLT and occasionally the HCAs as to how to undertake this, particularly with feeding and preparation of drinks. ICs at SA1 and at site B did not experience this and relied on direction from the yellow signs at the back of the patients' bed if available or self-direction:

Int: "So has anybody here ...said "we'll show you what to do" [to support] or anything like that?"

Marie: "No...I think they just presume you know how to do it." (Marie, IC, site B)

All ICs perceived that their interventions in supporting their relatives to eat and drink had beneficial results for their relative's nutritional intake. SLT and the nursing staff supported this across both sites, acknowledged in part to relieve the workload for RNs and HCAs at mealtimes. However, this was not prioritised with minimal promotion of IC support across both sites.

At both sites, the inconsistent employment of mechanisms to monitor patients' nutritional intake and status resulted in delayed identification and referral to the dietitians and medical team. At site A, although RNs accepted accountability for recording NICs, FBCs and MUSTs, the responsibility was delegated to the HCAs, who accepted this was part of their role but were inconsistent in its execution. At site B, responsibility for NIC, FBC and MUST completion was shared between RNs and HCAs, and inconsistently achieved. At site B, the WMs accepted accountability for ensuring these monitoring mechanisms were fully completed but did not check their completion. At both sites, NIC recordings were commonly omitted or partially and inaccurately completed. Members of the MDT at both sites including consultants, dietitians and dietetic assistants at site B, reported the same concerns with NIC and MUST completion. Of particular concern was the lack of monitoring of patients' weight as part of MUST. Leaving consultants and dietitians relying on subjective methods to assess patients' weight deemed highly unsatisfactory. At both sites, the rationale offered was understaffing of RNs and HCAs, though this was more apparent at site B than at site A. The monitoring of patients' nutritional intake and status was not prioritised at either site. For patients not supervised by the SLT, there was no specific monitoring of support requirements to enable patients to eat and drink.

7.1.4. Objective 4: To explore how support with eating and drinking is perceived by patients, informal carers and MDT members.

Despite the nursing teams at both sites perceiving that their patients received the support required to eat and drink adequately, this is not what consistently occurred. This was the result of a number of related factors also related to the previous objective including: limited senior nurse presence and leadership at mealtimes; inconsistent and limited education provision for RNs and HCAs with supporting eating and drinking and nutrition; understaffing and limited MDT working at mealtimes comprising of a lack of physical presence, supervision and effective communication from those members of the MDT with expertise in supporting eating, drinking and nutrition for the RNs and HCAs directly supporting patients at mealtimes. The consequences were that MDT members other than the nursing teams, and ICs lacked confidence that the optimum support required for stroke patients to eat and drink was provided. This compromised the rate of stroke patients' recovery and rehabilitation and engendered anxiety and frustration for stroke patients and their ICs.

At both sites, WMs perceived that the patients were adequately supported to eat and drink and the delegation of this work to other levels of nurses and HCAs was appropriate. HCAs across both sites were observed to deliver the most support with eating and drinking and they perceived that their patients received the necessary support to eat and drink and maintain adequate nutritional status. Other members of the MDT with specialist knowledge, patients and ICs, who identified inconsistent support with eating and drinking, contradicted these perceptions. Senior nurses, WMs, SRs and RNs stated that supporting patients to eat and drink was of paramount importance. However, at site A, nurses at these levels of seniority rarely directly supported or directed others to support patients to eat and drink. At site B, RNs and SRs did have more direct contact at mealtimes with patients, though minimal supervision of HCAs. At both sites, other than for the basic management of swallowing issues, nurses of all levels identified a lack of organised, ongoing training and education for nutrition and

supporting the specialist needs of stroke patients with eating and drinking, with other training requirements such as moving and handling prioritised. The lack of training may explain why patients support needs were inconsistently recognised and the required support not provided.

Across both sites, the wider MDT perceived ongoing daily support with eating and drinking as nurses' work and were rarely available at mealtimes to supervise and support nurses, patients and ICs. The rationale for this was discussed in 7.1.1. Although not in attendance at mealtimes the SLT, dietitians and medical teams were alerted to patients' requiring their intervention because of deterioration in swallowing or nutritional status. At site B, the preventable nature of some issues for which they received referrals, enhanced the consultants' perceptions that support with eating and drinking was inadequate. At both sites these perceptions were shared by the dietitians and less so the SLT. At site B, Consultants were aware of pressures on the nursing team to provide adequate support and the inconsistencies and omissions in this support. Over time, this was accepted as the status quo, a shortage of RNs being blamed.

Patients had similar perceptions of support with eating and drinking at both sites. Identification and delivery of direct support was considered inconsistent as discussed in objectives 7.1.1 to 7.1.3. Most patients perceived that asking for support engendered negative emotions such as embarrassment, frustration, infantilisation and feeling like a burden:

"I don't want to mither anybody because it's so busy. The nurse is so busy all the time and you don't like interrupting... you feel as though, yeah, you're a nuisance, yeah." (Don, patient, site A)

At times, these negative emotions were triggered by MDT responses. Some members of the MDT were perceived as less approachable and less supportive, more so at site B than site A. Patients at both sites perceived that there were

not enough nurses, and the nurse were too busy, so did not want to add to their work by asking for support. Patients with ICs perceived that asking them for support was easier than asking the nurses, but not all patients had ICs to ask:

“I’m not very good at asking for help, you know. I find it easier to ask my family for help than I do for the staff to ask for help because I know how busy they are. I know my family just want to make everything easier for me and there’s nothing that I can ask them that would put them out but the staff, I don’t want to be a burden.” (Alison, patient, site A)

Across both sites, ICs experienced mixed emotions when supporting their relatives to eat and drink. These included positive emotions such as relief and satisfaction if they knew their relatives had eaten and drunk something and feeling useful if they had been able to do something to support their relative, which they perceived reduced the nurses’ excessive workload. Counter emotions were also experienced at both sites, but more so at site B. These ICs experienced guilt and anxiety if unable to support relatives at all mealtimes, as experience had identified that relatives support requirements were often left unmet by the MDT. At site B, ICs experienced mistrust and frustration with the nurses when they observed delays or mistakes with support for their relative caused by errors in communication. At both sites, ICs perceived they were a nuisance to some MDT members including the nurses, dietitians and consultants if they asked too many questions. ICs perceived that supporting their relatives to eat and drink at times caused physical and emotional fatigue:

“And I feel, if I ask a question, I feel like I’m bothering them, because they’re so busy...I don’t want to piss them off and them get more defensive, like it’s a very fine line between asking someone for help and they feel like they’re being harassed.” (Lynne, IC, site A)

7.1.5. Objective 5: To understand how organisational and contextual factors influence provision of support with eating and drinking

Organisational level systems required to support stroke patients to eat and drink, did not result in the provision of adequate individualised support. This was a result of multiple factors at both sites including the lack of provision of adequately trained staff; the prioritisation of audited care procedures over supporting eating and drinking, motivated by national and within organisation publication of audit results and at site B limited flexibility in the provision of suitable food. The ramifications of this were that stroke patients' support requirements were often unidentified, support needs unmet and did not consistently receive appealing food and at site B adequate amounts of food.

The systems of meal delivery to the stroke units were dictated by the hospital catering services and this differed between site A and B. The methods employed at each site described at section 6.2, had some influence on patients' eating and drinking at each site and consequently their support requirements. Despite understanding their necessity, patients across both sites who required modified diet found the appearance and texture of these meals unpalatable. They frequently did not consume any of their meal or only partially consumed them and therefore failed to ingest adequate nutrition. At both sites, these observations were supported by comments from ICs and the MDT. Patients and ICs suggested that more consideration of the appearance of modified diets would improve their appeal and encourage patients to eat more:

“Generally speaking, the plate that she's given in the evening consists of a pool of brown sludge, a pool of dirty green sludge... I couldn't face it, I mean, it just, it would put me off, the appearance of it.” (Jim, IC, site A)

At site A, all food was plated in the hospital kitchen and presented in a more appealing way than at site B where the nurses plated all food. At site B, this

negatively influenced the patients desire to eat the food. The nurses who presented food in a more visually appealing way could not identify where they had learned this skill and were unable to recall any training for this, but were more aware of the importance appealing presentation:

“I think, when the patients here, they see blobs here and blobs there, it's not appetising, it doesn't look nice, so it isn't going to taste nice, and I think sometimes it looks a bit too stodgy for them to swallow.” (Shaun, HCA, site B)

At both sites, the dietitians acknowledged that patients' daily meal provision, more so for those on modified diets, did not provide the recommended daily calories for patients recovering from illness including stroke, which is 1840-2772kcal daily (British Dietetic Association (BDA), 2019). This was compounded when patients did not consume the food provided or as at site B were not served full meals:

“So, if they know they've got 20 [patients] wanting one thing and they've only got 15 portions, they'll make the portions smaller to go round because they don't want, so there'll be some that do that... but yeah, there's a risk of getting a smaller portion.” (Diana, dietitian, site B)

At site A, this deficit of calories and other nutrients had been acknowledged for modified meals and food supplements issued, placed on the meal tray by the catering team at each mealtime:

“Well, we've got some national standards involved with the British Dietetic Association but this hospital needs some work on that...there is some development needed for some of the menus really from an energy and protein point of view.” (Alice, dietitian, site A)

At site B, food supplementation was not generic, but dependent on the dietitian or the doctor prescribing them, which was in turn dependent on a nutritional deficit being identified as discussed in 7.1.1.

At both sites but especially at site B, the range and availability of food choices for those able to eat a normal diet was criticised. Some patients found what they perceived as foreign foods unappealing. The nursing team who thought the food frequently inappropriate for their usual patient demographic supported these comments. This was a lesser issue at site A where the patients had more flexibility in meal choice.

Despite national recommendations for MDT staffing to support stroke units (ISWP, 2016). Organisation systems failed to provide sufficient suitably skilled staff to adequately support patients at mealtimes, with the consequences discussed in the previous objectives. At site B, WMs and consultants suggested that a shortage of RNs deemed outside of their control, was the main reason for issues with MUST completion. They reported that national shortages of RNs affected recruitment, but also that stroke care was less prestigious to work in than other areas of healthcare, adding to difficulty with recruitment:

*“...so, there is a difficulty in recruiting because a) the directorate is geriatric and stroke medicine, so geriatric doesn't necessarily tend to appeal to a lot of people, and then combining it with stroke, yeah, it doesn't, doesn't get interest.”
(Katie, WM, site B)*

At the time of data collection at site B the WMs reported seventeen RN vacancies across SB1 and SB2 with non-specialist agency RNs but more frequently HCAs perceived to be less skilled, filling the gaps on daily rosters. No RN vacancies were reported at site A, though agency HCAs were often employed. At SA2, the WM supported by observations commented that they frequently did not work with the planned staff to patient ratio based upon patient dependency, as RNs and HCAs were moved to work on other areas, by other senior staff in the organisation who they perceived lacked understanding of stroke patient dependency, and their support requirements with eating and drinking:

“...because out of the 28 they’ll be a lot of patients, because of the stroke, can’t feed themselves so unless there’s lots of staff around for the numbers of patients that need help, they’re not necessarily going to get the help.” (Diana, D, Site B)

At both sites, some MDT members suggested that a change in work patterns, particularly of the therapists could partially alleviate the staff shortages at mealtimes and would benefit support with eating and drinking as discussed in the previous objectives. At both sites all the MDT were aware of the Protected Mealtimes Initiative [PMI], offered as a rationale as to why MDT members other than the nursing team, were unavailable to support patients at mealtimes. Other rationale was a shortage of therapy staff and the requirement to achieve the national guideline (ISWP, 2016) recommended 45 minutes of therapy time for each speciality for every patient each day, which left no time to support at mealtimes which had become the routine:

“It’s always been the nature that we’ve always just had our lunches at that time because of protected mealtimes, you’re not meant to be getting the patients up and doing physio” (Cara, PT, site A)

Apart from SLT, therapy managers did not consider that therapy sessions could be focused to re-enable patients to eat and drink at mealtimes, OT and PT undertook no direct patient work or took their own meal breaks during patient mealtimes, so patients’ or nursing staff did not receive their expert support and supervision during these times:

“...it was felt that feeding patients didn’t class as part of the 45-minute therapy... it was felt that feeding didn’t contribute to that 45 minute therapy target” (Julia, WM, site A)

At both sites, despite WMs acknowledged that supporting eating and drinking with stroke patients was a specialised skill, there was no monitoring of staff training or education and competence in supporting stroke patients to eat and

drink. At both sites, WMs were unaware what education and training for supporting eating and drinking their nursing teams had received suggesting that this was not an organisational priority. Some, but not all RNs and some HCAs reported receiving some initial training for feeding patients with swallowing difficulties, but this was not stroke specific and did not cover other support with eating and drinking. This had been at the start of their employment, which for some was many years previously:

“I haven’t been here long and I heard one of the HCAs say, I’ve been here 19 years I’ve never had any training [to support eating and drinking].” (Corinne, dietetic assistant, site B)

All levels of nursing staff reported that they had learned how to support patients to eat and drink by trial and error and in an ad hoc method from their peers, which supported the continuation of both poor and good practise. It was unknown what training if any, agency RNs and HCAs had received, leading to potentially dangerous errors in practice:

“...we could help in terms of training new staff to make them more aware of these things. But, well a) we’re not asked to do that and b) I’m not sure what time we’d have to do to fit that in.” (Diana, dietitian, site B)

7.2. Synthesis summary

Despite all participants across both sites acknowledging the importance of supporting patients to eat and drink and promoting adequate nutrition to enable recovery and rehabilitation following stroke, patients at both sites did not consistently receive the specialist, individualised support required to achieve this. This was a result of several findings identified and discussed, though sections 7.1.1 to 7.1.5. Regardless of some variation in findings between sites, when synthesised, the predominant finding was that supporting eating and drinking was not prioritised at the higher organisational level and by local MDTs

at the stroke units constituting the cases investigated in this study. This was a result of multiple factors identified in further findings. The consequences for stroke patients were that they often did not receive the individualised, specialist support required to eat, drink, and maintain adequate nutrition supporting their optimum recovery from stroke. The findings and the factors that influenced them is discussed further in chapter 9.

Chapter 8: Reflexive account

This reflexive account explores the outcomes of the reflexive processes initially identified at sections 3.4 and further at 4.7 and 4.8 of this study. It is argued, that in the production of a qualitative research study such as this case study, the researcher cannot exist as a separate entity, their life experiences must influence the research process and in essence, they become part of the phenomenon that is being investigated (Creswell, 2013; Gobo and Molle, 2017). Acknowledging these experiences and their influences, qualitative researchers practice reflexivity, making clear in their writing their position within the phenomenon under investigation including biases, values and experiences (Hamersley and Atkinson, 2007; Creswell, 2013). The researcher, as the main research instrument, must demonstrate reflexivity to support the validity of the study by allowing the reader to appraise the researcher's actions and behaviours (Simons, 2009). Simons (2009) suggests that the researcher must then know himself or herself and describes this as the 'subjective self'. Simons (2009) draws on the work of Peshkin (1986) arguing that we have subsets of personal qualities dependent on the research topic, described as 'I's, we each have lots of different 'I's. These qualities may alter the research process at any stage from inception to the final written report. Peshkin suggests that we know when our subjectivity is triggered when positive or negative feelings are evoked, we avoid or seek experiences and may wish to act beyond the researcher role (1986, p.18). This reflexive account explores the influences of my subjective self and my 'I's developed from my life experience and professional background, and how they influenced the production of this case study (Simons, 2009).

A brief introduction to my professional nursing history and how it influenced the inception of this study is offered in chapter 1. Reading this initial introduction, it is clear the situations I described when working with stroke patients and supporting them to eat and drink in the hospital setting had initiated an emotional response, suggesting my subjective self was aroused (Peshkin,1988). I recognised that my nursing 'I' was engaged from the study

inception and this would require my awareness and management throughout the study in order to understand when this and any other of my other 'I's were triggered. This reflection identifies how my different 'I's could have impacted the study by enhancing my understanding of the study contexts, changed how I progressed with the study or led to potential bias at any point in the study process (Dowling, 2006; Simons, 2009; Couture et al., 2012).

Prior knowledge and experience present challenges for qualitative researchers (Bonner and Tolhurst, 2003; Pellatt, 2003; Blythe et al., 2013). An initial challenge identified in the literature and applicable to my experiences was when in the field, I was a researcher, but also a registered nurse with specialist knowledge and therefore still had to practice to the current professional nursing standards (Bonner and Tolhurst, 2003; Hand, 2003; NMC, 2015). To prepare for this role, I reflected on my nursing experience and discussed areas of potential conflict when working in the field and during analysis with my supervisors and what actions I planned to take. My actions in some situations I encountered were dictated by the nursing regulations and my own morals and ethics. I intervened if I saw a patient come to immediate harm, for example calling for assistance and preventing patients falling on several occasions. In these situations, it would have been inappropriate to follow researcher role, allowing the situation to progress whilst taking observational notes and reflecting on the situation afterwards once the patient had been injured. I found other situations encountered in the field less straight forward to manage. Pellatt (2003) suggest that conflicts between the researcher and nurse role can be more complex. One example occurred when I felt pressured by an IC to pass complaints to the MDT about the quality of food their relative had received. I agreed with their comments, the food looked inedible, but I did not think it was my role as a researcher to pass on the ICs complaints suggesting that the IC discuss this with the Ward Sister or Ward Manager. Reflecting on the situation, I was aware that I experienced conflicting emotions. My nurse 'I' experienced guilt for not advocating for the IC, my researcher 'I' was concerned that my refusal to do as the IC wanted would affect the rapport that I had built with the IC potentially altering their response to me and their willingness to participate in the study. My thoughts and feeling about the situation were added to the reflective journal,

along with what I thought I had learned from the situation, my responses possibly changed the ICs actions - would they have had confidence to approach the MDT without my intervention. I justified my actions as the patient had not been in any immediate harm, and as a researcher further intervention may have influenced the usual practises I was there to observe, though clearly did have some effect (Spradley, 1980). I found debriefing with a trusted nurse colleague helpful regarding my professional responses. Also, discussion with my supervisory team about the reflective process and how this could be used during data analysis. The memos from the fieldnotes and the reflective journal were considered during data analysis, and their potentially influence coding and theme development (Blythe et al., 2013).

The qualitative research literature suggests that a researcher may be an 'insider' already part of the social group they are investigating, or an 'outsider' with no previous knowledge of the group under study (Baillie, 2013; Blythe et al., 2013). It is argued that both positions can offer challenges and rewards for the researcher during fieldwork and data analysis (Blythe et al., 2013). I perceived my situation in this study incorporated aspects of both the insider and outsider role. My professional experience, being part of a MDT and working with patients and ICs on stroke units, meant I had some considerable insider knowledge of stroke and its effects and how stroke units operated. In contrast, I was unknown to the participants at the stroke units identified as the cases under investigation in the study, and therefore an outsider to these social groups (Bonner and Tolhurst, 2003).

I considered my insider/ outsider position advantageous rather than being situated solely in one role or the other. My insider knowledge assisted my understanding of the context and cultures within the cases under investigation, and what I was hearing and observing (Rooney, 2005). For example, I recognised the effects of stroke, which are sometimes very subtle on patients' ability to eat and drink, whereas an outsider with no stroke knowledge may not (Pellatt, 2003). I was also conscious that my knowledge of the settings and topic area could lead to presumptions. An example being when interviewing one RN,

I asked if she prioritised foods when feeding patients such as high protein foods. The RN was unaware of which foods were considered higher protein. This alerted me to not making presumptions about participants' knowledge during data collection (Couture et al., 2012). My nursing experience and communication skills enabled me to develop a rapport with the patients and ICs, though brought some challenges as previously described with one IC. There were occasions when I found it difficult not to slip into my nurse role when patients and ICs discussed any issues with which I thought I could help or they asked for advice. This situation is common, with the researcher insider role and such potential therapeutic encounters are viewed from different perspectives in the qualitative research literature (Bonner and Tolhurst, 2003; Carolan, 2003). It is suggested that when entering a therapeutic role, the researcher can lose objectivity (Hammersley and Atkinson, 2007). I managed each situation on an individual basis. I occasionally offered advice when requested during interviews, for example advising on IC where they may source appropriate foods for their relative following discharge. I found, as did Carolan (2003) that this helped to develop rapport with the participants. When reflecting immediately following the interview and when reading the transcription during data analysis my nursing 'I' had once again been triggered. At other times, I directed the participants to the relevant members of the MDT, agreeing with Carolan (2003) and Hand (2003) that supporting participants in this way was a form of reciprocity for their participation, and for myself, helped to negate some of the conflict I experienced between my nurse and researcher roles.

I perceived my insider/ outsider role more complex with members of the MDT. Knowledge of my nurse experience affected recruitment and participation in the study both positively and negatively. Some members of the MDT at both sites acknowledged that they felt more at ease participating and divulging information as I was a nurse (insider) not only a researcher (outsider). During interviews participants from different professions made comments such as 'you know how it is', implying that I understood the issues they were discussing, and appeared more truthful and willing to divulge what could be considered sensitive information (Bonner and Tolhurst, 2003). At other times, I recognised that I was perceived as an outsider and suspected this altered participants' behaviours. At

such times, I made memos in my observational fieldnotes, which prompted me to investigate further, gathering evidence from other sources where possible (Miles et al., 2014). One example occurred during an observation of an evening meal at site A, an HCA I had not previously met asked what I was doing and I explained my presence. They proceeded to complete all the nutritional intake charts [NICs] for the patients I in the bay I was observing, contradicting behaviours previously identified. I gathered further observational and documentary data including NICs, which supported my hunches. Evidence from my documented reflections and memos, suggested that the extensive period of observation at each site encouraged the participants, in particular HCAs and RNs, to become habituated to my presence. This enabled me to discern their usual behaviours (Bonner and Tolhurst, 2003).

At site A, when approached to participate in focused observations or interviews, and having asked about my background the consultants declined in what I perceived to be a dismissive manner and asking who had given permission to allow me to conduct the study. I was unsure why I received this response, as they did not elaborate. Reflecting on these interactions, I identified several possibilities; they perceived me as an 'outsider' to the MDT and so was not trusted; lack of interest in the research topic area or the study being qualitative, perceived as less definitive and relevant than quantitative research in medicine (Blythe et al., 2013; Loder and Merino, 2016). Their reaction was disappointing and shaped the study with a more limited analysis of consultant perspectives from site B only.

Reflecting on the interview process, some situations, which occurred during the interviews and how I managed them, have been discussed previously. Identified during the transcription and analysis of interview data, my confidence as interviewer developed as the study progressed. Although I used the interview question guides, I was aware that these were inevitably influenced by some my preconceptions about the topic area and concept under investigation (Hand, 2003). This awareness and increasing confidence when conducting the interviews encouraged me to stick less rigidly to the question guide, to allow

participants to talk at length and probe participants for further information and explanations about the topic area.

As with the observations, during interviews I was perceived by some participants as an insider and by others as an outsider (Bonner and Tolhurst, 2003; Hand 2003). Patients and ICs were frequently complimentary about the MDT and particularly the 'nurses' though I had to seek clarity regarding if they meant RNs and / or HCAs in most interviews. At such times, I reflected that the participants saw me as an insider and were telling me what they thought I wanted to hear. ICs often prefixed their responses with comments such as 'I don't want to cause trouble'. I learned that I had to offer much more reassurance about confidentiality and anonymity throughout the interviews, to gain their trust and encourage them to be less guarded in their responses and conversations. When interviewing members of the MDT the HCAs often made similar comments about not wanting to cause or get 'into trouble'. I worked hard as the interviewer to reassure the participants to be as truthful as possible in their responses. I was aware that being perceived as an insider or outsider could have both positive and negative effects in participant sharing their thoughts and insights.

Reflecting during and after the interviews and reading interview transcripts, I felt that being an outsider to both case MDTs encouraged the participants to speak more freely than had I been an insider member of their MDT (Bonner and Tolhurst, 2003). Listening to the interview recordings, I was aware that I modified my communication including my use of language depending on whom I was interviewing. I found interviewing a demanding experience in terms of concentration and emotional responses to participants' discussion of their experiences. Awareness of my emotional responses was a trigger to reflexivity, which I practised during and after every interview. How I perceived participants' responses through my different 'I's. For example, it was difficult to hear some criticisms of the nurses particularly from other professions, even though I often agreed with them. These reflections influenced my approach in further interviews as well as awareness of potential bias during the analysis process.

Writing a reflective journal from inception to completion of the study encouraged me to identify and explore my own subjectivities. This supported the reflexivity required to aid transparency and credibility in qualitative research (Simons, 2009; Gobo and Molle, 2017).

Chapter 9: Discussion

9.1 Introduction

This chapter presents a summary of the findings identified in the case synthesis in chapter 7. The implications of key findings will be discussed within the context of the related literature, current national policy and delivery models for the management of stroke. This is followed with recommendations for the future direction of supporting stroke patients to eat and drink in the hospital setting.

9.2 Summary of key findings

The overarching finding that emerged from the synthesis was that supporting stroke patients to eat and drink adequately to improve or maintain their nutritional wellbeing was not a priority at both higher organisational and local levels. Further findings identified that multiple, complex and interwoven issues promoted the lack of prioritisation and are discussed below.

9.2.1. Competing priorities limiting the quality and quantity of available support with eating and drinking from the MDT

Initial screening for swallowing problems (dysphagia) within four hours of hospital admission conformed to recommendations from the National Clinical Guideline for Stroke (ISWP, 2016) the 5th edition and latest version of these guidelines. This was in accordance with guidance for the general hospital population and specific stroke guidance for nutritional management (NICE, 2006; NCCC, 2008). The MUST was employed for the assessment and monitoring of stroke patients' nutritional status (ISWP, 2016; NICE, 2008; 2019).

The MUST can identify patients at risk of, or who are malnourished, and should prompt further investigation to identify support needs. The completion of MUSTs along with NICs and FBCs was inconsistent at both sites. Despite medical, nursing, SLT and dietetic members of the MDT discussing the importance of MUST completion, this task was delegated via RNs to the HCAs who inaccurately reported that they were completed at least weekly. Inconsistent completion of these assessment tools is reported in the literature and associated with nurse staffing levels, lack of education and leadership. Ahmed et al. (2015) investigated compliance with MUST completion across 206 beds in the medical and surgical directorates in one UK hospital. They found compliance in the medical directorate was 51% compared to 61% across the surgical directorate and 92% in the Intensive Care Unit [ICU]. The authors proposed that the marked differences in these findings were due the increased nurse to patient ratio in ICU compared to other areas. In another UK study McDonald et al. (2011) found compliance with MUST completion for 53 patients across elderly and rehabilitation wards increased from 50% to 100% at 20 weeks later following implementation of a weekly Nutrition Screening Round [NSR] instigated and led by the dietitians. The effectiveness of the NSR was attributed to increasing awareness of MUST policy and delivering 'hands on' training. These issues are also reported in international studies as with Palmer et al. (2015) who reported poor compliance and consistency in the completion of food intake charts by nurses. The food intake charts for 15 patients were compared over 43 days with 93% of the charts recorded as incomplete leading the authors to conclude that nursing staff required ongoing training or another method of recording this information was required. These were relatively small-scale studies in clinical settings other than stroke units. Nonetheless, the findings highlight factors which were also evidence in Sites A and B in this study. Namely that staff engage in MUST completion had little or no structured training in nutritional screening and at HCA level had no direct responsibility for recording MUST scores in patient records.

Members of the MDT including Consultants, Dietitians, and Dietetic Assistants (Site B only), reported inadequate nutritional data on which to base their clinical decision making. The problem of poor compliance with MUST screening in both

sites was widely acknowledged but not directly addressed. Instead, MDT members used subjective observations and anecdotal information which may result in ineffective clinical decisions. In addition to the absence of consistent use of the MUST tool, there was no specific assessment of patients eating and drinking ability for those patients not experiencing swallowing difficulties and being managed by the SLT. Validated screening and assessment tools for identifying eating difficulties in stroke patients do exist; two separate tools identified in a systematic review by Westergren (2006). The implications of limited screening and no clear assessment of patients' ability to eat and drink independently were that support requirements for eating and drinking remain unidentified and support needs were unmet for longer than necessary, compromising their nutritional wellbeing.

Despite recommendations from the National Clinical Guidelines for Stroke (ISWP, 2016) that supporting patients with their daily activities including eating and drinking is a multidisciplinary process, responsibility for ensuring patients were supported with eating and drinking lay almost entirely with the nursing teams incorporating WMs, SRs, RNs and HCAs. The nursing teams accepted this responsibility. This finding is alluded to as previously discussed in the national and international stroke guidance and the wider literature investigating nutritional support in the hospital setting both nationally and internationally. This includes a large qualitative UK study by Chapman et al. (2015) which used nine profession specific focus groups with 28 nurses, 42 doctors and 10 dietitian participants to identify systematic issues affecting compliance with nutritional screening and improving nutritional care. In this work, nurses were identified as the professional group who directly implemented nutritional screening and nutritional care with doctors and dietitians suggesting improvements in practice to enable the nurses to do this more effectively. A smaller, Danish based study by O'Connell et al. (2017) specifically investigated nurses and HCAs (eight RNs and five HCAs) experience of barriers and facilitators delivering nutritional care using focus groups. Their findings corroborate the findings of Chapman et al. (2015), in that the RNs and HCAs perceived they were the professional groups responsible for nutritional care delivery within the MDT. Since 2015, the Nursing and Midwifery Council [NMC] code to which all UK RNs should adhere, has

listed nutrition and hydration as part of the fundamental care that nurses should deliver and that they should ensure assistance is provided for those patients unable to feed themselves (Evans, 2015). It was identified across the research literature that there is a common perception amongst healthcare professionals that supporting eating drinking is a nursing responsibility, nurses generally concur with this perception and in the UK at least, their professional body – the NMC, endorses this. However, this study found little evidence that RNs were adequately prepared for this fundamental role, or that the HCAs they delegated this part of fundamental care to, had the knowledge and skill required to carry out this role.

In this study, other than SLT delivering some specific therapies at mealtimes, no other MDT members considered it within their role to offer direct support with eating and drinking at mealtimes due to multiple factors. These included identified work role boundaries within the MDT, PMI and patterns of work. Issues with work role boundaries was a finding corroborated by Burton et al. (2009) who used a case study approach to investigate the organisational context of nursing care in two Canadian stroke units and further supported in a UK discussion paper examining the role of the MDT in post stroke recovery by Clarke and Forster (2015). In line with Burton et al. (2009) who found that perceived role boundaries limited the effectiveness of MDT working within stroke care, the medical staff and dietitians in Sites A and B did not consider regular direct support with eating and drinking at mealtimes to be within the remit of their role, and the implementation of any support they prescribed was delegated to the nursing teams. OTs and PTs recognised that their expertise could be valuable at mealtimes through therapeutic activities enabling patients' abilities to self-feed, advising and supporting nursing staff, patients and ICs. However, mealtime support was not prioritised within their teams for multiple reasons.

OTs and PTs stated that a lack of time prevented them supporting eating and drinking at mealtimes. This was influenced by pressure of meeting SSNAP audited timed therapy targets recommended by the National Clinical Guideline

for Stroke for 45 minutes of therapy for each patient each day which the teams struggled to attain (RCP, 2014; ISWP, 2016). Therapists stated that supporting patients to eat and drink was not traditionally recognised as therapy and could not be counted toward these therapy targets. Therapists felt pressured to provide therapy that enabled earlier patient discharge from hospital, which prevented them working on other areas of patient rehabilitation including eating and drinking. This was compounded by the understanding that the PMI initially developed by the Hospital Caterers Association (2004) and intended to prevent interruptions to patients' mealtimes presented an overall ban on therapy activities at mealtimes, other than those delivered by the SLT for swallowing reablement. Since its inception, the debate about the effectiveness of PMI has been questioned and its effectiveness investigated. Australian researchers Porter et al. (2017) carried out a RCT testing the effectiveness of a PMI intervention against usual care on patients' energy and protein intake across acute, sub-acute and ambulatory services over three separate hospital sites and incorporating 149 patient participants. They found no significant difference between the intervention and usual care groups, though reported that some observed practice changes may have been attributed to the intervention including 17.6% less negative disruption to patients' mealtimes and 26.2% more positive interruptions. The hypotheses that PMI would improve nutritional outcomes for patients was unproven. A commentary by Young (2017) on Porter et al's (2017) study corroborated their findings with Young (2017) surmising that PMI is either a flawed intervention or has not yet been adequately implemented and evaluated. Both OT and PT recognised that they could incorporate therapy into mealtimes re-enabling patients' eating and drinking abilities but perceived that they were not allowed access at these times. Traditional working patterns also influenced OT and PT availability at mealtimes. Team meetings often conflicted with patients' breakfast and lunchtimes. Time gained at patients' lunchtimes due to the PMI was used for staff breaks and to record the morning's therapy sessions. The shift finish time of 17.00 hours meant that most therapy staff were not available for the evening meal. These findings are corroborated by Clarke et al. (2018) in their large mixed-method qualitative case study evaluation incorporating over 1000 hours of non-participant observation and interviews with patients (n=49), carers (n=50) and MDT (n=131) participants. This study in eight stroke units in the UK investigated why stroke survivors did

not receive the recommended amount of active therapy. Clarke et al. (2018) found that stroke units providing therapy at a frequency and intensity consistent with the National Clinical Guideline for Stroke (ISWP, 2016) recommendations had undertaken patient focused reorganisation of therapists' working times and practices. The authors recommended review of the working practices of staff in stroke units to improve their effectiveness in terms of providing evidence based and patient focused practices.

The benefits of the recommendations for 45 minutes therapy time per specialism per patient per day is controversial (Taylor et al., 2018). The National Clinical Guideline for Stroke (ISWP, 2016) acknowledged limited evidence for this recommendation, developed from a consensus of best practice from their 2012 edition and suggest that therapy should be targeted to the individual's activities of daily living. However, meeting this recommendation is one of the 44 key indicators representative of high-quality stroke care audited by SSNAP (RCP, 2014). In a UK based, large ethnographic study incorporating 300 hours of observational data and 43 interviews with MDT staff, patients and one IC from stroke units across three hospital sites, Taylor et al. (2018) investigated how the SSNAP influenced rehabilitation provision on stroke units. They identified that there was inconsistency amongst therapy managers as to what activities constituted therapy and how this data were recorded. Therapy activities thought recordable for SSNAP were prioritised over other therapeutic activities that were still considered valuable to patients' rehabilitation. Therapy managers were aware that SSNAP audit results could be used by healthcare commissioners and service providers in decisions about service provision, further influencing how they recorded therapy activity bringing into question the reliability of the audit data. The implications of MDT members other than the nursing team not being available at mealtimes meant that patients did not benefit from their specialist knowledge at the times when it was most required. MDT members did not directly supervise the implementation of any specific support they had prescribed for eating and drinking and did not directly assess its effectiveness. Prescribed support requirements for eating and drinking frequently remained unmet. The findings relating to support for eating and drinking in Sites A and B in this study suggest the need for review of working

practices of all MDT members related to nutritional screening and supporting patients with eating and drinking.

Left to the nursing teams, inconsistent identification of support requirements and delivery of direct support with eating and drinking was undertaken by HCAs and occasionally RNs. Under detection of eating difficulties and subsequent support requirements had multiple causes. Other activities were often prioritised at mealtimes by WMs, SRs, RNs and HCAs, meaning there was less opportunity to supervise patients. These included managerial work, care planning and record keeping, medication administration, intentional roundings and direct supervision for falls prevention and delivery of other care requirements. These findings were endorsed by studies investigating hospital nutrition in stroke care and other in-hospital rehabilitation services. The Danish study by O'Connell et al. (2017) also identified the findings that competing activities are often prioritised over nutritional care by nurses at mealtimes. A finding of an Australian ethnographic study by Ottrey et al. (2018) investigating staff perceptions of visitors and volunteers at mealtimes, was that volunteers were helpful in relieving the pressure on nursing staff at mealtimes caused by competing work requirements. A small Hong Kong based qualitative study by Lai et al. (2018) further corroborates these findings. They interviewed 12 nurses about various aspects of stroke patients' eating difficulties, identifying those nurses were often too busy to assist with supporting patients' nutrition at mealtimes, delegating such work the HCAs. At Sites A and B, work requirements originating from various national policies were found to impact RN and HCAs work time identified to further limit time for activities seen to support with eating and drinking.

In line with Taylor et al's., (2018) findings about the influence of SSNAP on therapists' practice in stroke units, the nursing teams in Sites A and B were aware that organisational participation in ongoing audits of the incidence of specific preventable harms as per the NHS Safety Thermometer (NHS Improvement, 2013), meant that some activities such as intentional roundings to prevent pressure ulcers were prioritised over non-audited activities such as

supporting patients to eat and drink at mealtimes and maintain adequate nutrition. The prioritisation of other work by WMs, SRs and RNs and the higher ratio of HCAs to RNs on shift, meant that HCAs delivered most support with patients' eating and drinking and were often unsupervised. There was minimal leadership of mealtime work by senior nurses above the level of RN, identified to negatively influence the prioritisation of mealtime and nutritional work in hospital settings. This finding was corroborated by Papier et al. (2017) investigating hospital based Israeli nurses' perceptions of nutritional therapy found that head nurses (n=22) had a very limited understanding of the barriers perceived to negatively influence nutritional support for patients compared bedside nurses (n=78) from the results of a questionnaire. This finding suggesting that head nurses had limited exposure to patients at mealtimes. A conclusion of Naughton et al. (2021) from their Irish based mealtime observational study with older hospital patients, is that ward managers need greater autonomy and leadership to manage the barriers they identified with patients' nutritional support. Two further qualitative hospital-based UK studies investigated nurse and HCAs work role boundaries (Bach et al., 2012) and ward staff perceptions of food work (Heaven et al., 2012) who their findings suggest that supporting eating and drinking is often incorrectly perceived as common sense and 'lower order work' so thought suitable to be delegated to HCAs by more senior nursing staff. The implications for stroke patients in the current study were that less numbers of all levels of nurses and HCAs meant supervisory capacity generally and at mealtimes with less opportunity to identify their support requirements.

9.2.2. Use of communication mechanisms effect the delivery of support with eating and drinking

At both Sites A and B, SLT were the only professional group to prescribe and document detailed specific direct support with eating and drinking for those patients under their management. Additional opportunities to communicate support requirements between MDT members and from the MDT to patients and ICs were not fully utilised. At MDT meetings, there was inconsistent

communication of patients' nutritional status within the team and detailed direct support for eating and drinking was not prescribed. There was consistent goal setting for those patients under SLT management. WMs, SRs and RNs attending the MDT meetings were frequently unaware of their patients' eating and drinking abilities and nutritional status. These had not been communicated to them at shift handovers or in the patients nursing or MDT records, and as they did not directly support the patients had not gathered this information directly. Although HCAs were best placed to identify the patients' support requirements, due to having the most contact with them at mealtimes, they rarely and inconsistently communicated these findings to members of the MDT other than their peers and the RNs. Communication between HCAs and the wider MDT was filtered via the RNs. HCAs did not attend MDT meetings, whiteboard rounds, safety huddles, or document in the MDT records due to perceived role boundaries (Bach et al., 2012). Detailed and accurate information about patients' eating and drinking abilities and nutritional status was not consistently communicated across the MDT. Issues with less effective communication across the MDT have been well documented in stroke care, negatively affecting MDT working and potentially the patients' rehabilitation process as identified in the previously introduced studies by Burton, (2009) and Clarke (2018). More specifically, in relation to nurses' roles within MDTs in stroke units, a systematic review and meta-ethnography of 16 papers by Clarke (2014) identifies limited communication between the nurses and the wider MDT. A qualitative study by Danish authors Loft et al. (2017a) found that nurses and HCAs had a poorly defined role within the stroke rehabilitation team despite having most direct patient contact and an under recognised coordination role. Loft et al. (2017b) then published a model for behaviour change for stroke nurses with a guidance including required behaviours changes to nurses' communication with MDT colleagues. The implications of ineffective communication strategies are that patients do not consistently receive the specific support required for the re-enablement of their activities of daily living including eating and drinking.

Patients and ICs described limited communication from the MDT.

Consequentially, some patients developed and adapted their eating and

drinking methods and ICs developed their own mechanisms to support their relatives eating and drinking. Patients expressed that lack of communication heightened existing feelings of impotency, frustration, anger and anxiety, which in turn had negative impacts on their eating and drinking. These findings were consistent with those reported in empirical studies and three substantive systematic reviews in the stroke literature including a systematic review investigating patients' self-efficacy after stroke by authors from the Netherlands – Korpershoek et al. (2011) and a qualitative phenomenological study analysing ten patients autobiographical accounts of eating difficulties caused by dysphagia following stroke by Moloney and Walshe (2018). ICs also experienced anxiety about their relatives' nutritional intake. Exploring the experiences of five stroke survivors and three informal carers a smaller UK interview study by Eltringham et al. (2019) also found ICs had multiple anxieties about their relatives' nutrition and safety during the hospital rehabilitation period. These findings were corroborated in two systematic reviews with combined Australian and Swedish authorship by Luker et al. (2015; 2017) investigating first stroke patients (incorporating analysis of 31 qualitative studies) then carers experiences (incorporating analysis of 33 qualitative studies) during stroke rehabilitation. Further support for these findings was found in another systematic review of 21 mixed methods papers from the UK by Edwards et al. (2017) investigating patients', families' and healthcare professionals' perspectives of assistance at mealtimes in hospital and rehabilitation settings.

9.2.3. Wider organisational influences impact support with eating and drinking

In both Sites A and B, though more so at Site B, members of the wider MDT perceived that direct support with eating and drinking was affected by chronic understaffing of RNs and HCAs. The National Clinical Guideline for Stroke (ISWP, 2016) make recommendations for MDT staffing. These include ratios of qualified and unqualified nurses for hyper-acute and acute stroke care. The NSNF (2016) recommends that the nursing establishment should be the same for the stroke rehabilitation setting as for acute stroke settings. Overall numbers

of qualified and unqualified nurses did not meet these recommendations. In addition, the recommended ratios of qualified to unqualified staff were not met in any of the cases investigated for this study. Where possible agency staff with little or no stroke experience were employed to fill the gaps. The organisations reportedly had difficulty recruiting and retaining RNs. This is recognised as a concern by the UK government who commissioned a report from The Health Foundation's REAL Centre. This is a UK organisation providing independent analysis and research to support long term decision making in health and social care. The report was authored by Buchan et al. (2020) and found the UK ranks below other comparable high income countries including Australia, Germany and the USA for both the actual number of practicing nurses and the annual number of new nurse graduates relative to the countries' populations. A discussion paper by Lightbody (2017) chair of the NSNF, focused specifically on creating a sustainable nursing workforce in stroke care. They reported that recruitment issues were further compounded by increased difficulties of attracting and retaining nurses into the stroke specialty, due to lack of funding for training and education, staff shortages and increased workload demands. At both Sites A and B, the impact of insufficient numbers of adequately trained RNs and HCAs was that all MDT members, patients and ICs perceived those nurses were too busy and this affected the identification, communication of, and delivery of support with eating and drinking leading to what has been termed 'missed episode of care'. These are ongoing issues identified in previous stroke specific research literature including the previously introduced studies by Loft (2017a, b), Luker (2015; 2017). A systematic review of 18 research papers by UK authors Griffith et al. (2017) used both qualitative and quantitative analysis tools to investigate missed episodes of nursing care in acute adult hospital wards. The included studies used subjective nursing reports rather than objective measures of missed care and staffing levels, leading the review authors to surmise that low RN staffing levels appeared to be associated to missed episodes of care, though further objective measures were required in future research.

An additional factor at the organisational level at both Sites A and B identified by MDT members, patients and ICs, was the lack of provision of food and drink

of adequate nutritional quality, which appealed to patients. Modified meals for those on staged diets were of particular concern and recognised to affect the patients' compliance with eating them and quality of life. The provision of nutritionally inadequate and unpalatable modified diets and the effect on patients' quality of life were corroborated by the Irish author O'Keeffe (2018) in their discussion paper about the prescription of modified diets in patients with dysphagia. In the current study, at both Sites A and B, it was acknowledged that catering budgets were affected by funding and financial constraints within NHS budgets, but improvement was required. These concerns were mirrored in a recent review of hospital food (Department of Health and Social Care, 2020). Whilst some of the issues with the appearance of meals could be improved at local ward level, the purchasing and preparation of food by hospital-catering departments was not under the control of the MDT at local level. The impact of this was that patients often did not attempt to eat or complete the meals supplied and did not meet their nutritional requirements.

9.2.4. Knowledge and skills to support eating and drinking with stroke was not prioritised across the MDT

At both Sites A and B, there was a lack of provision of consistent standardised education and training for nutrition and nutritional support in stroke care across the MDT despite National clinical guidelines recommendations (ISWP, 2016). This finding was corroborated by Perry et al. (2012) in their extensive literature review carried out by a combined Australian and UK based author team investigating nursing interventions for improving the nutritional status and outcomes for stroke patients. Further support for these findings was identified in a discussion paper from the USA by DiMaria-Ghalili et al. (2014) and the Australian paper by Palmer et al. (2015) suggesting that concerns with nurse education for nutrition are recognised internationally and not only in the UK. NHS England (2019) highlight that except for dietitians and SLT, reliance on healthcare professionals receiving adequate nutrition education and training during preregistration programmes was ill founded. Gaps were identified in some standard curricula including medical training. In the current study,

although the most senior nurses - WMs and SRs, acknowledged that supporting stroke patients with eating and drinking was a specialised skill, the lack of ongoing stroke specific training programmes for nutritional support suggests that this was not a priority. The implications for stroke patients are that support requirements are not recognised and met. This may compromise their rehabilitation outcomes and increase the risk of morbidity and mortality rates as identified by Mosselman et al. (2013) and reported in chapter 2.

9.2.5. Policy Implications

Health policy for the management of stroke illness continues to evolve in the UK as highlighted in chapter 1. The implications of the most recent policies on the findings of this study will be explored here. It was identified in this study that in-hospital stroke patients were frequently not receiving optimal or even adequate support to eat and drink and improve or maintain their nutritional wellbeing. It was recognised that understaffing across the MDT but predominantly in the nursing teams was a major factor. Published in 2019 the NHS Long Term Plan acknowledges a general shortage of NHS staff across the health professions and discusses how this will be addressed (NHS England, 2019). The plan establishes stroke as a national priority, with one of the projected milestones being stroke workforce modernisation. However, this workforce modernisation pertains to the training of medical staff for thrombectomy. No other professions that make up the stroke MDT including nurses, are mentioned in the modernisation of the workload milestones (NHS England, 2019). This implies that within the NHS plan, stroke is not recognised as a speciality for other professions including nurses, and there is no specific milestone or plan for recruiting specialist staff other than medical staff to stroke care. Understaffing in the NHS is of continued concern, with a 100,000 shortfall in 2018 which is predominantly nurses, and predicted to rise to 250,000 by 2030, but could potentially reach 350,000 by that time (NHS Improvement, 2018; The Health Foundation et al. 2018). The NHS Plan proposes several workforce actions to improve this situation working with Health Education England and NHS Improvement with Local Workforce Actions Boards accountable health service

employers (NHS England, 2019). At local level, participants in this study highlighted difficulties in recruiting RNs to the stroke specialty and in the short term, these difficulties are likely to increase.

The National Stroke Programme was launched in 2019 and jointly developed by NHS England and the Stroke Association, purported to build on the National Stroke Strategy which completed its 10-year premise in 2017 (DH, 2007a; Stroke Association, [no date]). The programme promotes the use of Integrated Stroke Delivery Networks (ISDNs) which guide local level Integrated Care Systems (ICSs) (partnerships between the organisations that meet health and care needs across an area) and sustainability and transformation partnerships (STPs) (health and social care systems working together to meet patients' needs). An ISDN, the National Stroke Service Model was published in 2021 and aims to "improve the quality of stroke care for better clinical outcomes, patient experience and patient safety" (NHS England and NHS Improvement, 2021, p.6). The ISDN has 10 stroke pathway specifications, number 6. Rehabilitation is relevant to the findings of this study. Pertaining to points made in the previous paragraph, nursing is not identified as a requirement for in-patients' rehabilitation services though therapy roles are (NHS England and NHS Improvement, 2021). This suggests that the nurses' role in stroke rehabilitation is not recognised or prioritised, despite being the only professional group in direct contact with the patients over the 24-hour period.

Another of this study's findings was that a lack of an assessment of patients eating and drinking abilities was identified as a factor in patients support needs remaining unmet. A requirement for individualised assessment and treatments plans was introduced to health commissioners in 2017 via the RightCare pathway for stroke (NHS England, 2017). The National Stroke Service Model published in 2021 adopted them. One of the service outcomes identified in the National Stroke Service Model specification for rehabilitation, is that patients should have a rapid initial multidisciplinary assessment, in order to develop a personalised rehabilitation plan and patients should receive patient - centred care (NHS England and NHS Improvement, 2021, p.25). If fully met, this

outcome should also incorporate assessment of eating and drinking abilities, going some way to identify the patients support requirements.

Relevant to this study, is that the NHS Plan proposes that robust audit of stroke delivery services already exists, referring to SSNAP (ISWP, 2019; NHS England, 2019). However, as previously discussed, such audit can have a negative effect on MDT working and patient care (Taylor et al., 2018). SSNAP measure 44 key indicators drawn from the recommendations of the National Clinical Guideline for Stroke (ISWP, 2016). Several recommendations are identified which should influence how patients are supported to eat and drink – see chapter 4. However, the only key indicator audited by SSNAP directly pertaining to patients' nutrition is “applicable patients screened for nutrition and seen by a dietitian by discharge” (ISWP, 2021). Similarly audits such as those compiled by the Patient Safety Measurement Unit subsuming the NHS Safety thermometer gather data on the incidence of preventable harms though not undernutrition (NHS Improvement, 2021). No specific audit exists for the assessment of eating and drinking activities. One of the main findings of this study being that other audited activities are prioritised over activities that support eating and drinking. Requirements for improving nutritional care continue to be identified during CQC hospital inspections (CQC, 2020). These themes run throughout policy guidance over the past 20 years suggesting limited influence on the behaviour of frontline staff responsible for this patient group care (BAPEN, 2015). It is reported that more than forty percent of hospital patients do not receive any form of nutritional support when screened and identified as at risk of malnutrition (Brotherton et al., 2017; BAPEN, 2018).

9.3. Recommendations

The following recommendations are made in response to the study findings. Identification of patients eating and drinking support requirements would benefit from evidence-based, specific multi-professional guidance and recommendations for the initial and ongoing identification of patients' support

needs with eating and drinking. Such guidance incorporating a recommended assessment tool should be included in future National Clinical Guideline for Stroke (ISWP, 2016). Going forward such guidance and recommendations should form part of the individual multi-disciplinary person-centred treatment plans espoused by Taylor et al. (2018) and included the National Stroke Service Model (NHS England and NHS Improvement, 2021). The development of multidisciplinary hospital nutritional support teams has been positively reported in improving patient experience at mealtimes and nutritional wellbeing (Delegge et al., 2013; Young et al., 2013). The extra MDT staff resource at mealtimes would help alleviate issues with the identification of support requirements and timeliness of support with eating and drinking, precipitated by insufficient nursing staff to meet patient dependency with this activity. Partnership with patients and ICs is required in the development of person-centred treatment plans (NHS England and NHS Improvement, 2021). This should encourage communication between the MDT, patients and ICs, identified as a contributing factor to patients not receiving optimal support with eating and drinking.

Once included in the National Clinical Guideline for Stroke (ISWP, 2016), the completion of eating and drinking assessment tools, and tools used to monitor malnutrition such as MUST should be audited ideally in the Sentinel Stroke National Audit Program (SSNAP) as part of the key indicators of a quality stroke service. Despite some of the negative influences identified with the auditing of clinical practises, it is clear from the literature that audited practises are prioritised and auditing of practice is projected to continue (NHS England, 2019; NHS Improvement, 2021).

The NHS plan suggests that employers offering NHS staff continuing professional development (CPD) and education is key to staff retention (NHS England, 2019). Mandatory education and training for all members of the MDT for patient nutrition and eating and drinking support with periodic updates is required to increase prioritisation of this work amongst the MDT. This should include education about: specific nutritional requirements of stroke patients, malnutrition screening tools, assessment and identification of eating difficulties

using appropriate tools, development of communication and physical skills to support eating and drinking, psychological issues impacting eating and drinking after stroke including delivery and appearance of food, the importance of monitoring food and fluid intake using appropriate tools, the processes of food provision in local care settings and how to communicate with relevant partners such as catering departments.

National education and training programmes are available that could be employed to deliver some of the educational requirements discussed previously. These include the Stroke-Specific Education Framework (SSEF) and the Stroke Training and Awareness Resources (STARS) (UK Stroke Forum, [no date]; Chest Heart and Stroke Scotland, 2021). The STARS are identified in the SSEF and offers training for essential core competencies in stroke care and more advanced modules including nutrition and assistance with eating and drinking following stroke. The course is online and accessible to all staff working with stroke patients. Patient case studies are used to work through some of the more common issues encountered with nutrition, eating and drinking following stroke. The provision of further online education and training would enable easier access and flexibility for learners and employers in managing study time.

It is recognised that in hospital settings where nutritional care and support has improved this required support from chief executive through to leadership at a local stroke unit level. Further, more collaborative working between those members of the MDT with specialist knowledge of nutrition and the requirement of stroke patients and catering services is required to improve the quality of provision for stroke patients (Department of Health and Social Care, 2020). A particular area that requires more research and technological innovation is textured modified diets to improve acceptability to patients (O'Keeffe, 2018). It is proposed that increasing the quality of mealtime experiences and implementing individualised nutrition plans relies on ward manager leadership and the dynamic and cohesive nature of the wider multidisciplinary team (Naughton et al., 2021). Critical reflection on normative ward routines including mealtimes

and challenging mediocre practice and attitudes is required (Papier et al., 2017). It is recommended that observation of practice rather than audits of documentation provide a more accurate indicator of ward practice. Ward managers in collaboration with the wider MDT need the capability and skills to undertake small-scale observational studies and lead quality improvement initiatives to improve fundamental care, including nutrition (O'Keeffe, 2018).

9.4 Strengths and limitations of the study

9.4.1 Strengths

A strength of this study is the unique in-depth exploration of how stroke patients were supported to eat and drink in two stroke units. No other study appears to have specifically focused on the phenomena of support with eating and drinking during the stroke patients' hospital experience from the perspective of the patients, their informal carers and the MDT tasked with ensuring sufficient support was delivered. The findings of the study make a distinct and important contribution to the knowledge of how multiple factors and mechanisms interact in order to support stroke patients to eat and drink or not. This resulted from employing a qualitative case study approach (Simons, 2009). A strength of the study methods was that the two cases providing acute and rehabilitation stroke services and providing different quality of service were selected utilising the SSNAP data (Royal College of Physicians Sentinel Stroke National Audit Programme, 2017). This enabled cross case analysis, increasing the robustness of the findings and allowing for greater transferability of findings (Seawright and Gerring, 2008). A strength of this approach is the detailed reporting of each stage of the study enhancing transparency of the steps followed and the development of the study findings. In particular, the employment of both general and focused observations allowed the researcher to directly observe the activities and interactions identified as creating the phenomena of support with eating and drinking from the multiple perspectives of the patients, their informal carers and the MDT within the specific context of acute and rehabilitation stroke units. Observations combined with individual

semi-structured interviews gave the researcher unique access to explore the different aspect of the phenomena. This enabled exploration of contested viewpoints from the participants and those activities and interactions identified during the observations which conflicted with participants accounts during interviews and from documentary data. Supported by Simons (2009), detailed direct quotations taken directly from participant interviews and incorporated into the study findings adds strength to the participant voice and allows the reader access to the personal experience described by the participants and supports transparency of the study findings.

A further strength of this study is that the researcher has had continued engagement with one of the study sites and presented the study findings to the MDT in that stroke unit. The study findings have also been presented to nursing staff from a stroke unit local to the researcher's base, and to multiple stroke professionals at a National Stroke Nurses Forum webinar. Currency of the study findings was authenticated as participants at these events recognised all or some various aspects of the study findings in their current in hospital stroke care practise.

9.4.2 Limitations

A limitation of this study is that it was a single researcher study with associated temporal limitations further impinged by the Covid 19 pandemic as highlighted in chapter 1. Regarding the single researcher and study design, the number of cases included in the collective case study approach was limited to two cases, potentially impinging on the dependability and transferability of the study findings (Guba and Lincoln, 1994). In response to this concern, Stake (2009) suggests that two cases can be sufficient for the in-depth exploration of a phenomenon enabled by the collective case study approach. This view is supported by Simons (2009) when taking into consideration the accumulation of mass data generated from this approach.

Constraints on sample size for patient, IC and MDT member participants can be viewed as a limitation of this study. A larger sample could have provided a wider range of responses and thereby enhanced the dependability and transferability of the study findings (Gobo and Molle, 2017). A further limitation was the variation in the MDT participant samples for Site A and Site B. The researcher was unable to recruit a consultant level doctor at Site A, whereas as two consultants were recruited to the study at Site B. Ward assistants and housekeepers were recruited at Site B, however these roles did not exist at site A. The nature of the composition of multidisciplinary teams also influenced the numbers of participants from smaller professional groups such as SLTs and dietitians, though the numbers of both professions include in the samples were comparable between the two sites. With consideration to limitations of sample size and variation between Site A and Site B, the researcher identified points at both sites when they thought a level of data saturation was achieved for the three participant groups.

Data collection and analysis was completed by the single researcher which according to Simons (2009) raises concerns about personal involvement with the participants and researcher subjectivity or bias potentially affecting the validity of the findings. Conversely, it is proposed that researcher subjectivity is inevitable in qualitative case studies and should be used to develop in-depth understanding of cases investigated. The researcher counteracted the concerns of bias and subjectivity following Simons' (2009) guidance by employing reflexive practices and ensuring that each stage of the study process is clearly reported and transparent. These practices enable consumers of the research to make their own judgement on the authenticity of the study findings.

9.5. Conclusion

The systematic literature searches revealed evidence suggesting that stroke patients were not adequately supported with eating and drinking. In addition, limited evidence directly addressed how stroke patients are or should be

supported with eating and drinking in stroke units was identified. The employment of the case study designed with reference to supporting literature Flyvbjerg (2006), Simons (2009), Yin (2009) enabled in-depth exploration of the practice of supporting eating and drinking within the bounded system of stroke units(cases) and was thought to be the best method to investigate this phenomenon. The findings of this case study identify that stroke patients do not receive optimal and at times adequate support to eat and drink following stroke in the hospital setting. This is likely to negatively impact their general and nutritional wellbeing and slow recovery and rehabilitation following stroke. Much of the supporting literature especially around the identification of eating difficulties is approaching fifteen years old (Westergren, 2006). Further multidisciplinary research into the identification and management of eating and drinking difficulties following stroke in the hospital setting is required.

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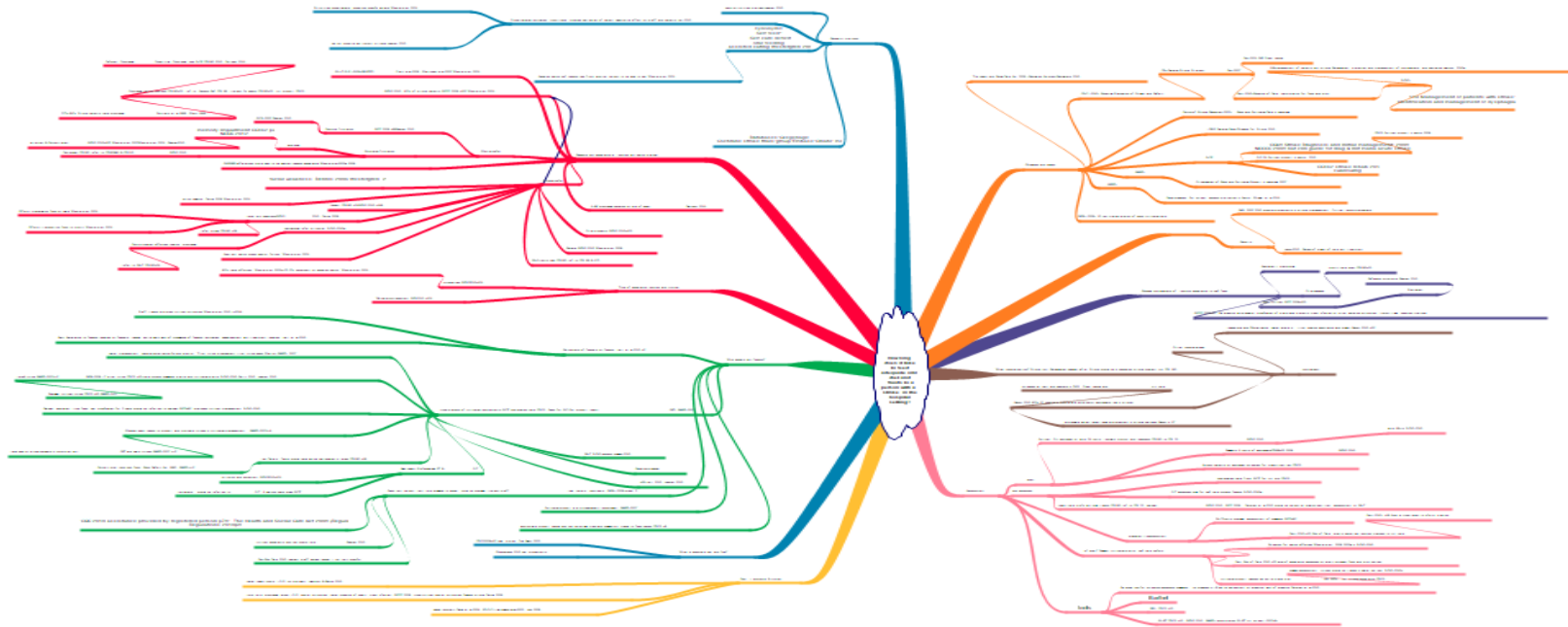
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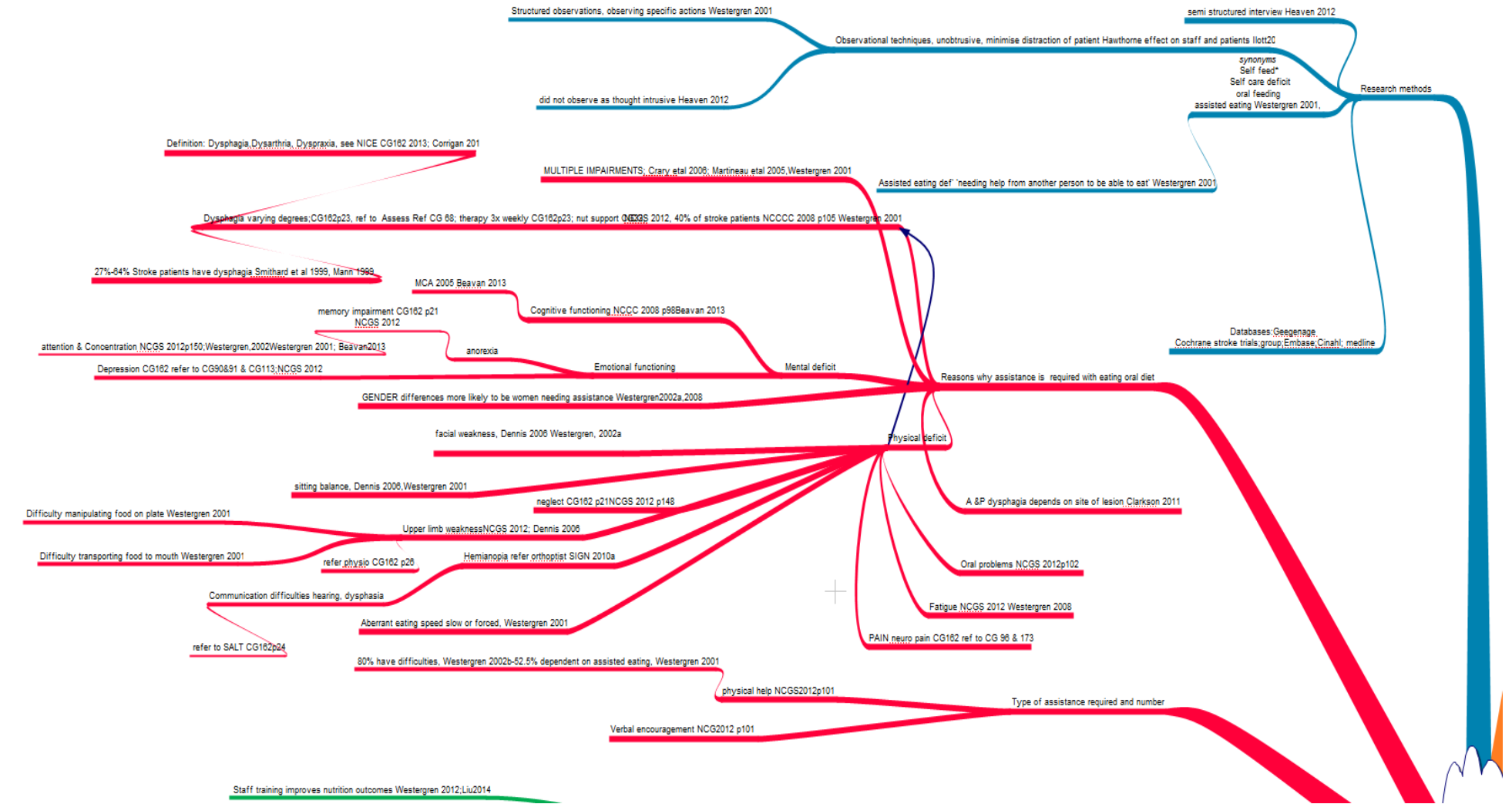
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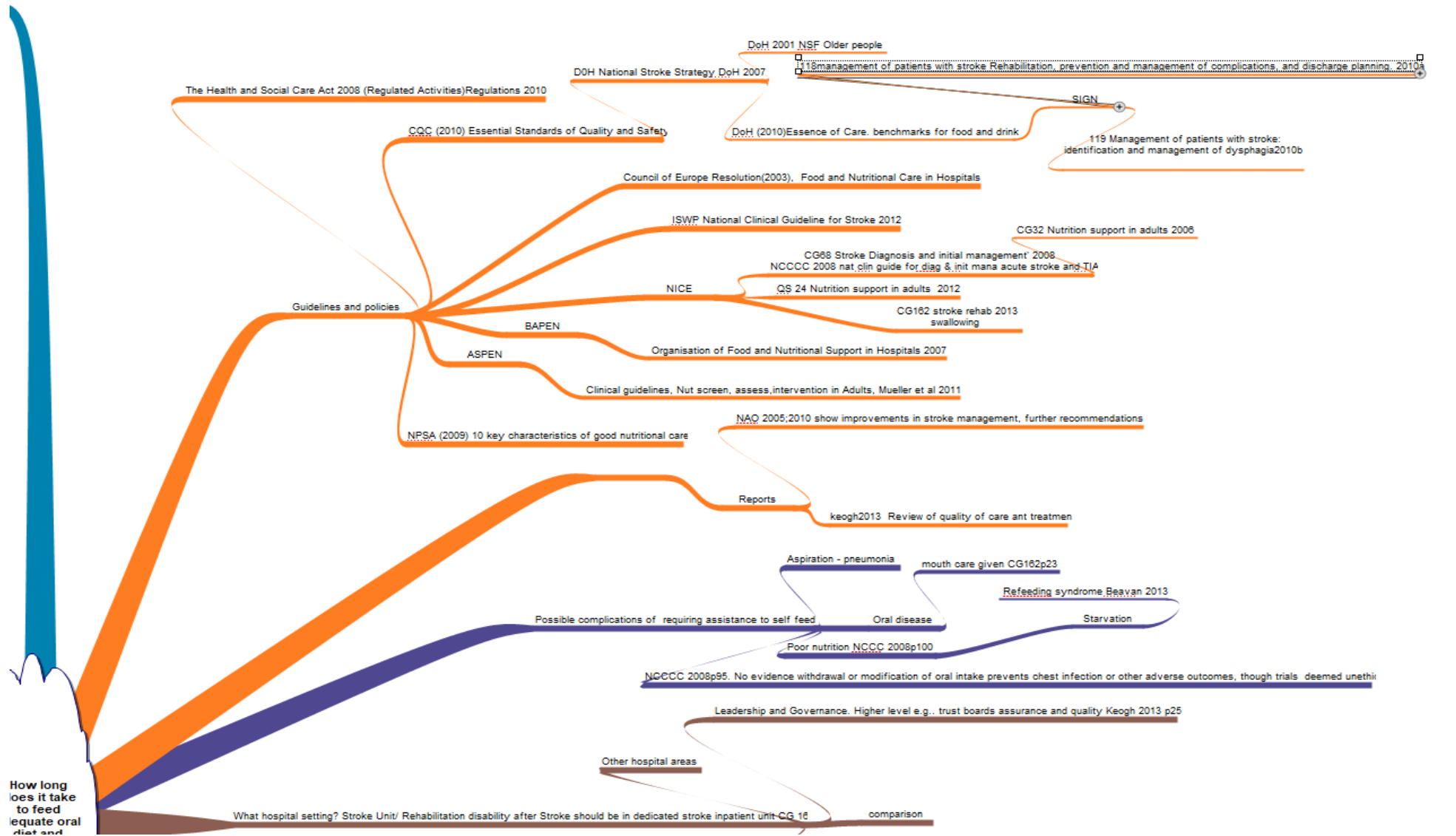
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Appendix A: Mind Map Eating and Drinking with Stroke: overview and quarter views

Mind Map 1: commenced Nov' 13 - Ideas from initial search for evidence Stroke Eating
Drinking full view of mind map diagram











Appendix B: Example search strategy

Example of Search strategy for included databases 2014 and 2019 searches.

2014 Searches

Stroke terms and MeSH descriptors used by Cochrane Stroke group and incorporated into other database searches.

Search Name: S Batt Eating and Stroke and support 10.6.14 using MeSH

Last Saved: 23/06/2014 10:35:23.170

Description:

ID	Search
#1	MeSH descriptor: [Cerebrovascular Disorders] this term only
#2	MeSH descriptor: [Basal Ganglia Cerebrovascular Disease] explode all trees
#3	MeSH descriptor: [Brain Ischemia] explode all trees
#4	MeSH descriptor: [Carotid Artery Diseases] explode all trees
#5	MeSH descriptor: [Stroke] this term only
#6	MeSH descriptor: [Brain Infarction] explode all trees
#7	MeSH descriptor: [Cerebrovascular Trauma] explode all trees
#8	MeSH descriptor: [Hypoxia-Ischemia, Brain] explode all trees
#9	MeSH descriptor: [Intracranial Arterial Diseases] explode all trees
#10	MeSH descriptor: [Intracranial Arteriovenous Malformations] this term only
#11	MeSH descriptor: [Intracranial Embolism and Thrombosis] explode all trees
#12	MeSH descriptor: [Intracranial Hemorrhages] explode all trees
#13	MeSH descriptor: [Brain Injuries] explode all trees
#14	MeSH descriptor: [Vasospasm, Intracranial] this term only
#15	MeSH descriptor: [Vertebral Artery Dissection] this term only
#16	MeSH descriptor: [Aneurysm, Ruptured] this term only
#17	MeSH descriptor: [Brain Injury, Chronic] this term only
#18	MeSH descriptor: [Carotid Arteries] explode all trees
#19	MeSH descriptor: [Endarterectomy, Carotid] this term only
#20	MeSH descriptor: [Endarterectomy] this term only
#21	MeSH descriptor: [Heart Septal Defects, Atrial] this term only
#22	MeSH descriptor: [Atrial Fibrillation] this term only
#23	((brain* or cerebr* or cerebell* or cortical or vertebrobasilar or hemispher* or intracran* or intracerebral or infratentorial or supratentorial or MCA or "anterior circulation" or "posterior

circulation" or "basal ganglia") and (ischemi* or ischaemi* or infarct* or thrombo* or emboli* or occlus* or hypox* or vasospasm or obstruction or vasculopathy)):ti,ab,kw

#24 ("lacunar infarct*" or "cortical infarct*"):ti,ab,kw

#25 (brain* or cerebr* or cerebell* or intracerebral or intracran* or parenchymal or intraventricular or infratentorial or supratentorial or "basal gangli*" or subarachnoid or putaminal or putamen or "posterior fossa") and (haemorrhage* or hemorrhage* or haematoma* or hematoma* or bleed*):ti,ab,kw

#26 ("vertebral artery dissection" or "cerebral art* disease*"):ti,ab,kw

#27 ((brain or intracranial or "basal ganglia" or lenticulostriate) and (vascular) and (disease* or disorder or accident or injur* or trauma* or insult or event)):ti,ab,kw

#28 ((ischemic or ischaemic or apoplectic) and (event or events or insult or attack*)):ti,ab,kw

#29 (("cerebral vein" or "cerebral venous" or sinus or sagittal) and (thrombo*)):ti,ab,kw

#30 (CVDST or CVT):ti,ab,kw

#31 ((intracranial or "cerebral art*" or "basilar art*" or "vertebral art*" or vertebrobasilar or "vertebral basilar") and (stenosis or ischemia or ischaemia or insufficiency or arteriosclero* or atherosclero* or occlus*)):ti,ab,kw

#32 ((brain or cerebral) and (angioma* or hemangioma* or haemangioma*)):ti,ab,kw

#33 (carotid*):ti,ab,kw

#34 ("patent foramen ovale" or PFO):ti,ab,kw

#35 ((atrial or atrium or auricular) and fibrillation) .ti,ab,kw

#36 ("asymptomatic cervical bruit") .ti,ab,kw

#37 (aphasi* or apraxi* or dysphasi* or dysphagi* or "deglutition disorder*" or "swallow* disorder*" or dysarthri* or hemipleg* or hemipar* or paresis or paretic or hemianop* or hemineglect or spasticity or anomi* or dysnomi* or "acquired brain injur*" or hemiball*) .ti,ab,kw

#38 ((unilateral or visual or hemispacial or attentional or spatial) and neglect) .ti,ab,kw

#39 ((brain or cerebral or intracranial or communicating or giant or basilar or "vertebral artery" or berry or saccular or ruptured) and aneurysm*) .ti,ab,kw

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Description:

ID	Search
#1	MeSH descriptor: [Cerebrovascular Disorders] this term only
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#3	MeSH descriptor: [Brain Ischemia] explode all trees
#4	MeSH descriptor: [Carotid Artery Diseases] explode all trees
#5	MeSH descriptor: [Stroke] this term only
#6	MeSH descriptor: [Brain Infarction] explode all trees
#7	MeSH descriptor: [Cerebrovascular Trauma] explode all trees
#8	MeSH descriptor: [Hypoxia-Ischemia, Brain] explode all trees
#9	MeSH descriptor: [Intracranial Arterial Diseases] explode all trees
#10	MeSH descriptor: [Intracranial Arteriovenous Malformations] this term only
#11	MeSH descriptor: [Intracranial Embolism and Thrombosis] explode all trees
#12	MeSH descriptor: [Intracranial Hemorrhages] explode all trees
#13	MeSH descriptor: [Brain Injuries] explode all trees

- #14 MeSH descriptor: [Vasospasm, Intracranial] this term only
- #15 MeSH descriptor: [Vertebral Artery Dissection] this term only
- #16 MeSH descriptor: [Aneurysm, Ruptured] this term only
- #17 MeSH descriptor: [Brain Injury, Chronic] this term only
- #18 MeSH descriptor: [Carotid Arteries] explode all trees
- #19 MeSH descriptor: [Endarterectomy, Carotid] this term only
- #20 MeSH descriptor: [Endarterectomy] this term only
- #21 MeSH descriptor: [Heart Septal Defects, Atrial] this term only
- #22 MeSH descriptor: [Atrial Fibrillation] this term only
- #23 ((brain* or cerebr* or cerebell* or cortical or vertebrobasilar or hemispher* or intracran* or intracerebral or infratentorial or supratentorial or MCA or "anterior circulation" or "posterior circulation" or "basal ganglia") and (ischemi* or ischaemi* or infarct* or thrombo* or emboli* or occlus* or hypox* or vasospasm or obstruction or vasculopathy)):ti,ab,kw
- #24 ("lacunar infarct*" or "cortical infarct*"):ti,ab,kw
- #25 (brain* or cerebr* or cerebell* or intracerebral or intracran* or parenchymal or intraventricular or infratentorial or supratentorial or "basal gangli*" or subarachnoid or putaminal or putamen or "posterior fossa") and (haemorrhage* or hemorrhage* or haematoma* or hematoma* or bleed*):ti,ab,kw
- #26 ("vertebral artery dissection" or "cerebral art* disease*"):ti,ab,kw
- #27 ((brain or intracranial or "basal ganglia" or lenticulostriate) and (vascular) and (disease* or disorder or accident or injur* or trauma* or insult or event)):ti,ab,kw
- #28 ((ischemic or ischaemic or apoplectic) and (event or events or insult or attack*)):ti,ab,kw
- #29 (("cerebral vein" or "cerebral venous" or sinus or sagittal) and (thrombo*)):ti,ab,kw
- #30 (CVDST or CVT):ti,ab,kw
- #31 ((intracranial or "cerebral art*" or "basilar art*" or "vertebral art*" or vertebrobasilar or "vertebral basilar") and (stenosis or ischemia or ischaemia or insufficiency or arteriosclero* or atherosclero* or occlus*)):ti,ab,kw
- #32 ((brain or cerebral) and (angioma* or hemangioma* or haemangioma*)):ti,ab,kw
- #33 (carotid*):ti,ab,kw
- #34 ("patent foramen ovale" or PFO):ti,ab,kw
- #35 ((atrial or atrium or auricular) and fibrillation) .ti,ab,kw
- #36 ("asymptomatic cervical bruit") .ti,ab,kw
- #37 (aphasi* or apraxi* or dysphasi* or dysphagi* or "deglutition disorder*" or "swallow* disorder*" or dysarthri* or hemipleg* or hemipar* or paresis or paretic or hemianop* or hemineglect or spasticity or anomi* or dysnomi* or "acquired brain injur*" or hemiball*) .ti,ab,kw
- #38 ((unilateral or visual or hemispacial or attentional or spatial) and neglect) .ti,ab,kw
- #39 ((brain or cerebral or intracranial or communicating or giant or basilar or "vertebral artery" or berry or saccular or ruptured) and aneurysm*) .ti,ab,kw
- #40 MeSH descriptor: [Aphasia] explode all trees
- #41 MeSH descriptor: [Hemianopsia] explode all trees
- #42 MeSH descriptor: [Paresis] explode all trees
- #43 MeSH descriptor: [Deglutition Disorders] this term only
- #44 MeSH descriptor: [Anomia] this term only
- #45 MeSH descriptor: [Hemiplegia] this term only
- #46 MeSH descriptor: [Dysarthria] this term only
- #47 MeSH descriptor: [Pseudobulbar Palsy] explode all trees
- #48 MeSH descriptor: [Muscle Spasticity] this term only
- #49 (stroke or poststroke or post next stroke or cerebrovasc* or "brain vas*" or "cerebral vas*" or cva* or apoplex* or "ischemi* attack*" or "ischaemi* attack*" or tia* or "neurologic deficit*" or SAH or AVM) .ti,ab,kw
- #50 {or #1-#49}
- #51 (SR-STROKE)
- #52 #50 not #51
- #53 MeSH descriptor: [Eating] this term only
- #54 MeSH descriptor: [Drinking] this term only
- #55 MeSH descriptor: [Mastication] this term only
- #56 (oral near/2 intak*) .ti,ab,kw
- #57 (intake near/5 (food or drink* or fluid* or nutrition* or dietary)) .ti,ab,kw
- #58 ((eat* or feed*) near/2 (difficult* or complicat* or problem* or experience*)) .ti,ab,kw
- #59 MeSH descriptor: [Feeding Behavior] this term only
- #60 MeSH descriptor: [Eating Disorders] this term only
- #61 MeSH descriptor: [Malnutrition] explode all trees

- #62 (chew*) .ti,ab.kw
- #63 (swallow*) .ti,ab.kw
- #64 (ingest*) .ti,ab.kw
- #65 MeSH descriptor: [Deglutition Disorders] this term only
- #66 (meal*) .ti,ab.kw
- #67 {or #53-#66}
- #68 (help*) .ti,ab.kw
- #69 (support*) .ti,ab.kw
- #70 (assist*) .ti,ab.kw
- #71 (aid*) .ti,ab.kw
- #72 (encourag*) .ti,ab.kw
- #73 (intervention*) .ti,ab.kw
- #74 MeSH descriptor: [Nutrition Assessment] this term only
- #75 MeSH descriptor: [Rehabilitation] this term only
- #76 MeSH descriptor: [Stroke] explode all trees and with qualifier(s): [Diet therapy - DH]
- #77 MeSH descriptor: [Social Support] this term only
- #78 {or #68-#77}
- #79 #52 and #67 and #78 Publication Year from 1990 to 2014

2019 Search

When running the original search string from 2014, although there was term assist*.tw. in the third section of the search lines or /58-67 [support terms] on further testing it was found that it was not identifying up some of the feeding assistance results. Therefore, the information specialist advised adding it in at line 47 - assist*.tw. was added into the search string ((eat* or feed*) adj2 (difficult* or complicat* or problem* or experience*).tw. This resulted in extra relevant results - see the search string below.

Database: Ovid MEDLINE(R) and Epub Ahead of Print, In-Process and Other Non-Indexed Citations and Daily <1946 to September 05, 2019>

Search Strategy:

-
- 1 cerebrovascular disorders/ (45913)
 - 2 exp basal ganglia cerebrovascular disease/ (529)
 - 3 exp brain ischemia/ (103286)
 - 4 exp carotid artery diseases/ (46062)
 - 5 stroke/ (93515)
 - 6 exp brain infarction/ (35656)
 - 7 exp cerebrovascular trauma/ (6982)
 - 8 hypoxia-ischemia, brain/ (5325)
 - 9 exp intracranial arterial diseases/ (60320)
 - 10 exp intracranial arteriovenous malformations/ (8451)
 - 11 exp "Intracranial Embolism and Thrombosis"/ (20754)
 - 12 exp intracranial hemorrhages/ (68433)
 - 13 vasospasm, intracranial/ (3061)
 - 14 vertebral artery dissection/ (1242)
 - 15 aneurysm, ruptured/ and exp brain/ (584)

- 16 brain injuries/ (51251)
- 17 brain injury, chronic/ (734)
- 18 exp carotid arteries/ (57446)
- 19 endarterectomy, carotid/ (8472)
- 20 *heart septal defects, atrial/ or foramen ovale, patent/ (11279)
- 21 *atrial fibrillation/ (41822)
- 22 (stroke or poststroke or post-stroke or cerebrovasc\$ or brain vascul\$ or cerebral vascul\$ or cva\$ or apoplex\$ or isch?emi\$ attack\$ or tia\$1 or neurologic\$ deficit\$ or SAH or AVM).tw. (319686)
- 23 ((brain\$ or cerebr\$ or cerebell\$ or cortical or vertebrobasilar or hemispher\$ or intracran\$ or intracerebral or infratentorial or supratentorial or MCA or anterior circulation or posterior circulation or basal ganglia) adj5 (isch?emi\$ or infarct\$ or thrombo\$ or emboli\$ or occlus\$ or hypox\$ or vasospasm or obstruction or vasculopathy)).tw. (117960)
- 24 ((lacunar or cortical) adj5 infarct\$).tw. (4774)
- 25 ((brain\$ or cerebr\$ or cerebell\$ or intracerebral or intracran\$ or parenchymal or intraventricular or infratentorial or supratentorial or basal gangli\$ or subarachnoid or putaminal or putamen or posterior fossa) adj5 (haemorrhage\$ or hemorrhage\$ or haematoma\$ or hematoma\$ or bleed\$)).tw. (70146)
- 26 ((brain or cerebral or intracranial or communicating or giant or basilar or vertebral artery or berry or saccular or ruptured) adj5 aneurysm\$).tw. (34901)
- 27 (vertebral artery dissection or cerebral art\$ disease\$).tw. (997)
- 28 ((brain or intracranial or basal ganglia or lenticulostriate) adj5 (vascular adj5 (disease\$ or disorder or accident or injur\$ or trauma\$ or insult or event))).tw. (1405)
- 29 ((isch?emic or apoplectic) adj5 (event or events or insult or attack\$)).tw. (28496)
- 30 ((cerebral vein or cerebral venous or sinus or sagittal) adj5 thrombo\$).tw. (6450)
- 31 (CVDST or CVT).tw. (1411)
- 32 ((intracranial or cerebral art\$ or basilar art\$ or vertebral art\$ or vertebrobasilar or vertebral basilar) adj5 (stenosis or isch?emia or insufficiency or arteriosclero\$ or atherosclero\$ or occlus\$)).tw. (23134)
- 33 ((venous or arteriovenous or brain vascul\$) adj5 malformation\$).tw. (15836)
- 34 ((brain or cerebral) adj5 (angioma\$ or hemangioma\$ or haemangioma\$)).tw. (938)
- 35 carotid\$.tw. (114564)
- 36 (patent foramen ovale or PFO).tw. (5496)
- 37 ((atrial or atrium or auricular) adj fibrillation).tw. (65145)
- 38 asymptomatic cervical bruit.tw. (12)
- 39 exp aphasia/ or anomia/ or hemiplegia/ or hemianopsia/ or exp paresis/ or deglutition disorders/ or dysarthria/ or pseudobulbar palsy/ or muscle spasticity/ (61717)
- 40 (aphasi\$ or apraxi\$ or dysphasi\$ or dysphagi\$ or deglutition disorder\$ or swallow\$ disorder\$ or dysarthri\$ or hemipleg\$ or hemipar\$ or paresis or paretic or hemianop\$ or hemineglect or spasticity or anomi\$ or dysnomi\$ or acquired brain injur\$ or hemiball\$).tw. (95788)

- 41 ((unilateral or visual or hemispatial or attentional or spatial) adj5 neglect).tw. (2790)
- 42 or/1-41 [Cochrane Library Stroke group stroke search strategy] (823179)
- 43 Eating/ (51207)
- 44 Drinking/ (13954)
- 45 (oral adj2 intak*).tw. (8195)
- 46 (intake adj5 (food or drink* or fluid* or nutrition* or dietary)).tw. (99294)
- 47 ((eat* or feed*) adj2 (difficult* or complicat* or problem* or experience* or assist*)).tw. (8168)
- 48 Feeding Behavior/ (78670)
- 49 Eating Disorders/ (14511)
- 50 Malnutrition/ (12530)
- 51 chew*.tw. (16370)
- 52 swallow*.tw. (28151)
- 53 Mastication/ (9628)
- 54 ingest*.tw. (97781)
- 55 Deglutition Disorders/ (19396)
- 56 meal*.tw. (68954)
- 57 or/43-56 [eating difficulty terms] (425418)
- 58 help*.tw. (751368)
- 59 support*.tw. (1444583)
- 60 assist*.tw. (372793)
- 61 aid*.tw. (337640)
- 62 encourag*.tw. (142199)
- 63 Social Support/ (67608)
- 64 Nutrition Assessment/ (14219)
- 65 Rehabilitation/ (17918)
- 66 intervention*.tw. (913731)
- 67 *Stroke/dh [Diet Therapy] (56)
- 68 or/58-67 [support terms] (3506650)
- 69 42 and 57 and 68 [stroke and eating difficulty and support terms] (5098)
- 70 limit 69 to (english language and yr="2015 -Current") (1560)
- 71 remove duplicates from 70 (1558)

Appendix C: Record of database searches

Record of database searches to 18.7.2014

Research question:	Does the support provided for patients with eating and drinking difficulties after stroke results in adequate nutrition?			
Places to search for information:	CINAHL; Cochrane reviews ; Cochrane trials; EMBASE and EMBASE classic; MEDLINE; PROQUEST (Dissertations and Theses, IBSS, Social Services Abstracts, ASSIA, Sociological abstracts; Psych Info; TRIP; Web of Science			
List of sources searched:	Date of search	Search strategy used, including any limits	Total number of results found	Comments
CINAHL	15/6/14	See appendix (ii)	2109	Limits were applied to dates 1990 forwards to date of search and to English language.
Cochrane reviews	23/6/14	See appendix (ii)	68	Limits were applied to dates 1990 forwards to date of search and to English language.
Cochrane trials	23/6/14	See appendix (ii)	3	Limits were applied to dates 1990 forwards to date of search and to English language.

EMBASE + Classic	17/7/14	See appendix (ii)	5584	Limits were applied to dates 1990 forwards to date of search and to English language.
MEDLINE	14/7/14	See appendix (ii)	2752	Limits were applied to dates 1990 forwards to date of search and to English language.
PsychInfo	18/7/14	See appendix(ii)	378	Limits were applied to dates 1990 forwards to date of search and to English language.
TRIP	23/6/14	See appendix(ii)	2065 Stroke and nutrition 133049 neurology Combined 216	Text of search: Search terms: Stroke and Nutrition and neurology. Search : Stroke and nutrition yielded 2065 results, ordered by quality; manually searched 3 retrieved for further analysis Search: Neurology yielded 133049 Combined search: #1 and #2 yielded 216 results Ordered by quality; manually searched 10 retrieved for further analysis and imported to Endnote. Limits were applied to dates 1990 forwards to date of search and to English language.
Web of Science	15/6/14	See appendix(ii)	230	Limits were applied to dates 1990 forwards to date of search and to English language.
ProQuest - dissertations and theses; IBSS; social services abstracts; ASSIA;	14/6/14	See appendix(ii)	144	Search terms used same for all ProQuest data bases on advice from IRS (DA) Limits were applied to dates 1990 forwards to date of search and to English language.

sociological abstracts				
TOTAL			11,118	

Record of database searches 1.1.14 to 9.9.19

Research question:	Does the support provided for patients with eating and drinking difficulties after stroke results in adequate nutrition?			
Places to search for information:	CINAHL; Cochrane reviews ; Cochrane trials; EMBASE and Embase classic; MEDLINE; PROQUEST (Social Services Abstracts, ASSIA, Sociological abstracts; Psych Info; Web of Science			
List of sources searched:	Date of search	Search strategy used, including any limits	Total number of results found	Comments
CINAHL	9/9/19	See appendix (ii)	603	Limits were applied to dates 1/1/14 forwards to date of search and to English language.

Cochrane reviews	9/9/19	See appendix (ii)	143	Limits were applied to dates 1/1/14 forwards to date of search and to English language.
Cochrane trials	9/9/19	See appendix (ii)	691	Limits were applied to dates 1/1/14 forwards to date of search and to English language.
EMBASE + Embase classic	4/9/19	See appendix (ii)	4013	Limits were applied to dates 1/1/14 forwards to date of search and to English language.
MEDLINE	5/9/19	See appendix (ii)	1712	Limits were applied to dates 1/1/14 forwards to date of search and to English language.
PsychInfo	August Week 4 2019	See appendix(ii)	180	Limits were applied to dates 1/1/14 forwards to date of search and to English language.
Web of Science	15/6/14	See appendix(ii)	230	Limits were applied to dates 1/1/14 forwards to date of search and to English language.
ProQuest - dissertations and theses; IBSS; social services abstracts; ASSIA; sociological abstracts	9/9/19	See appendix(ii)	1	Search terms used same for all ProQuest data bases on advice from IRS (DA) Limits were applied to dates 1/1/14 forwards to date of search and to English language.
TOTAL			7430	

Appendix D: Title and abstract screening tool

Title and abstract screening tool- for question: Does the support provided for patients with eating and drinking difficulties after stroke result in adequate nutrition?

Include publications that:		YES	NO
1	Does the publication report on research which is focused on support provided for hospitalised stroke patients with eating and drinking difficulties. Or Is the publication a systematic review of research focused on supporting hospitalised stroke patients with eating and drinking difficulties	continue	exclude
2	Published in English	continue	exclude
3	Was the study published after 1990	Include	exclude
Exclude publications that:			
	Refer to stroke patients post discharge from hospital		
	Refer to stroke patients fed via enteral or parenteral methods		

Definitions:

Eating difficulties: “any activity and emotional requirement and relations, which alone or in combination interfere with the process of preparing food, transferring food to mouth, chewing and swallowing”. Definition synthesised by Klinker et al 2013.

Support: To give physical and/ or verbal assistance with eating and drinking.

“The need for assisted eating is defined as needing help from another person to be able to eat”.

Definition from Westergren, 2001, p258.

Adequate nutrition: nutritional prescription for those not severely ill or injured: 25-35 kcal/kg/day total energy including derived from protein; 0.8-1.5g protein (0.13-0.24g nitrogen)/kg/day; 30-35 ml fluid/kg (make allowances for extra losses from drains, wounds and extra intake e.g., IV meds); adequate electrolytes, mineral, fibre if required dependent on previous demands (National Collaborating Centre for Acute Care, 2006); Serum Albumin in range 35-50g/l (Higgins, 2007).

Stroke: The damaging or killing of brain cells starved of oxygen as a result of the blood supply to part of the brain being cut off. Types of stroke include ischaemic stroke caused by blood clots to the brain, or haemorrhagic stroke caused by bleeding into the brain (ISWP, 2012, p xxii).

Appendix E: Eligibility proforma

Eligibility form

Does the support provided for patients with eating and drinking difficulties after stroke result in adequate nutrition?

Study ID number:

Name of reviewer:

Are the participants Adults (age 18y or over) with a stroke? No → Exclude

YES ↓

Are the participants in a hospital setting? No → Exclude

This does not include nursing homes or residential homes.

YES ↓

Do the participants require some form of support with eating or drinking?

No → Exclude

Support is defined as: giving physical and/or verbal assistance with eating and drinking

YES ↓

Are the participants receiving parental nutrition or enteral feeding?

YES → Exclude

Enteral or parenteral feeding is defined as

“Enteral tube feeding – the delivery of a nutritionally complete feed directly into the gut via a tube.

Parenteral nutrition – the delivery of nutrition intravenously” (NICE, 2006, p4)

NO ↓

Is the study a form of empirical research, or literature review?

No → Exclude

YES ↓

Is the study published in English?

No → Exclude

YES ↓

Is the study published after 1990?

No → Exclude

YES ↓

Include study in review: Yes / No

Comments:

Appendix F: Example of Inclusion and exclusion decisions

Inclusion and Exclusion decisions for remaining 106 articles following screening of title and abstract. Key - Y = include N = Not include

Full paper or abstract	Article	Any comments e.g., linked to other papers	Reviewer 1	Reviewer 2	Reviewer 3 (if 3 rd decision required)	Final Decision
1.Full text	Anonymous. 2009. Cluster randomised controlled trial (CRCT) of a multidisciplinary, team-building intervention to manage fever, sugar and swallowing (FeSS) in acute stroke. Nursing Monograph. (1), pp.19-21.	Unable to obtain full text	N	N		N: Unable to review
2. Full paper	Anonymous. Incredibly easy! Helping patients with dysphagia eat.Nursing.33 (5) p68.		N	N		N : Short Discussion abstracted from book
3.Full paper	Adams, C. et al.2011.Implementing the evidence: errorless learning intervention in a meal preparation task... Occupational Therapy Australia, 24th National Conference and Exhibition, 29 June - 1 July 2011. Australian Occupational Therapy Journal. 58, pp.82-82.		N	N		N: Discusses participants with traumatic brain injury only
4.Full paper	Alt Murphy, M. et al. 2012. Movement kinematics during a drinking task are associated with the activity capacity level after stroke. Neurorehabilitation and Neural Repair. 26(9), pp.1106-15.		N	N		N: Research of movement required for eating, muscle usage at extremities, does not discuss what support may be required

Appendix G: Data extraction form

Data Extraction form: Does the support provided for patients with eating and drinking difficulties after stroke result in adequate nutrition?

Adapted from guidelines published in the Cochrane Handbook for Systematic reviews (Higgins and Deeks, 2011); Supplementary guidance for Inclusion of Qualitative Research in Cochrane Systematic Reviews of Interventions (Noyes et al., 2011)

Reviewer Notes:

Some sections are for specific types of study please apply to the study under review as appropriate.

Extraction Information	Reviewer comment	Data extracted and comments
<p>Source</p> <p>Review author ID (created by review author).</p>	<p>Reviewer name.....</p>	
<p>Paper ID (created by review author).note; there may be multiple reports of the same study, list all reports</p>	<p>List: First paper; last name of first author and date Second paper (if applicable); last name of first author and date Third paper (if applicable); last name of first author and date.</p>	
<p>Study ID original /main study (created by review author). In some cases, the 'main' paper will be the one which provides the fullest or the latest report of the study. In other cases, the decision about which is the 'main' report will have to be made on an arbitrary basis.</p>	<p>List: last name of first author and date, this will be the same as one of the papers listed in paper ID as one of these will have been chosen as the main paper.</p>	

Citation	Enter the complete citation of the paper data is being extracted from on this form	
Eligibility Confirm eligibility for review using inclusion/ exclusion criteria on eligibility form	Did the paper meet all eligibility criteria? Yes No (if no give reason for exclusion)	
Methods Study design	Reviewer state if clear Quantitative methods such as <ul style="list-style-type: none"> • RCT • none randomised study such as none • randomised control study, • case control study • cohort study • cross sectional study Qualitative methods such as <ul style="list-style-type: none"> • Participant observation • In depth interviews • Focus groups Mixed methods Systemic review	
Total study duration.	How long did the study take: From.....to.....	
Sequence generation.	Randomised trials only state method of sequence generation.	
Allocation sequence concealment.	Randomised trials only state method of allocation sequence concealment.	
Blinding.	Randomised trials only state method of blinding.	
Other concerns about sources of bias such as:	List any other concerns about bias in any type of study <ul style="list-style-type: none"> • is the method appropriate to the research question • is the sampling process clearly described • is the data collection method appropriate to the research question 	

	<ul style="list-style-type: none"> • Have the authors declared a particular perspective towards participants in the research. • Have you been given enough information about the methods used 	
Participants How was the sample generated?	<ul style="list-style-type: none"> • Probability • Nonprobability • Convenience • Stratified • any other methods 	
Total number.	<ul style="list-style-type: none"> • Total number of participants at start of study • Total number of participants at close of study 	
Setting.	<ul style="list-style-type: none"> • Participants in acute setting (hospital) • Participants in rehabilitation setting (hospital) • Participants in hospital setting not specified 	
Diagnostic criteria.	Participants diagnosed with a stroke illness <ul style="list-style-type: none"> • Are stroke types specified within the study 	
Age.	<ul style="list-style-type: none"> • Mean Age • Upper and lower range of participants if specified 	
Gender.	<ul style="list-style-type: none"> • female • male 	
Country.	Country or countries where research study was conducted	
Comorbidity.	Record if participants had acknowledged co morbidities, if yes please list.	
Interventions Total number of intervention groups.	State number of interventions under investigation	
Specific intervention	<ul style="list-style-type: none"> • Intervention 1(name intervention) • Intervention 2(name intervention) • Reviewer add more if required 	
Intervention details	List intervention number e.g., 1, 2 then details (sufficient for replication, if feasible). ; Who delivered the intervention; how long for. Reviewer add others if required e.g., format of delivery, when started / completed.	

	<ol style="list-style-type: none"> 1. Who delivered the intervention; how long for. 2. Who delivered the intervention; how long for. 	
<p>Integrity of intervention.</p> <p>Reviewer to comment on points listed if information available in the paper.</p> <p>(Dane and Schneider ,1998)</p>	<ul style="list-style-type: none"> • The extent to which specified intervention components were delivered as prescribed (adherence). • Number, length and frequency of implementation of intervention components (exposure). • Qualitative aspects of intervention delivery that are not directly related to the implementation of prescribed content, such as implementer enthusiasm, training of implementers, global estimates of session effectiveness, and leader attitude towards the intervention (quality of delivery). • Measures of participant response to the intervention, which may include indicators such as levels of participation and enthusiasm (participant responsiveness). • Safeguard checks against the diffusion of treatments, that is, to ensure that the subjects in each experimental group received only the planned interventions (program differentiation). 	
<p>Outcomes Quantitative studies:</p> <p>Outcome 1.</p>	<ul style="list-style-type: none"> • When data collected. • When data reported. • Outcome definition (with diagnostic criteria if relevant). • Unit of measurement (if relevant). <p>For scales:</p> <ul style="list-style-type: none"> • Name of scale. • who collected data if information available (staff type, grade, trained) • upper and lower limits, • Whether high or low score is good. 	

<p>Outcome 2.</p> <p>Add more outcomes if required</p>	<ul style="list-style-type: none"> • When data collected. • When data reported. • Outcome definition (with diagnostic criteria if relevant). • Unit of measurement (if relevant). <p>For scales:</p> <ul style="list-style-type: none"> • Name of scale. • who collected data if information available (staff type, grade, trained) • upper and lower limits, • Whether high or low score is good. 	
<p>Outcomes Qualitative studies:</p> <p>Outcomes 1</p> <p>Outcome 2</p> <p>Add more outcomes if required</p>	<ul style="list-style-type: none"> • What outcome measure were adopted • What was the impact of the study for the participants • What outcome measure were adopted • What was the impact of the study for the participants 	
<p>Data Collection qualitative and mixed methods studies</p>	<ul style="list-style-type: none"> • What data collection methods were used • Was the data collection adequately described • Was the data collection rigorously conducted • What is the role of the researcher within the setting • Are there any potential conflicts of interest • Field work: is the process of fieldwork adequately described. 	
<p>Data Analysis Quantitative studies: Type of analysis used</p>	<ul style="list-style-type: none"> • Intention to treat • per protocol, • other quantitative analysis methods 	
<p>Data Analysis Qualitative studies</p> <p>(The British Psychological Society and Gaskell, 2007)</p>	<ul style="list-style-type: none"> • How are the data analysed • How adequate is the description of the data analysis 	

	<ul style="list-style-type: none"> • Is adequate evidence provided to support the analysis (use of original data; iterative analysis; efforts to establish validity and reliability) • Is the study set in context in terms of findings and relevant theory • Are the researchers own position, assumptions possible biases outlined? • Could the researcher's biases affect the analysis and interpretation of the data? • Are the findings substantiated by the data? • Has consideration been given to any limitations of the methods or data that may have affected the result? 	
<p>Results Quantitative studies: Number of participants allocated to each intervention group.</p> <p>For each outcome of interest:</p> <p>Outcome 1.</p> <p>Sample size.</p> <p>Missing participants*.</p> <p>Summary data for each intervention group (e.g., 2x2 table for dichotomous data; means and SDs for continuous data).</p> <p>Outcome 2.</p> <p>Sample size.</p>	<ul style="list-style-type: none"> • Intervention 1: number.... • Intervention 2: number.... 	

<p>Missing participants.</p> <p>Summary data for each intervention group (e.g., 2x2 table for dichotomous data; means and SDs for continuous data). Add more outcomes if required</p>		
<p>Findings Qualitative studies</p>	<ul style="list-style-type: none"> • What are the themes of the study • What are the conclusions of the researchers • What opinions are put forward by the researchers • What are the strengths and limitation of the study according to the researchers • How does this study add to the existing literature 	
<p>Ethics</p>	<ul style="list-style-type: none"> • Ethical committee approval obtained • Informed consent obtained • Does the study address ethical issues adequately • Has confidentiality been maintained 	
<p>Miscellaneous</p>	<ul style="list-style-type: none"> • Funding source. • Key conclusions of the study authors • Conflict of interest • Miscellaneous comments from the study authors. • References to other relevant studies. • Correspondence required. • Sample size calculation performed • Implications for policy • Implications for practice 	

Appendix H –Characteristics of included studies

Characteristics of Included studies developed from Popay et al. (2006), CASP (2013), NICE (2014)

Review title: Does the support provided for patients with eating and drinking difficulties after stroke result inadequate nutrition?

Ordered by study design.

Reference & Country	Study design /theoretical approach and aim	Participants type of stroke/ severity How recruited/Number/ specific inclusion-exclusion criteria	Outcomes & Outcome measures	Data collection. Method/ by whom/ when. Data analysis methods.	Setting	Results/Key themes All relevant to review question	Quality assessment ++good quality +lesser quality -poor quality (NICE / LEGEND rating)
Blackwell, Z & Littlejohns, P. 2010. A review of the management of Dysphagia: A South African perspective. The Journal of neuroscience nursing: Journal of the American Association of neuroscience nurses. 42 (2) .pp 61-70 South Africa	Retrospective case note audit. 3 Aims: 1.measure prevalence of dysphagia in the three rehabilitation clinics 2.measure level of assessment for dysphagia 3.measure management strategies for dysphagia	Type not recorded/ severity subjectively recorded using clinical judgement of SLT's/ site of lesion recorded. Randomly sample, method of randomisation not stated. n=90 medical records of Stroke patient's included . No inclusion/exclusion criteria discussed just that all were stroke patients.	N/A	Records were reviewed using a data collection form generated by the primary author. Informal interviews with SLP's to clarify data in records or add missing information number of interviews not stated/ Jan 2006 –Dec 2006 (12 months) Data collection tool not presented but available for inspection. Not clear who collected data, though 10% were blind reviewed by a	3 separate Rehabilitation Units privately funded facilities Not stated whether solely for stroke rehab	1. Prevalence and variation of patients feeding status. High proportion were able to feed independently (42) 47%;(35) 38% on oral diet required assistance 2. Dysphagia diagnostic methods utilised by the rehabilitation facilities. SLPs aim to assess all patients. (88) =98% (had bedside assessment). Small number (9) =10% assessed using	-poor, does not discuss who collected data, or frequency of Interventions from SLP and dietician, no significance of findings given, no Standard Deviation of results.

				second person (SLP) to check reliability and correlated using Cohen's kappa		<p>VF. No time frame given.</p> <p>3. Dysphagia intervention techniques utilised by the rehabilitation facilities. Dietician input for all patients requiring an individualised diet included dietary modifications, nutritional modifications counselling. No discussion of frequency.</p> <p>Swallowing monitored by SLP's dietary modification by SLP's; oral sensorimotor and behaviour intervention (swallowing techniques) assessed by SLP, no mention of frequency.</p> <p>Nursing staff involved in the care of stroke patients could help identify the presence of dysphagia by increasing awareness when it comes to the assistance of improved patient monitoring. Call to increase nursing</p>	
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						knowledge in S.Africa around monitoring swallowing, diet consistency, performance of sensorimotor interventions, feeding dependent patients.	
Reference & Country	Study design /theoretical approach and aim	Participants type of stroke/ severity How recruited/Number/ specific inclusion-exclusion criteria	Outcomes & Outcome measures	Data collection. Method/ by whom/ when. Data analysis methods.	Setting	Results/Key themes All relevant to review question	Quality assessment ++good quality +lesser quality -poor quality (NICE / LEGEND rating)
Carlsson, e. et al. 2010. Multidisciplinary recording and continuity of care for stroke patients with eating difficulties. <i>Journal of Interprofessional Care</i> . 24(3), pp. 298-310 Sweden	Retrospective audit/survey of patients records. Aim to describe multidisciplinary stroke care as represented in patient records including notes from physicians, nurses, OT's, Physio, SLT's for patients with eating difficulties and describe the written information that was transferred from hospital to elderly care in discharge letters.	Type and severity of stroke not recorded/Convenience sample consecutively recruited records/ n=59/ Inclusion , notes include comment on eating difficulties, no exclusions	1.Multidisciplinary stroke care as represented in in patients records for patients with eating difficulties Measure: 30 item protocol 2.Written information transferred from hospital to elderly care Measure 3 point scale	January – July 2003. First author. Descriptive statistics for demographic data and frequency of recording per profession in profession specific records. Discharge information gathered on a 3 point scale of comprehensiveness of information, descriptive statistics for comprehensiveness.	Stroke combined acute and rehabilitation unit	Multidisciplinary stroke care as represented in in patients records for patients with eating difficulties 358 notes on eating difficulties found Percentage of notes per profession. Physician 13%; registered nurse 78%; OT 4 %; Physio 1%; SLT 4% Care plans were unstructured and few contained steps for managing eating. Written information transferred from	-poor , small sample, no randomisation, risk of bias in data collection survey only

						<p>hospital to elderly care 80%</p> <p>Frequency of comprehensive discharge info Care history and interventions related to eating difficulties , no info 94%, partial info 4%, comprehensive info 2%</p> <p>Actual eating difficulties at discharge no info 38%, partial info 57%, comprehensive info 4%.</p> <p>Prevention related to eating difficulties no info 96%, partial info 2%, comprehensive info 2%.</p> <p>Communication ability no info 49%, partial info 25%, comprehensive info 25%.</p> <p>Eating difficulties reported in over 50% of patient records, but few signs of systematic assessment and documentation, few traces of multidisciplinary</p>	
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						collaboration in the field of eating. Majority of notes on eating were made by nurses. Anticipated that nurses consider themselves as having the major responsibility for nutritional assessment.	
Rosenvinge, S.K. & Starke, I.D. 2005. Improving care for patients with dysphagia. <i>Age and Ageing</i> , 34 (6). pp. 587-593 UK	Pre and post observational audit before and after targeted intervention None randomised Objective: 1.to determine compliance with swallowing recommendations in patients with dysphagia. 2. investigate the effectiveness of changes in practice in improving compliance	Type and severity of stroke not recorded/ Convenience sample. Two part study. Total participants in study 31 before (audit 1) and 54 after (audit 2) intervention, of these from stroke ward on oral diet n= 9 in audit 1 and n=14 in audit 2. No specific exclusion criteria. All patients on SLT caseload for dysphagia included.	Adherence to SLT recommendations 1.for consistency of fluids 2. dietary modifications 3. Amounts to be given at one meal/drink 4. Swallowing strategies 5. General safe swallow recommendations 6. level of supervision required All outcomes measured on a Specifically designed checklist, noted if recommendations adhered to or not and reason for non-compliance.	Observation by one SLT on both audits. Data collected 16 times over a 5 day period from each ward. All mealtimes and drinks throughout the day were recorded. Audit one over 5 days in May 2002, audit 2 over 5 days in Sept 2003. Percentage compliance scores calculate for each recommendation on ward. Reasons for non-compliance recorded and analysed for each recommendation in first audit. Levels of compliance compared between the two audits, 95% CI calculated and Chi squared test used to analyse the significance of any differences.	Stroke ward, care of the elderly, medicine and surgical wards in acute hospital	1Adherence to SLT recommendations for consistency of fluids improved following intervention. 2 Adherence to SLT recommendations for dietary modifications, no change following intervention. 3 Adherence to SLT recommendations for Amounts to be given at one meal/drink improved following intervention. 4 Adherence to SLT recommendations for Swallowing strategies no change following intervention. 5 Adherence to SLT recommendations for General safe swallow recommendations improved following intervention.	+ small sample size though found significant results

						<p>6 Adherence to SLT recommendations for level of supervision required improved following intervention.</p> <p>Greater overall compliance on stroke unit than other wards highlights benefits of dysphagic patients being managed on specialist units.</p>	
<p>Takahata, H. 2011. Early intervention to promote oral feeding in patients with intracerebral hemorrhage: a retrospective cohort study. <i>BMC Neurology</i>. 11(6),pp. 1-7 Japan</p>	<p>Before and after retrospective cohort study Aim to establish the feasibility, risks and clinical outcomes of early intensive oral care and a new SLT/nurse led structured policy for oral feeding in patients with an acute intracerebral haemorrhage (ICH).</p>	<p>Convenience sample/ Total participants n=219. Intervention group n=129. Control group n=90. Inclusion criteria, all participants had ICH diagnosed by CT or MRI, severity measured using GCS, functional outcome measured using Modified Rankin scale/ Excluded if initial brain damage or complications attributed to ICH caused death, multiple haematoma, and intraventricular haemorrhage.</p>	<p>The feasibility, risks and effects of early intensive oral care and new SLT/nurse led structured policy for oral feeding in patients with ICH compared to usual care. Outcomes measured: amount and type of oral intake. Occurrence of chest infection. Functional abilities. Outcomes measured using: Functional oral intake scale (FOIS). Functional outcome modified Rankin scale. Incidence of chest infection three or more symptoms (fever>38°C;</p>	<p>Gathered from patients medical records. Intention to treat Associations between baseline characteristics and clinical variables measured using χ^2 test of Fisher's exact test and Student's t-test for quantitative data. Logistical regression analysis used to identify clinical variables that were significantly associated with oral intake without nutritional supplementation. Kaplan-Meier curves used to estimate the cumulative rate of supplementation- free</p>	<p>Acute medical setting</p>	<p>Early initiation of oral feeding and oral care after sufficient preparation may safely improve clinical outcomes of ICH patients in terms of survival, chest infection, LOS and swallow function Proportion of patients who could tolerate oral feeding significantly higher in the early intervention group than control.</p>	<p>+ no blinding open to bias, limitations reported</p>

Reference & Country	Study design /theoretical approach and aim	Participants type of stroke/ severity How recruited/Number/ specific inclusion-exclusion criteria	Outcomes & Outcome measures	Data collection. Method/ by whom/ when. Data analysis methods.	Setting	Results/Key themes All relevant to review question	Quality assessment ++good quality +lesser quality -poor quality (NICE / LEGEND rating)
			productive cough; tachypnoea >22 bpm; inspiratory crackle; abnormal CXR; arterial hypoxaemia; isolation of relevant pathogen) Incidence of use of antibacterial drugs	survival compared with log-rank statistics. Cox proportional hazard model was used to estimate the adjusted hazard ratio.			
Foley, N. et al. 2006. Energy and protein intakes of acute stroke patients. <i>The journal of nutrition, health and aging.</i> 10 (3), pp. 171-175. Canada	Prospective Observational study. Aims to report 1. Level of protein and energy intake 2. Adequacy of intake during first 21 days of hospitalization 3.the differences in nutritional intake associated with diet type (regular texture, modified texture, enteral feeding)	N= 76 ischaemic & n=15 haemorrhagic strokes/ , location of lesion recorded from CT/ stroke severity assessed using Canadian neurological scale (CNS)10 point ordinal scale. Convenience sample/ n=91/ Inclusion: ischaemic or haemorrhagic stroke; onset of symptoms within 5 days of arrival	1. Average protein intake and adequacy of intake of stroke patients in first 21 days of admission to hospitalization. Results for patients on dysphagia diet only as they are only ones that definitely require assistance/ support. Measure:	Calorie counts for energy and protein intake / completed by registered nurse in charge of care over a 48 hour period on 5 occasions (admission, days 7,11,14,21) Data analysis using ANOVA with post hoc multiple comparisons (Bonferroni method) was used to compare mean protein and energy intakes in patients taking	Neurology and rehabilitation	No significant difference in intake of calories and protein between regular and dysphagic diet patients. Patients receiving enteral nutrition had significantly higher energy intakes (Kcals) compared to regular diets (p=0.023) and dysphagia diets (p=0.039).	+ Would have liked clearer comparisons between all groups

		at hospital; absence of previous stroke or SAH; classified as normally nourished; able to obtain informed consent. Exclusion; previous SAH, traumatic brain injury, major systematic illness.	protein intake grams per kg per day (g/kg/day) compared to recommended level 1g/kg/day 2. Average energy intake and adequacy of intake of stroke patients in first 21 days of admission to hospitalization. Results for patients on dysphagia diet only as they are the only ones that definitely require assistance or support. Measure: Kilo calories per kilogram per day (Kcal/kg/day)	regular diets, enteral nutrition and dysphagia diets at each of the testing intervals. Two tailed tests of significance were used.		Patients receiving enteral nutrition exceeded energy requirements compared to patients receiving regular diets on days 11, 14, 21 and those on dysphagia diet on days 11, 21. Protein intakes for enterally fed patients were significantly higher compared to intakes of patients on dysphagia diets at all testing intervals except admission. Intake of protein and energy increased across first 21 days post stroke.	
Huang, J. et al. 2006. Training in swallowing prevents aspiration pneumonia in stroke patients with dysphagia. <i>The Journal of International Medical Research</i> . 34 (3).pp.303-306 China	Comparison study Consecutive sample Aim to compare frequency of aspiration pneumonia in conscious stroke patients those fed by family given general nursing information and those fed by trained nurses and receiving training in swallowing from the nurses	Type and severity of stroke not stated, area of lesion recorded but not reported/ n=96 stroke patients consecutively recruited Inclusion criteria: acute stroke onset within 24 hours of admission, dysphagia, receiving oral diet. Exclusion: admission after 24 hours of stroke onset, coma on admission or during hospital stay, endotracheal intubation	Development of aspiration pneumonia. Measured by development of 3 of six diagnostic symptoms of aspiration pneumonia	Data about absence or presence of pneumonia collected daily during patient's hospital stay .Positive diagnosis if three or more of the following symptoms were present, temp > 38°C; productive cough with purulent sputum; abnormal resp exam; abnormal CXR; isolation of a relevant pathogen; arterial hypoxaemia. Does not state who collected data.	Acute hospital	Incidence of pneumonia significantly lower in group of patients who were fed by trained nurses and had received training on swallowing techniques compared to those patients who had been fed by family members who had only received general nursing information via video	+ adequate sample size More detail required on length of follow up.

				Data analysed using Pearson χ^2 test to analyse differences in the incidence of aspiration pneumonia			
Carr, E.K. & Mitchell, J.R.A. 1991. A comparison of the mealtime care given to patients by nurses using two different meal delivery systems. International journal of nursing studies. 28 (1) ,pp19-25. UK	Comparison study To describe and compare mealtime care given by nurses using different meal delivery systems	Type and severity of stroke not stated/States random selection but no mention of randomisation, appears to be a convenience sample. 40 participants, 20 of which had stroke. No inclusion/exclusion discussed	To describe the mealtime care given to stroke patients with eating difficulties. Who was supervising the serving and delivery of food to patients? Who actually served and delivered food. Whether nurses made any checks about the patients' meal related needs when they took the food to them. Whether nurses observed the patients specific feeding difficulties. Whether the nurses gave any help while the patients were eating. Who cleared away dishes and observed whether any food was left.	Nonparticipant observation techniques. Observer not named. Mann Whitney U test for comparison of group characteristics. Descriptive techniques for analysis of majority of data.	One medical ward in each of two separate teaching hospitals.	Nurses in a hospital using kitchen plated meal systems (1) were less involved in mealtimes than those in a hospital using ward plated meal systems (2). Stroke patients with feeding difficulties in Hosp 2 more likely to be observed by qualified nursing staff and given nursing help than in Hosp 1. Supervision of meal trolley 68.2% (2) v 22.2% (1). Involved in serving 40.9% (2) v 22.2% (1).meals delivered by qualified staff 36.4% (2) v 11.1% (1); mealtime care stroke patients 54.4% (2) v 33.3% (10). Not checking for discarded food 66.7% (1) v 9.1% (2). The nursing staff themselves should decide how to use to its full advantage a system which was	- Poor Limited detail on methodology. Not clear on relevance of including medical patients as a control

						designed to give them greater opportunity for direct contact with their patients.	
McGrail, A. & Kelchner, L.N. 2012. Adequate oral fluid intake in hospitalized stroke patients: Does viscosity matter? <i>Rehabilitation nursing</i> .37 (5).pp 252-257. USA	Cross sectional survey. Observation Aims: To determine if elderly hospitalised patients with acute stroke met a minimum standard of fluid intake. To determine if there is a difference in intake between those taking thickened and those taking unthickened fluids. To compare fluid intake of acute stroke patients with healthy community living individuals.	Ischaemic stroke diagnosed by CT-MRI/severity of stroke not recorded/ Stratified sample from stroke admissions. Convenience sample of community participants. N=20 hospital patients, two groups of 10. 10 community dwellers. Inclusion criteria: Hospital patients included if diagnosed with ischaemic stroke and primary nutrition met by mouth and were able to communicate wants and needs. Community dwellers, primary nutrition by mouth-none modified diets. Independent	1.Post stroke patients receiving thickened fluids (STH) consume insufficient amounts of fluid Oral Intake of Fluids measured in ml's over 72 hours using Nursing flow charts. . 2. Post stroke patients receiving unthickened fluids (STL) consume insufficient amounts of fluid Oral Intake of Fluids measured in ml's over 72 hours using Nursing flow charts. Nursing personnel recorded hourly. 3. Older people in community setting take adequate amounts of fluid orally Oral Intake of Fluids measured in ml's over 72 hours Measured against a minimal level of 1500ml/day	Hospitalised patients: Data gathered by Nursing personnel recorded hourly over 72 hours. Community participants' Fluid intake log completed by participant instructed to be recorded at time of fluid consumption over 72 hours. Data analysed using ANOVA and Tukeys HSD for post hoc analysis.	Acute hospital setting and community setting	Post stroke patients receiving thickened fluids (STH) consume insufficient amounts of fluid Post stroke patients receiving unthickened fluids (STL) consume insufficient amounts of fluid Older people in community setting take adequate amounts of fluid orally. Other findings discussed that were not part of the stated aims observed in unannounced visits, Such as timing of drinks offered not frequent enough, correct consistency - often incorrect and variety of drinks offered, seen to be not to patients liking. Need to determine if service delivery practices improve fluid intake in patients hospitalised post stroke.	+ Due to a number of limitations and small numbers involved.

		with ADL's, no acute illness. Exclusion same for both groups: History of degenerative neuro disease, radiation to head or neck, required maximum assistance for bladder management, fluid restrictions, tube feeding, tracheostomy in place.				Recommended daily fluid intake 1500ml/day	
McLaren, S.M.G. & Dickerson, J.W.T. 2000. Measurement of eating disability in an acute stroke population. <i>Clinical effectiveness in nursing</i> .4 (1), pp. 109-120 UK	Cross sectional study. Aim to identify the prevalence, range and combination of eating problems following acute stroke. Develop an ordinal scale instrument to measure post stroke eating disability. To investigate extraneous variables which could influence dietary intakes	Type and severity of stroke not stated, area of lesion not recorded /Diagnosed with CT/ n=75 consecutive patients recruited over study duration. patients with comorbidities resulting in degenerative disorders resulting in functional impairments affecting eating were excluded	Development of an ordinal scale to quantify post stroke eating disability Eating disability assessment instrument containing eight categories of functional impairments graded for severity, level, and resulting dependence on mealtime assistance assessed with Cronbach's coefficient for internal consistency for the instrument.	Not stated who collected the data. Data collected by observation using the 'eating disability assessment tool' this was then compared to amount of food offered and amount actually consumed. Data collected at day 8-10 of admission. Data analysed using parametric statistics (multiple regression analysis) and non-parametric statistics for remaining analyses	Acute hospital setting does not state if this is a stroke unit.	Impaired arm movement (89%) and posture (84%) were the most prevalent eating disabilities. Moderate Negative correlation shown between dietary energy provided and eating disability score (Spearman's rho - 0.583). Strong negative correlation between dietary energy consumed and eating disability score (Spearman's rho - 0.867, p<0.001). Dietary energy consumption lower	+ Not clear on some aspects of study. Who collected data?

						<p>than provision across all levels of eating disability ($p < 0.001$).</p> <p>Weak correlation between protein offered and eating disability (Spearman's rho -0.243).</p> <p>Strong negative correlation between protein consumed and eating disability score (Spearman's rho -0.634, $p < 0.001$).</p> <p>Across all levels of eating disability, level of protein consumption lower than protein offered ($p < 0.0001$).</p> <p>Use of the eating disability assessment instrument can assist in the bedside identification of patients at nutritional risk and focuses attention on disabilities which increase dependence and require skilled intervention from nurses and therapists.</p> <p>The tool is intended for use by nurses and does not replace swallowing screens for dysphagia</p>	
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<p>Medin, J. et al. 2011. Eating difficulties among stroke patients in the acute state: a descriptive, cross-sectional, comparative study. <i>Journal of clinical nursing</i>. 20 (17/18), pp. 2563-2572 Sweden</p>	<p>Descriptive, cross sectional comparative study. Aims to examine eating difficulties among stroke patients- a comparison between women and men</p>	<p>N= 83 ischaemic, n=21 type not stated, n=31 had previous stroke. Type/ severity of stroke measured using national Institute of health stroke scale (NIHSS) used to assess severity of stroke. Convenience sample from stroke unit admissions n=104 Inclusion , newly diagnosed stroke Excluded – unconscious, non-Swedish speaking, severe aphasia, Confusion ,no spouse for gaining consent, had no oral food intake, were discharged before observation</p>	<p>More women than men had significantly one or more eating difficulties</p> <p>Patients observed for eating difficulty using a Structured observation protocol. Nutritional status measured using Mini nutritional assessment MNA score<17 implies malnutrition, 17-23.5 at risk of malnutrition, ≥24 well nourished. Oral status using Revised oral assessment guide. Barthel index to assess independence with ADL.NIHSS used to assess severity of stroke.</p>	<p>Using Structured observation protocol for eating difficulty. Not stated who collected data. On days 1-19 post stroke during one meal. From Jan 2007-March 2008. Analysis of covariance ANCOVA used to assess when to end inclusion. Logistic regression to examine associations between gender and eating difficulties. Chi square test to assess proportions.</p>		<p>More women than men had significantly one or more eating difficulties (p=0.031) most common were managing food on plate (p=0.016), food consumption (p<0.001), sitting position (p=0.065). Significant gender differences in nutritional status (p=0.003) Women were more likely to be malnourished than men whether they had eating difficulties or not. But more men were at risk of malnourishment. When adjusted for functional status and stroke severity Odds ratio the only eating difficulty that had an association with gender was inadequate food consumption. Structured observation of mealtimes including assessment of food intake might be necessary in acute stroke care to detect patients needing</p>	<p>+, unclear as to who collected data and specifically when in days 1-19 during hospital stay</p>
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						closer supervision and nutritional intervention. This may help focus rehabilitation on eating related activities and also use mealtimes as a rehabilitation opportunity.	
Reference & Country	Study design /theoretical approach and aim	Participants type of stroke/ severity How recruited/Number/ specific inclusion-exclusion criteria	Outcomes & Outcome measures	Data collection. Method/ by whom/ when. Data analysis methods.	Setting	Results/Key themes All relevant to review question	Quality assessment ++good quality +lesser quality -poor quality (NICE / LEGEND rating)
Nakamura, T. & Fujishima, I. 2013. Usefulness of ice Massage in triggering the Swallow Reflex. <i>Journal of stroke and cerebrovascular diseases</i> .22 (4), pp.378-382. Japan	Cross over study. To evaluate the usefulness of ice massage for eliciting the swallow response	Cerebral infarction n=19 & intracerebral haemorrhage n=3 & sub arachnoid n=2, lesion of CI recorded, severity of stroke not recorded/ convenience sample/ N=24 in total. Study inclusion stroke, able to follow commands, Exclude non-stroke, severely altered conscious state, unable to follow commands	Usefulness of ice massage in triggering the swallowing reflex Time between command to swallow and actual swallow in seconds No lower limit, upper limit 10 seconds Lower time score good	October – November 2010 Observation via VFES by 2 researchers- medical doctors. Intention to treat t test for significance in latency of swallow, significance of number of responses by Wilcoxon rank sum test	Not stated directly researchers from Dept. of rehabilitation	Those who could manage swallow in all four trials With ice 1.55±0.420 secs v without ice 2.17 ±1.53 secs p=0.00366 Those who could not manage all four swallows With ice 1.30±0.70 secs v without ice 0.50±0.50secs p=0.0267 ? results reported incorrectly in table	+ Not sure at what stage the patients were post stroke

<p>Perry, L. 2004. Eating and dietary intake in communication-impaired stroke survivors: a cohort study from acute-stage hospital admission to 6 months post stroke. <i>Clinical nutrition</i>.23 (6), pp. 1333-1343. UK</p>	<p>Descriptive case series. Explore eating related impairments and dietary intake in communication-impaired stroke patients during the first 6 months post stroke</p>	<p>Type of stroke not recorded/ severity not recorded but assessed function using Barthel index/convenience sample from consecutive admissions for stroke to an acute hospital in South London/ n=36/ Included, Patients diagnosed with stroke, diagnostic test not stated. ICD 10 codes 160-164, both impairments in response to language component of the NIHSS and motor deficit in upper of lower limbs. Excluded: those who died in first week or were never assessable.</p>	<p>1. Eating disabilities more common in those with communication difficulties remaining at discharge. Measure- EDAS score by trained research nurse 2 Some significant deterioration in some anthropometric indices particularly MAC and TSF Measure- Demi span, mid arm circumference (MAC), Triceps skin fold thickness (TSF), weight. 3 Energy consumption varied with diet type. Reduced energy intake with modified diets, nutritional support interventions failed to meet participant's needs. Measurement of Nutritional intake during hospital stay, nurses recording of all oral intake food and fluid in a 24 hour period. Compared to national recommendations Estimated average requirements (EAR) Trained research nurse</p>	<p>Trained research nurse/ ward nursing staff. Within one week of admission, after one month if still in hospital, at discharge. Analysis includes Standard Deviation, mean. All test were two sided.</p>	<p>Acute trust hospital</p>	<p>1. Eating disabilities more common in those with communication difficulties. At first assessment median score 13.5, 83 % subjects scored >9 representing severe disablement. At discharge median 5.5, 46% still severely disabled High score poor, low score good 2. Some significant changes in some anthropometric indices. Measurement of anthropometric indices during hospital stay. Demi span not reported; mid arm circumference (MAC), Triceps skin fold thickness (TSF) analysed together men $p < 0.004$ and women $p < 0.03$, weight reduced none significantly for those measured as did BMI. High score good, low score poor Energy consumption varied with diet type.</p>	<p>+ good though difficult to work out exact numbers for each test then compare results, small sample size</p>
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						<p>34</p> <p>3. Oral intake; Mean (SD) Energy intakes were 1182 (444) k calories/day; 52 (19) gm/day protein. Compared to recommended levels met mean (SD) 60% (21%) energy requirements range 21%-102%; mean (SD) protein intake 131% (48%) EAR for protein and 105 % (39%) of RHI. Mean energy and protein intake higher for men than women 1371v 1076 kcal/day and 60v 47g/day protein</p> <p>High score good, low score poor</p> <p>Degree of language impairment correlated with overall mean adequacy of energy intake ($p < 0.023$) Eating disability and MAC measure at discharge linked with in hospital adequacy of energy intake ($p, 0.022$).</p>	
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						<p>Closer attention to the nutritional requirements of communication impaired stroke survivors is clearly warranted.</p>	
<p>Poels, B.J.J. et al. 2006. Malnutrition, eating difficulties and feeding dependence in a stroke rehabilitation centre. <i>Disability and Rehabilitation</i>. 28 (10), pp.637-643 Netherlands</p>	<p>Case series observational study. To describe the prevalence of malnutrition at admittance and after 4 weeks in stroke rehabilitation; to analyse existing eating difficulties and feeding dependence in the stroke patient and their relation to malnutrition</p>	<p>n=15 haemorrhagic & n=52 ischaemic strokes, severity of stroke not recorded, not stated how diagnosed/ n=69/ convenience sample/ inclusion stroke, age 18 and over, admitted to the rehab centre. Exclusion, pregnancy, used diuretics, had oedema or ascites, patients with aphasia who could not give informed consent</p>	<p>1. The occurrence of malnutrition at admission and after 4 weeks in rehabilitation</p> <p>Unintentional weight loss >5% in last month or > 10% in 6 months. BMI<18 (<65 years); <22 (≥ 65 years), triceps skin fold <90% of 12.5mm (men) or 16.5mm(women), mid arm muscle circumference <90% of 23.5cm (men) or 23.3cm (women) , fat free mass≤16kg/ m²(men) ≤ 15kg/ m²(women), serum albumin < 35g/L</p> <p>2.Relationship of feeding dependence and eating difficulties to malnutrition</p> <p>11 potential Eating difficulties observed and counted Observed for feeding dependence Score 1-4</p>	<p>1. At admission and 34 days later by dietician during an interview. Physical assessment , observation 2. At one meal at admission by SLT observation.</p> <p>Analysis using Fishers exact test, chi square test, McNemmar test, Mann-Whitney U-test and student t-test for independent observations. Confidence intervals were calculated using the Wilson method.</p>	<p>Stroke rehabilitation</p>	<p>35 % malnourished at admission, 3% after 4 weeks in rehab (p<0.05) 43% had an eating difficulty; 16% had feeding dependence. Having two or more eating difficulties and being dependent on feeding was significantly associated with malnutrition (p<0.05) at admission not after 4 weeks in hospital.</p> <p>Authors note that a lack of a 'gold standard' measure for malnutrition is a problem in nutritional research.</p>	<p>+ some funding from food manufacturer,</p>

Reference & Country	Study design /theoretical approach and aim	Participants type of stroke/ severity How recruited/Number/ specific inclusion-exclusion criteria	Outcomes & Outcome measures	Data collection. Method/ by whom/ when. Data analysis methods.	Setting	Results/Key themes All relevant to review question	Quality assessment ++good quality +lesser quality -poor quality (NICE / LEGEND rating)
Mosselman, M.J. et al.2013. Malnutrition and risk of malnutrition in patients with stroke: prevalence during hospital stay. <i>Journal of neuroscience nursing</i> .45 (4), pp. 193-204 Netherlands	Prospective descriptive study Aim to investigate the prevalence of malnutrition and risk of malnutrition of patients with acute stroke during the first 10 days of hospitalization	N=58 ischaemic & n=15 haemorrhagic strokes, not stated how diagnosed, area of lesion not recorded/ severity of stroke measured with Rankin scale and Barthel index/ Convenience sample on admission to stroke unit. N=73 at admission. N=23 completed at follow up. Inclusion – stroke Exclusion- too ill, bed bound, not able to communicate	Proportion of stroke patients with malnutrition or at risk of malnutrition increases significantly in the first 10 days of hospital admission. Measured using the Mini Nutritional Assessment (MNA). Score ≥ 24 well nourished; MNA ≤ 17 malnourished. MNA ≥ 17 and < 24 at risk of malnutrition High score ≥ 24 good	Measured using MNA by Two specially trained nurses At Day 2-5 from admission and again at days 9-12 from admission Analysis Per protocol used Statistical analysis McNemmar test, Fisher's t test, Barnard's test, Pearson's Chi square	Acute Stroke unit	At admission (T1) all cases: well-nourished 59(81%); at risk of malnourishment 10 (14%); malnourished 4 (5%). Change in nutritional status for completed case n=23. At measurement 1(day2-5), 21 patients well-nourished =91%; 2 at risk of malnourishment =9%, 0 malnourished. Measurement 2 (day 9-12): 8 patients well-nourished =35%; 9 patients at risk of malnutrition =39%; 6 patients were malnourished =26% 65% at risk or malnourished at measurement 2 from measurement 1 $p \leq 0.005$. Nutritional status of stroke patients deteriorates significantly in the first	- small sample at follow up could affect results, no statistical significance with follow up group

						ten days of hospital admission. Suggest nurses' responsibility to assess for nutritional status at regular intervals and act on findings.	
Mould, J. (2009). "Nurses 'must' control of the nutritional needs of stroke patients." British Journal of Nursing 18(22): 1410-1414. UK	Observational audit study/ To review nutritional practice within an acute stroke unit and compare it against NICE, NPSA and national Stroke agenda	Type and severity of stroke not stated, area of lesion not recorded. Convenience sample. Number not stated. No inclusion exclusion criteria though all on an acute stroke unit	1. Activities and behaviour. Measured by Effectiveness of protected mealtimes ; red tray system; hand hygiene. 2. Skill attainment and performance. Measured by Individual confidence and competence. 3. Environment. Measured by amount of Interruptions or attempted interruptions by MDT, layout of dept. 4. Verbal and non-verbal communication. Measured by Interactive verbal and non-verbal communication between staff and patients and verbal communication between staff. 5. Quantity and quality of food. Measured by score in appearance, temperature, quality and taste. 6. Documentation standards. Measured by	Observation of practise and nursing and medical records/ senior nurse from unit and the Trust nutritional steering group/ on eight occasions.	Acute stroke unit	1. Protected mealtimes work well when staffing levels are above average more food consumed than when staffing lower or patients acuity higher Better interaction when staffing levels good this occurred 3/8 observations. Lower interaction resulted in less food consumed. Staff behaviour improved and more needs met as observations continued. Red tray system effective on 7/8 observations of meals reflecting correct diet; hand hygiene offered 8/8 observations. 2. Identified lack of individuals confidence and competence around swallow assessments, use of MUST tool,	- Difficult to appraise as an audit, information not available about timing of study and number of patients and staff observed.

			<p>documentation of nutritional needs, care plan reflects needs, documentation consistent, assessed on admission and at regular intervals. In nursing and medical records.</p>			<p>documentation of portion sizes 3. Members of MDT attempted to access patients on 5/8 observations. Physical layout of dept. meal trolley central in a long ward, next to physio room with much movement? Interrupting serving. 4. Comfortable interactions of verbal and non- verbal observed 6/8 occasions staff to patients. All communication improved when ward sister present. Communication deteriorated when staffing levels were low. 5. Food scored 9.1 /10 on appearance, temperature, quality and taste. 6. Documentation, Initially not accurately recording portion size, appearance or content of meal, this improved as observations continued. Recommendations:</p>	
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						OT's have been enlisted into protected mealtimes to gather information on how patients feed, and to ensure professional assistance is available. Relatives and Carers are involved with planning, implementing and assessment of nutritional needs and care.	
Unosson, M. et al. 1994. Feeding dependence and nutritional status after acute stroke. <i>Stroke</i> 25(2): pp.366-71. Sweden	Descriptive observational study. Aim to describe the nutritional status in elderly patients with acute stroke on admission and after 2 and 9 weeks and to evaluate the patient's nutritional state in relation to food intake and dependence on assisted feeding.	Stroke patients clinically diagnosed n=35 Cerebral Infarction; n=4 ICH; n=8 unspecified; n=3 TIA, total n= 50. Convenience sample. Excluded if suffering from hepatic, renal or malignant disease.	1 Nutritional status of elderly patients with acute stroke at admission in relation to food intake and dependence on assisted feeding 2. Nutritional status of elderly patients with acute stroke at 2 weeks after admission in relation to food intake and dependence on assisted feeding 3. Nutritional status of elderly patients with acute stroke at 9 weeks after admission in relation to food intake and dependence on assisted feeding. Outcome Measures: Bodyweight ,<80% ref weight men and women;	Anthropometric data collected by same investigator; not stated who collected other data from medical records. Data collected within 48 hours of admission, at 2 weeks & 9 weeks. Data analysis: Student's t test for dependent and on dependent groups, Fisher's exact test, Mann-Whitney U test, multiple regression analysis.	Initially Neurological followed by rehab unit and home	On admission four patients were protein energy malnourished. Those Dependent for feeding after admission had lower serum albumin (p<.05) lower body cell mass (p<.01) more anergic (p<.01) than independent patients. Two weeks after admission patients dependent for feeding had lower concentration of serum albumin (p<0.001)and transthyretin (p<0.01) and higher concentration of α 1-antitrypsin(p<0.001), lower body cell mass	+ Small sample size.

			<p>Tricep skinfold (TSF) ≤6mm (men) ≤12mm (women); arm muscle circumference (AMC) ≤23cm men ≤19cm (women) in those aged ≤79 years and ≤21cm (men) ≤18cm (women) those aged >79 years.</p> <p>Serum protein analysis (albumin < 36g/L men and women; transthyretin <0.20g/L men and <0.18g/L women, α1antitrypsin); delayed hypersensitivity skin testing reactive if measure >10mm, anergic if <10mm at 48 hours after. Severity of stroke measured using modified Norton scale.</p>			<p>(p<0.001) compared to independent patients. Within the dependent group TSF and serum Albumin concentration decreased between admission and week 2 TSF (P<.05); Serum Albumin (P<.01). Patients who were independent showed decline in TSF and body fat (P<.05). Nine weeks after admission lower serum albumin and lower body cell mass in dependent group compared to independent group (p<.01). Feeding dependence significantly related to loss of body cell mass (p<0.002). Dependent group consumed 64% of the food served compared to the independent group who consumed 75% (P<.05). No significant differences in dependent and independent patients prior to admission.</p>	
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						<p>Complications developed in the neuro unit in 16 (32%) patients of which 13 were in the dependent group.</p> <p>Both dependent and independent groups broke down fat to compensate for energy needs. Body cell mas appeared to relate to functional condition after stroke.</p>	
<p>Westergren, A. et al.2001a. Eating difficulties, need for assisted eating, and nutritional status and pressure ulcers in patients admitted for stroke rehabilitation. <i>Journal of Clinical Nursing.</i> 10 (2), pp. 257-269. Sweden same study population as Westergren (2002) but presents</p>	<p>Descriptive observational study. Aim to describe and compare patients without a need for assisted eating and those with a need regarding types and extent of eating difficulties, nutritional status, and pressure ulcers when admitted for stroke rehab. Also to analyse relationship between eating difficulties, nutritional status and pressure ulcer development.</p>	<p>Type of stroke not specified. Convenience sample. n=162. Inclusion; diagnosed with stroke illness for rehabilitation Exclusions not stated Severity of stroke measured with Katz ADL index.</p>	<p>1.Description and Comparison of patients with and without a need for assisted eating with extent of eating difficulties</p> <p>Measure: Fed self no assistance or required assistance</p> <p>2.Description and Comparison of patients with and without a need for assisted eating with nutritional status</p> <p>Measure; Subjective global assessment</p> <p>3.Description and Comparison of patients with and without a need for</p>	<p>1.At a regular meal Registered nurse functional ability assessed by Katz ADL index</p> <p>Analysed using Mann Whitney U test</p> <p>2.Registered nurses</p> <p>Medical notes Analysed using Mann Whitney U test</p>	<p>Elder care rehabilitation ward</p>	<p>Extent of eating difficulties significantly greater for those requiring assisted eating than those not requiring assistance. When admitted for stroke rehab 32% were at risk of or were already undernourished according to Subjective global assessment. Significantly more patients who needed assisted eating were at risk of or were already undernourished compared to those without this need.</p>	<p>+ no blinding or randomisation Potential observer bias</p>

different findings			<p>assisted eating with pressure ulcers</p> <p>Measure: Not named scored 0-4. Zero good</p> <p>4.The relationship between eating difficulties, nutritional status and pressure ulcer development</p>	<p>3.Registered nurse Measured on a scale ;0-No pressure ulcers 4- full thickness damage with deep cavity Analysed using Mann Whitney U test</p> <p>4.Registered nurse Analysed using Multiple logistic regression to determine risk factors</p> <p>Age and body mass index compared using t-test.</p>		<p>Increased incidence of pressure ulcers in those requiring assistance with eating than those who are independent with eating. For patients with at least one dependency, nutritional status significantly predicts pressure ulceration. Eating difficulties with the strongest predictive value for nutritional status are 'swallowing difficulties', 'eats three quarters or less of served food', 'alertness', 'aberrant eating speed'.</p>	
Reference & Country	Study design /theoretical approach and aim	Participants type of stroke/ severity How recruited/Number/ specific inclusion-exclusion criteria	Outcomes & Outcome measures	Data collection. Method/ by whom/ when. Data analysis methods.	Setting	Results/Key themes All relevant to review question	Quality assessment ++good quality +lesser quality -poor quality (NICE / LEGEND rating)
Westergren, A. et al. 2001b. Eating difficulties, complications and nursing interventions during a period of three months	Descriptive Observational study/ To describe eating difficulties and swallowing in patients with dysphagia, types of nursing intervention, development of	Patients diagnosed with stroke by CT and area of lesion recorded. Infarct n=19 & haemorrhage n=5. Total n=24. Convenience sample.	1 Patients unable to complete a meal due to difficulty concentrating, lack of alertness/ energy, impaired swallow Measure: unable to complete meal 2. Completed meals with great difficulties.	Data collected by observation and assessment of mealtimes or test meal observing for neurological deficits, oral praxia, oral gnosis, ADL, nutritional status(BMI<20;bodyweight ≤80% of reference weight; weight loss >5% from admission; TSF or MUAC subnormal; serum	Medical clinic or geriatric rehabilitation ward	At 3 months 66.7% of participants had improved their ability to swallow and needed none or fewer restrictions and compensatory strategies (p<0.0005).	+ Small sample size. No control

<p>after a stroke. Journal of Advanced Nursing 35(3): 416-426. Sweden</p>	<p>complications over 3 months</p>	<p>Inclusion criteria stroke, positive dysphagia screen. Exclusion unconscious, terminally ill, previous history of dysphagia. Severity of stroke measured with Katz ADL index.</p>	<p>Measure: could complete a meal with supportive strategies 3. Complete meal with minor difficulties. Measure: Compensated for problems on their own. 4. Course of difficulties. Measure: Ability to swallow; level of malnutrition; occurrence of respiratory infections; transition to more regular food from baseline</p>	<p>albumin < 36g/ L⁻¹, respiratory infection. Structured observations of eating carried out by lead author. Observations carried out at baseline (within 48 hours of stroke), 2 weeks, 1 month and 3 months post stroke. Neurological deficits were extracted from medical notes. Data analysis compared dependant variables. Friedman's test used to compare 3-4 dependent samples; kruskal- Wallis used to compare 3 samples, Mann- Whitney U test to compare 2 samples. Severity of stroke measured using Katz ADL index</p>		<p>Number of patients with malnutrition at 3 months from admission increased significantly (p<0.012). Number of patients malnourished at admission 2/24. Serum albumin increased (p<0.003). Occurrence of respiratory infections decreased significantly (p<0.007) between first and 3 month assessment. Transition to more regular food from admission to 3 months significant (p<0.0005). None lived in sheltered accommodation prior to admission but 15 did after discharge (p<0.0005)</p> <p>Three subgroups of patients were identified; those unable to complete a meal; those who could complete a meal with great difficulties; those who could complete a meal with minor difficulties.</p>	
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						Eating and swallowing difficulties stood out as heterogeneous problems among patients after stroke. Alertness/ energy was a conspicuously important obstruction for those with the most severe eating difficulties.	
Westergren, A. et al. 2002. Eating difficulties in relation to gender, length of stay, and discharge to institutional care, among patients in stroke rehabilitation. <i>Disability and Rehabilitation</i> . 24(10): 523-33. Sweden same study population as Westergren (2001a) but presents different findings.	Descriptive Observational study. To describe and compare eating difficulties from admissions to discharge with regard to length of stay(LOS).Discharge to institutional care (LIL) and relation to gender	Type of stroke n=10 haemorrhagic, n=98 ischaemic. Not stated how diagnosed. Convenience sample consecutively recruited over 12 month period. n=108 stroke patients. Inclusion criteria: over 65 years; stroke diagnosed; at least one eating difficulty using Axelsson's protocol (not published) on admission. Severity of stroke measured with Katz ADL index.	1. Eating difficulties and LOS Protocol developed by Axelsson not published in study. Length of stay from admission to rehab ward to day of discharge. Measure: Divided according to median length LOS, 23 days or less short, 24 or more long. 2. Eating difficulties and gender. Measured using protocol for eating difficulties developed by Axelsson not published in study scored either 0 no difficulty or 1 eating difficulty. Outcome 3. Eating difficulties and LIL (level of independent living). Measured by; Discharged to own home (with or without help) or discharged to institutional care. Functional ability measured by Katz ADL index.	Demographic data gathered from medical records or interviews with patient or significant others. Stroke diagnosis from department's patient administration system. Eating difficulty data collection mainly by one RN trained to observe for eating difficulties on admission and discharge also trained other staff to collect data but not stated how many, was observed by author of study. Data analysed between two dependent groups using McNemmar change test for data on a nominal level and Wilcoxon signed ranks test for data on an ordinal level. Paired t-test for interval level of data that were normally distributed. Differences between two independent groups analysed with a Chi square test or Fisher's exact test for nominal level of data, Mann-Whitney U test for	Stroke rehabilitation unit	1. Patients with shorter LOS had 2.9 eating difficulties on admission and 2.3 at discharge, improvement seen most in component ingestion followed by deglutition. Longer LOS had 4.2 difficulties on admission and 2.6 at discharge, improvement in components ingestion followed by energy. Patients with fewer eating difficulties had shorter length of stay ($p < 0.002$). On discharge the mean number of difficulties did not differ between the two groups ($p < 0.253$) 2. More women than men had low food intake on admission	+ no blinding, potential observer bias

				<p>ordinal level data. LOS within rehab divided according to median short 23 days or less, long 24 days or more. Multiple linear regression analysis was performed with LOS as dependent variable.</p>		<p>(women 86%, men 70% $p < 0.040$) and at discharge (women 77%, men 52% $p < 0.010$). Low energy problems higher at discharge for women than men ($p < 0.007$). Most common eating difficulties were low food consumption, difficulties manipulating food on plate and transporting it to mouth. Number of ingestion problems decreased for both genders over hospital stay. 3. Patients returning to own home had a mean of 2.6 eating difficulties on admission and 1.7 at discharge. Discharged to institutional care had mean of 4.2 difficulties on admission and 3.0 at discharge. Those going to own home at discharge had fewer eating difficulties on admission ($p < 0.0005$) also on discharge ($p < 0.0005$). Ingestion difficulties were the most</p>	
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							common followed by low energy. Most common single difficulties were low food consumption; difficulty manipulating food on the plate and transporting it to the mouth.	
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Reference and Country	Study design /theoretical approach and aim	Intervention	Participants type of stroke/ severity How recruited/Number/ specific inclusion-exclusion criteria	Outcomes and Outcome measures	Data collection. Method/ by whom/ when. Data analysis methods.	Setting	Results/Key themes All relevant to review question	Quality assessment ++good quality +lesser quality -poor quality (NICE / LEGEND rating)
Carnaby, G. et al. 2006. Behavioural intervention for dysphagia in acute stroke: a randomised controlled trial. <i>Lancet neurology</i> .5 (1), pp. 31-37. Australia	RCT/ Ascertain whether a standard behavioural intervention for swallowing function after stroke by SLT for 1 month could improve function measured by number returning to pre stroke normal diet 6 months after	Control – usual care (n=102). 1. Standard low intensity intervention (n=102). 2. Standard high intensity intervention and dietary prescription (n=102).	Type of stroke infarct n=273, haemorrhage n=29, unknown n=4/Stroke severity measured with modified Rankin score and modified Barthel index/ total sample n=306/ consecutively recruited/patients presenting over a three year period with stroke/	1 Proportion returned to normal diet at six months. Measure; Needed restricted consistency or special preparation. 2. Time taken to return to normal diet. Every month for six months. Measure: Time.	All data collected every month for six months by independent SLT. Intention to treat Statistical tests, parametric statistical tests e.g. t tests for normally distributed variables. Non parametric tests e.g. Mann Whitney U tests	Acute medical setting	Consistent trend towards more favourable outcomes for standard care v usual care(free of abnormal diet at 6 months p≤0.04; reduction of death and institutionalisation p≤0.06; death and reduction dependency p≤0.87;; reduction medical complications p≤0.05, chest infection p≤	++ Most of questions fulfilled outcome would not differ with changes , unable to blind patients and SLT to treatment, assessor blinded

	stroke compared to usual care. To determine whether intervention improved swallow function; reduce complications; died or institutionalised; dependency for ADL's. Whether there was a dose dependency effect for high or low intensity interventions		Inclusion- clinical diagnosis of stroke, no history of swallowing treatment or surgery to head and neck ; if written consent could be obtained	3. Number of patients who recovered functional swallow Every month for six months Measure: Return to pre stroke diet without swallowing complications	for skewed variables. Odds ratio and CI's for all primary and secondary outcomes. Logistic regression models. Used ANOVA χ^2 test used for discrete counts of patients with particular categories of adverse and dietary events.		0.003; significant rise patients regaining swallow function $p \leq 0.02$) in dysphagic stroke patients who are assigned a standard programme of early behavioural swallowing intervention, including active therapeutic approaches and dietary modification.	
DePippo, K.L. et al.1994. Dysphagia therapy following stroke: A controlled trail. <i>Neurology</i> .44 (9), pp. 1655-1660. USA	RCT/ To determine the effect of graded levels of interventions by a dysphagia therapist on the occurrence of pneumonia, dehydration, calorie- nitrogen deficit, recurrent upper airway obstruction, death, following stroke	No control 1. Patients managed by diet and compensatory swallowing recommendations alone (n=38). 2. Patients managed by a therapist-prescribed diet and compensatory swallowing technique recommendations (n=38). 3. Therapist prescribed and controlled the diet and provided	Type and severity of stroke not stated area of lesion recorded / consecutively recruited/ n=115/ Inclusion: stroke confirmed by CT or MRI; age 20-90; no history of significant oral or pharyngeal anomaly; lab values below end point criteria; failure on Burke dysphagia screening test; modified barium swallow test evidence of dysphagia.	1. The effect of graded levels of intervention by a dysphagia therapist on the occurrence of pneumonia. Measures: +CXR; or three of following- febrile illness>100f; rales or ronchi on auscultation; arterial Po ₂ >10 torr compared to baseline measures; sputum showing significant leukocytes; sputum culture showing	From twice weekly monitoring assessments by SLT to record whether patients were using the compensatory swallowing techniques. Medical notes checked every other week to monitor occurrence of end point variables. Assessed by Intention to treat. Comparability of demographic details between	Stroke patient rehabilitation unit	Group A (least intervention) less likely to develop pneumonia than group B, no mention of group C $p=0.03$. For other 4 outcomes no significant difference between intervention groups. Conclusion: The intensity of treatment using diet alteration and compensatory swallowing techniques did not affect the development of the complications under investigation, pneumonia, dehydration, calorie	++, confidence intervals not given, patients and therapists not blinded, Not controlled to usual care.

		daily reinforcement of the recommended swallowing techniques (n=39).	Exclusion; patients who aspirated \geq 50% of all consistencies	respiratory pathogen 2. The effect of graded levels of intervention by a dysphagia therapist on the occurrence of dehydration. Measure: Serum sodium > 145 or BUN (blood urea nitrogen) >50 not due to primary renal insufficiency or diuretics. 3. The effect of graded levels of intervention by a dysphagia therapist on the occurrence of calorie- nitrogen deficit. Measure: Serum albumin <2.5 or sustained ketonuria without glycosuria over 2 weeks. 4. The effect of graded levels of intervention by a dysphagia therapist on the occurrence of recurrent upper	three groups using kruskal Wallis test for age; Chi square test for distribution of sex, site of lesion, stroke type; ANOVA for admission MMSE score, Barthel score; Chi square test for proportions to compare frequency of MBS abnormalities and of any end point, rates of use of compensatory swallowing techniques among the three groups and the development of any end point. Cox regression model to compare the distribution of time until the development of any end point and its relation to the three treatment groups and the MBS based variables.		Nitrogen deficit, upper airway obstruction.	
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				airway obstruction. Measure: Heimlich manoeuvre on 2 or more occasions 5. The effect of graded levels of intervention by a dysphagia therapist on the occurrence of death measure death				
Xia, W. et al. 2011. Treatment of post stroke dysphagia by vitalstim therapy coupled with conventional swallowing training. <i>Journal of Huazhong University of Science and Technology. Medical Sciences</i> .31(1), pp. 73-76 China	RCT. Aim to investigate the effects of Vitalstim coupled with conventional swallowing training on the recovery of post stroke dysphagia	Control group - conventional swallowing therapy (n=40). 1. Vitalstim therapy only, twice daily for 30 minutes five days a week for four weeks. 2. Vitalstim therapy twice daily for 30 minutes five days a week for four weeks. And conventional therapy	Type of stroke n=44 cerebral haemorrhage; n= 65 cerebral infarcts; n=11 others. Severity of stroke not assessed. Diagnosed by CT or MRI. Consecutively recruited sample n=120. Inclusion: fulfilled diagnostic criteria for cerebrovascular diseases; diagnosed as having cerebral infarction or haemorrhage by CT or MRI; swallow disorder confirmed by water drinking	The effect of vitalstim therapy coupled with conventional swallowing training on swallowing ability post stroke dysphagia. Measured by: Standard swallow assessment (SSA); Surface electromyography (sEMG); Video fluoroscopic swallow study (VFSS); Swallow related QoL questionnaire (SWAL-QOL).	SLT collected data; assessment by SLT of VFSS, SWAL-QOL questionnaire, SSA, SEMG. Data collected prior to commencement of treatment and after treatment which lasted for four weeks. T-test and analysis of variance used for comparison of measurement data. Correlation analysis performed using Pearson test.	Neurology and rehabilitation	No significant differences in SSA, VFSS, SWAL-QOL prior to treatment among the three groups (P<0.05). All groups improved after their particular treatment significantly. Significant improvement from vitalstim and conventional therapy group compared to other two groups. Conventional swallowing therapy sEMG increased significantly after therapy p<0.01 378.7 ±56.2 to 702.2±87.4. higher better	++.RCT but blinding of participants not possible. Assessors blinded to experimental design only

			test; no pulmonary diseases; 40-80 years old; conscious and able to cooperate; provide written informed consent;				<p>SSA $p < 0.01$ lower better 40.9 ± 6.4 to 30.1 ± 3.8 VFSS $p < 0.01$ higher better 2.74 ± 1.64 to 5.32 ± 1.43 SWAI-QOL $p < 0.01$ lower better 863 ± 83 to 624 ± 45</p> <p>Vitalstim therapy</p> <p>sEMG increased significantly after therapy $p < 0.01$ 396.3 ± 62.4 to 733.4 ± 88.3 higher better SSA $p < 0.01$ lower better 38.7 ± 6.9 to 29.6 ± 4.2 VFSS $p < 0.01$ higher better 2.65 ± 1.56 to 5.63 ± 1.57 SWAI-QOL $p < 0.01$ lower better 850 ± 75 to 645 ± 58 Conventional and vitalstim therapy sEMG increased significantly after therapy $p < 0.01$ 382.4 ± 58.6 to 987.1 ± 91.2 higher better SSA $p < 0.01$ lower better 39.5 ± 7.1 to 21.4 ± 3.5</p>	
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							VFSS p<0.01higer better 2.53±1.58to6.88±1.58 SWAI-QOL p<0.01 lower better 885±60 to 458±35	
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Appendix I: Quality assessment of included studies

Summary of evidence evaluation using quality appraisal tools for study type – ordered by study type

Study ID	Study type	Quality appraisal Tool used	Questions and answers from appraisal tool. To be read in conjunction with the relevant appraisal tool. Y=yes N=No ?=Don't know NA = Not Applicable ■ = no questions of that number on this tool															Quality score ++good quality +lesser quality -poor quality (see key below table)	
			Q 1	Q 2	Q 3	Q 4	Q 5	Q 6	Q 7	Q 8	Q 9	Q 10	Q 11	Q 12	Q 13	Q 14	Q 15		
Carnaby, G. et al. 2006.	RCT	CASP RCT	Y	Y	Y	N	Y	Y	Y	?	Y	Y	Y	■	■	■	■	■	++
DePippo, K.L. et al.1994	RCT	CASP RCT	Y	Y	Y	N	Y	Y	Y	N	Y	Y	Y	■	■	■	■	■	++
Xia, W. et al. 2011.	RCT	CASP RCT	Y	Y	Y	N	Y	Y	Y	?	Y	Y	Y	■	■	■	■	■	++
Blackwell, Z and Littlejohns, P. 2010.	Retrospective case note audit	LEGEND descriptive	Y	Y	Y	Y	Y	Y	Y	Y	N	N	Y	Y	Y	NA	Y	Y	-
Carlsson, E. et al. 2010.	Retrospective survey of records	LEGEND descriptive	Y	Y	Y	Y	Y	Y	Y	?	N	N	Y	NA	Y	NA	Y	Y	-
Rosenvinge, S.K. and Starke, I.D. 2005.	Before and after study	CASP cohort	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	■	■	■	■	+
Takahata, H. et al. 2011.	Before and after	CASP cohort	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	?	Y	■	■	■	■	+
Huang, J. et al. 2006.	Comparison study Before and after design study	CASP cohort	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	NA	■	■	■	■	+
Nakamura, T. and Fujishima, I. 2013.	Cross over study	CASP cohort	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	■	■	■	■	+
Foley, N. et al. 2006.	Prospective cohort study	CASP cohort	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	NA	■	■	■	■	+

Carr, E.K. and Mitchell, J.R.A. 1991.	Comparison cross sectional study	LEGEND cross sectional	Y	?	Y	Y	Y	Y	Y	Y	N	N	N	Y	?	Y	NA	Y	-
McGrail, A. and Kelchner, L.N. 2012	Cross sectional study	LEGEND cross sectional	Y	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	Y	NA	Y	+
McLaren, S.M.G. and Dickerson, J.W.T. 2000.	Cross sectional study	LEGEND cross sectional	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	Y	NA	Y	+
Medin, J. et al .2011.	cross sectional study Descriptive design	LEGEND cross sectional	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	Y	NA	Y	+
Perry, L. 2004.	Case series Descriptive observational study	LEGEND descriptive	Y	Y	Y	Y	Y	Y	Y	Y	Y	?	Y	Y	Y	Y	NA	Y	+
Poels, B.J.J. 2006.	Case series Descriptive observational study	LEGEND descriptive	Y	Y	Y	Y	Y	?	Y	Y	Y	Y	Y	Y	?	Y	NA	Y	+
Mosselman, M.J. et al 2013.	Descriptive observational study	LEGEND descriptive	Y	Y	Y	Y	Y	Y	Y	N	Y	N	Y	?	Y	NA	Y	-	
Mould, J. 2009.	Observational audit	LEGEND descriptive	Y	N	N	Y	N	N	N	?	Y	N	Y	Y	Y	Y	?	N	-
Unosson, M. et al. 1994.	Descriptive observational study	LEGEND descriptive	Y	Y	Y	Y	Y	Y	Y	N	?	Y	Y	Y	Y	Y	Y	Y	+
Westergren, A. et al. 2001a.	Descriptive observational study	LEGEND descriptive	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	Y	NA	Y	+	
Westergren, A. et al. 2001b.	Descriptive observational study	LEGEND descriptive	Y	Y	Y	Y	Y	Y	Y	N	?	Y	Y	Y	Y	Y	Y	Y	+
Westergren, A. et al. 2002b.	Descriptive observational study	LEGEND descriptive	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	Y	NA	Y	+	

NICE ratings key (NICE, 2014)

++ All or most of the checklist criteria have been fulfilled, and where they have not been fulfilled the conclusions are very unlikely to alter.

+ Some of the checklist criteria have been fulfilled, and where they have not been fulfilled, or are not adequately described, the conclusions are unlikely to alter.

- Few or no checklist criteria have been fulfilled and the conclusions are likely or very likely to alter.

LEGEND ratings key (CCHMC, 2012)

++ Good quality descriptive/ epidemiologic study; + Lesser quality descriptive/ epidemiologic study; - Not valid, reliable or applicable (poor)

Appendix J: Example of themes by outcome from literature review

AIM: To identify and synthesize evidence from research focusing on support for eating and drinking via the oral route in patients soon after stroke in the hospital setting and examine the reported impact on nutritional status.

Objectives: To determine:

1. The nature of support provided for stroke patients with eating and drinking difficulties in hospital settings.
2. Reported barriers and facilitators to provision of support for eating and drinking post-stroke.
3. Whether stroke patients requiring support with eating and drinking are adequately nourished during their hospital experience.

Studies with ++ or + ratings only included.

Theme by name	Study outcomes	Study ID
<i>2.3.2.1.1 Multiple agents provide support with eating and drinking</i>	Those receiving therapy from SLT had improved outcomes following stroke received swallowing compensation strategies, diet prescription,	Carnaby et al 2006 ++
	Early /increased SLT therapy decreases development of medical complications- Pneumonia, dehydration, calorie nitrogen deficit, recurrent upper airway obstruction, death.	Carnaby et al (2006)++
	Early /increased SLT therapy does not affect development of medical complications The intensity of treatment using diet alteration and compensatory swallowing techniques did not affect the development of the complications under investigation	De Pippo et al (1994)++

	<p>Delivered by SLT. All groups improved after their particular treatment significantly.</p> <p>Significant improvement from vitalstim with conventional therapy group compared to other two groups, vital stim alone and Conventional swallowing therapy alone</p>	Xia et al (2011) ++
	Adherence to SLT recommendations for dietary modifications, no change following training intervention due to unavailability of required diet textures	Rosenvinge and Starke (2005)+
	Staff compliance with SLT recommendation for direct supervision only 36% does not state who are the staff but implied nursing staff.	Rosenvinge and Starke (2005)+
	Adherence to SLT recommendations for consistency of fluids improved following training intervention	Rosenvinge and Starke (2005)+
	Adherence to SLT recommendations for Amounts to be given at one meal/drink improved following training intervention	Rosenvinge and Starke (2005)+
	Adherence to SLT recommendations for Swallowing strategies no change following training intervention	Rosenvinge and Starke (2005)+
	Adherence to SLT recommendations for General safe swallow recommendations improved following training intervention	Rosenvinge and Starke (2005)+
	Adherence to SLT recommendations for level of supervision required improved following training intervention	Rosenvinge and Starke (2005)+

	Adherence to SLT recommendations for consistency of fluids improved following training intervention	Rosenvinge and Starke (2005)+
	Greater overall compliance with SLT instruction on the stroke unit than on other wards highlights the benefits of dysphagic patients being managed on specialist units.	Rosenvinge and Starke (2005)+
	Proportion of patients who could tolerate oral feeding significantly higher in the early intervention group than control. Intervention primarily carried out by nurses under SLT guidance.	Takahata et al (2011)+
	Early initiation of oral feeding and oral care after sufficient preparation by SLT and nurses may safely improve clinical outcomes of ICH patients in terms of survival, chest infection, LOS and swallow function	Takahata et al (2011)+
	SLT support. Swallowing monitored by SLP's dietary modification by SLP's; oral sensorimotor and behaviour intervention (swallowing techniques) assessed by SLP	Blackwell and Littlejohns (2010)+
	Dietetic support. Dietician input for all patients requiring an individualised diet included dietary modifications, nutritional modifications counselling.	Blackwell and Littlejohns (2010)+
	Ice massage shortened latency to triggering swallow reflex in stroke patients with dysphagia compared to dry swallow treatment could be offered by trained therapists.	Nakamura and Fujishima (2013)

Appendix K: Analysis of measures used to assess nutritional status

<i>Name of measure used to assess nutritional status.</i>	<i>Measure indicates cause for concern or undernourished</i>	<i>Studies using this measure</i>
Body Mass index (BMI)	<18 (<65 years) <22 (≥ 65 years)	Poels (2006)
	< 20 (all ages)	Westergren (2001b)
	< 18	Perry (2004)
Unintentional weight loss	> 5% last month > 10% last six months	Poels (2006)
	>5% from admission or Body weight ≤ 80% reference weight	Westergren (2001b)
	Body weight <80% reference weight	Unosson (1994)
Mini nutritional Assessment (Includes BMI, MAC, calf circumference, weight loss, global assessment questionnaire, dietary questionnaire, and self-assessment score.	MNA ≥ 24 well nourished. MNA ≥17 <24 at risk of malnutrition MNA < 17 malnourished	Mosselman (2013)
Tricep skin fold thickness (TSF)	<90% of 12.5mm (men) or 16.5mm(women)	Poels (2006)
	Measure not given	Westergren (2001b)
	Significant deterioration seen during hospital stay	Perry (2004)

	≤6mm (men), ≤12mm(women)	Unosson (1994)
Mid Arm Muscle Circumference(MAC)	<90% of 23.5cm (men) or 23.3cm (women)	Poels (2006)
	Measure not given	Westergren (2001b)
	Significant deterioration seen during hospital stay	Perry (2004)
	≤23cm (men) ≤19cm (women)in those aged ≤ 79years and ≤21cm (men) ≤18cm (women) those aged >79years;	Unosson (1994)
Fat Free Mass (FFM)	≤16kg/ m ² (men)	Poels (2006)
	≤ 15kg/ m ² (women)	
Serum Albumin	serum albumin <35g/L	Poels (2006)
	serum albumin < 36g/ L ⁻¹	Westergren (2001b)
	<2.5	DePippo (1994)
	albumin < 36g/L men and women;	Unosson (1994)
Serum transthyretin	transthyretin<0.20g/L men and <0.18g/L women	Unosson (1994)
Serum sodium	>145	DePippo (1994)
Blood urea Nitrogen (BUN)	>50	DePippo (1994)
Ketonuria	Ketonuria without glycosuria > 2 weeks	DePippo (1994)
Delayed hypersensitivity skin testing	Reactive if measure>10mm, anergic if <10mm at 48hours after administered.	Unosson (1994)

Appendix L: Example of a participation information sheet (MDT)



UNIVERSITY OF LEEDS

STROKE EATING AND DRINKING STUDY

STROKE MULTIDISCIPLINARY TEAM (MDT) INFORMATION SHEET

Version 2 (14/10/16)

Introduction

I would like to invite you to part in a research study. This sheet tells you about the study and what your participation in the study would involve. Please read the following information carefully and ask me about anything that is not clear or you require more information about.

Please discuss this with others if you wish.

What is the purpose of the study?

Some stroke patients may need support with eating and drinking. The study will explore what support is being delivered and by whom. We need to understand what kind of support is sufficient for patient needs and why, and if support could be improved.

Why have you been invited to take part?

You have been approached because you are a member of the (insert name of stroke unit) MDT and you assist with or observe the support they receive with eating and drinking.

Do I have to take part?

No, it is entirely up to you if you want to take part or not. This study has three components: Observing support provided to patients for eating and drinking; and review of medical and care records to see how this support has been documented; and interviews with patients, their informal carers and members of the stroke unit team to discuss support provided. If you decide to take part, you will be asked to sign a consent form for the parts of the study you agree to participate in. You will be given a copy of the consent form and this information sheet to keep. You remain free to withdraw from any part of the study at any time without the need to give a reason. A decision to withdraw from or not take part in the study will not affect others' attitudes towards you at any time. Your information will be kept strictly confidential.

Are you interested? If so please read on

Part 1 – Observations of care and documentary analysis

What will be involved if I agree to participate in part 1?

If you consent to take part, the researcher will agree with you when it would be appropriate to observe the support with eating and drinking you are planning, delivering or recording. The researcher will not take part in any activity, she will watch and make some notes about what she sees occurring. The researcher will ask for permission on every occasion before observing you and will not watch anything that you do not want her to.

Part 2 – Interview

What will be involved if I agree to participate in part 2?

If you consent to take part, the researcher will agree with you when it would be appropriate to interview you to ask you about your experiences with support for eating and drinking as a member of the MDT in the stroke unit. The interview would be conducted at a place and time convenient to you. It is envisaged that the interview would take between 30 minutes to an hour. The researcher will audio record the interview session and may take some written notes in order to accurately recollect what you say.

What are the possible disadvantages and risks of taking part?

The researcher does not anticipate that there will be any risks involved in taking part in the study. During the observations or interview you can stop or take a break at any point. Your professional standing on the stroke unit will not be affected if you choose not to take part.

What are the possible benefits to taking part?

The information gained from this study will probably not directly impact on your practice in the short term. However, it may help us develop and test recommendations designed to enhance support with eating and drinking for future stroke patients.

What if there is a problem?

Any complaint about the way you have been dealt with in the study or any possible harm you might suffer will be addressed. If you have a concern about any aspects of this study, you should ask to speak to the researcher or her supervisor. If you remain unhappy and wish to complain formally, you can do this through the NHS complaints procedure at the hospital.

What will happen if I choose not to carry on with the study?

You are free to withdraw from the study at any time. If you withdraw, the information already collected from you will be included in the final study analysis unless you withdraw consent for your information to be used in which case the information will be confidentially destroyed. If you want to withdraw from the research, please speak to the researcher.

Will my taking part in the study be kept confidential?

Yes. If you decide to take part in the study, all information which is collected about you during the course of the study will be kept **strictly confidential**. The researcher will transfer hand written or audio-recorded notes about her observations onto a password protected University of Leeds computer. The information will be anonymised. You will be given a unique identification number and a pseudonym for the study and only the researcher will be able to identify you from this information. The information will be securely stored at the Academic Unit of Elderly Care and Rehabilitation - Bradford, which is part of Leeds Institute of Health Sciences at the University of Leeds and archived for a period of 3 years at the end of the study. Anonymised research data may be used in future research studies.

What will happen to the results of this study?

The results of this study will be published in a PhD thesis. In addition, the researcher will seek to publish the result in an academic journal and present the results at conferences. You will not be identified in any report or publication. If you wish to obtain a copy of the report on completion of the study this can be requested from the researcher.


What if I need more information or there is a problem?

If you need any further information or have any concerns about any aspects of this study, please contact the researcher Sarah Batt on 01484 472081 or email s.batt@hud.ac.uk or Dr David Clarke (study supervisor) on 01274 383441 or d.j.clarke@leeds.ac.uk .

IF YOU DECIDE THAT YOU WOULD LIKE TO TAKE PART IN THIS STUDY PLEASE READ THE CONSENT FORM. THE RESEARCHER WILL WORK THROUGH THE CONSENT PROCESS WITH YOU.

THANK YOU FOR TAKING THE TIME TO READ THIS INFORMATION.

Appendix M: Recruitment poster



'The Stroke Eating and Drinking Research Study'

What is this about? A researcher is carrying out a study that aims to understand how stroke patients are supported with eating and drinking whilst in hospital.

What is the purpose? Some stroke patients may need support with eating and drinking. The study will explore what support is being delivered and by whom. We need to understand what kind of support is sufficient for patient need and why, and if support could be improved.

How is the study to be conducted? The study has two parts:


1. A period of observations of daily routine activities on the stroke unit, followed by more focused observations of support with eating and drinking involving patients, their informal carers and stroke unit staff. Review of patient care records of those patients who have been observed.
2. Interviews with patients, informal carers and stroke unit staff who have been observed in phase 1.

** You may see the researcher present on the ward, however, unless you agree to participate in the study the researcher will not include you in data collected for the study; they will not ask you for, or record any personal information relating to you*.*

If you require further information please contact:

Sarah Batt (researcher) - 01484 472081 or s.batt@hud.ac.uk or write to Ramsden Building, University of Huddersfield, Queensgate, Huddersfield, HD1 3DH.

Or: Dr David Clarke (study supervisor) – 01274 383441 or d.j.clarke@leeds.ac.uk or write to Academic unit of Elderly Care, Temple Bank House, Bradford Royal Infirmary, Duckworth Lane, Bradford, BD9 6R



Appendix N: Observation recording guide

After Clarke, D. 2012 University of Leeds (Emerson et al., 2011; Spradley, 1980)

Study title: An in-depth inquiry into how stroke patients are supported with eating and drinking (E and D) in stroke units. Non - participant observations and document analysis: Common field note and analysis record.		
		Comments descriptive and reflexive
Date		
Unit Identifier		
Researcher identifier		
Visit number		
Participant identifier (for focused observations only)		
Total duration of non-participant observation		
Locations for observations (with time spent if appropriate)		<p><i>Locations for general unit observations will include</i></p> <ul style="list-style-type: none"> -day rooms or other social communal areas -patient dining areas -bed areas -shared workstation or any area where stroke unit team members routinely congregate to discuss patient activity or meet with patients and informal carers -staff meeting rooms (this can include attending multidisciplinary team meetings) -therapy rooms/gymnasiums/occupational therapy kitchens or facilities which allow patients and informal carers to spend time independent of stroke unit staff in preparation for discharge home <p><i>any additional areas where the researcher determines that it would be appropriate and gains consent to engage in non-participant observation</i></p> <p><i>Focused observations may also include most of the above areas, but will require written informed consent to undertake observations during specific therapy sessions or activities taking place in defined areas of the stroke units</i></p>
Focus of non-participant general observation		<p><i>Areas of focus for general observations will include:</i></p> <ul style="list-style-type: none"> -description of general activities routinely involving interaction between staff, patients and where appropriate with informal carers -description of what appears to be important and meaningful for staff, patients and informal carers in respect of support for E and D activity, for instance staff, patient and informal carers concerns, beliefs and preoccupations where these are verbalised -description of specific activities focusing on provision of support with E and D with other members of the stroke unit team -description of the conditions under which patients, informal carers and staff members conduct their E and D activities and interactions in the units,

		<p>including perceived barriers and facilitators</p> <ul style="list-style-type: none"> -description of staff interactions concerning E and D -description of informal unplanned E and D activity, which appears to contribute to or reinforce E and D activity -summary records of dialogue between participants may also be recorded when this is considered appropriate. Where verbatim recording of dialogue is considered important then written informed consent will be required from the participants. In the case of recurring dialogue, content which relates broadly to meeting the aims of the study, should not require consent. <p>Additional areas of focus may emerge in each study site - researcher will develop fieldnotes in these areas</p>
Focus of non-participant focused observations		<p>The focused non-participant observations will include the above, but here the researcher is seeking more fine-grained and detailed description (and later explanation), which will aid in understanding:</p> <p>Including:</p> <ul style="list-style-type: none"> -the context of the activity supporting E and D -who leads and is participating in supporting E and D activity -the nature and purpose of supporting E and D activity as articulated by the nursing staff, nursing assistants, therapists, therapy or rehabilitation assistant or other member of the stroke team -how the participants appear to respond to, participate in, feel about, describe, explain and make sense of the activity supporting E and D -the researcher's perceptions of the relationship of the activity to the aims of the study (how does this activity support E and D?) <p>Additional areas of focus may emerge in each study site - the researcher will develop fieldnotes in these areas</p>
Documents reviewed in relation to the focused observations only (written consent will be needed)		<p>Documentary analysis is designed to capture any textual information which will aid in understanding how support with E and D activity is reported upon by stroke unit staff.</p> <p>Documents reviewed may include:</p> <ul style="list-style-type: none"> -shared patient records (for example, multidisciplinary team notes) -individual patient records (for example, the medical notes, the notes developed by nurses, therapists or any other stroke unit team member working with patients and informal carers) -information sheets describing E and D activities in the unit or information on involvement of informal carers in supporting E and D activities. - carer /family contextual information for example discussions in MDT meetings, records of home visits, assessments of preparedness for discharge regarding E and D activities
Expanded field note record		<p>Detailed notes and reflections of the researcher completed during the period of non-participant observations or documentary analysis (these will of course be written up following the period of observation). Ideas, impressions, thoughts, and/or any criticisms you have about what you observed. Include any unanswered questions or concerns that have arisen from analyzing the observation data. Clarify points and/or correct mistakes and misunderstandings in other parts of field notes. Include insights about what you have observed and speculate as to why you believe specific phenomenon occurred.</p> <p>Record any thoughts that you may have regarding any future observations.</p> <p>The researcher may use notebooks and a digital recording device in the field, but overall observation records will be completed and saved (securely) electronically using this document</p>
Linked memo number		<p>The researcher will record and develop memos</p> <p>Memos are not simply "ideas." They are involved in the formulation and revision of explanations for the processes observed and later in the development of theory during the research process. Writing theoretical memos is an integral part of doing qualitative field research.</p>
Other relevant information		

Appendix O: Example of fieldnotes

<p>13.7.17 Visit 5 11.30</p>	<p>SB2</p>	<p>Ward entry area is quiet and on entering the main ward corridor, the ward appears calm. I can see two members of staff going in and out of a bay; they appear calm in movements and unhurried. It is a bright sunny day outside and the ward appears bright. I note the staffing number off the window by the nurse's station.</p> <p>Early – 4 RNs and a SR in charge, 4 CSWs Late – 3 RNS +SR in charge, 3 CSWs Nights – 2 RNs, 3 CSWs.</p> <p>The whiteboard shows that all 28 beds are occupied.</p>	
	<p>11.55</p>	<p>The WA is taking the drinks trolley around the ward with hot drinks. I seat myself in bay 6 where I have 3 pts recruited to the study. The bay is very bright and sunny as it has very long windows. I sit on the window seat, which runs under the window approx. 12" off the floor. The pts. all say hello and we engage in some general conversation about how they are and what has been happening on the news. 2 pts. are in bed and 2 are sat out. P1 is in bed, he starts to tell me about what he did before he retired. He then starts to talk about his experiences on the acute stroke unit about E and D, stats that he really didn't want to eat, he just couldn't face food when he first came in after having his stroke. After a few days, one of the Drs had a conversation with him, was quite blunt, and said if you don't start to eat you are not going to get any better. P1 then put his mind to getting better and made himself eat even if he did not feel like it, he says it was hard to do at times (48).</p> <p>During this time two of the pts. have been behind curtains and there is an odour of faeces hanging in the bay (49).</p>	<p>48. Cross check with interview evidence with pt. 1.</p> <p>49. Unpleasant smell at mealtimes, ask at interviews if pts notice or if this has any effect on E and D.</p>

Appendix P: Interview topic guides

Interview topic guide - Patient

Preparation

Ensure private room with enough space to accommodate the patient and the interviewer comfortably - not encroaching on each other's personal space. Ensure that there are no barriers between the patient and the interviewer. Ensure recording equipment is prepared and spare batteries are available.

Introduction

- Welcome the patient to the interview and express thanks for agreeing to participate
- Check written informed consent.
- Outline the aim of the study and the interview session.
- Explain that the interview will be recorded and the interviewer may take written notes.
- Explain again that the interview can be stopped at any time.
- Explain again that the patient does not have to answer questions they do not want to.
- Explain that if it becomes apparent during the discussions that they are at risk of harm, or have experienced professional malpractice, the researcher will follow the University of Leeds Safeguarding Adults Procedure. The researcher will talk to them about their views and wishes, including whether they wish any action to be taken. There may be circumstances when the researcher is obliged to act and breach confidentiality, including: if they lack capacity and it is in their best interests; if there is a life-threatening situation; if they are subject to coercion; or if there is risk to others.
- Provide an opportunity for the patient to ask any questions.

Questions

This is a guide to questions that may be asked during the interview. Further questions may be developed from observation sessions and documentary analysis.

If not initiated by the patient, the interviewer opens questioning by asking:

(Bullet points denote sub- questions and prompts)

1. 'Could you tell me a little bit about yourself?'
 - Life prior to stroke.
2. 'Could you tell me about how your stroke has affected you?'
 - Functionally, Emotionally, Socially
3. 'Could you tell me how your stroke has affected your ability to eat?'
 - Functionally, Emotionally, Socially
4. 'Could you tell me how your stroke has affected your ability to drink?'
 - Functionally, Emotionally, Socially

5. 'Could you describe a time when you required support to eat whilst in the stroke unit?'
 - Functionally, Emotionally, Socially
 - 'Where did this occur?'
6. 'Could you describe a time when you required support to drink whilst in the stroke unit?'
 - Functionally, Emotionally, Socially
 - 'Where did this occur?'
7. 'Could you tell me who decided you needed support to eat or drink?'
 - Functionally, Emotionally, Socially
 - You; relative/ friend; member of the MDT
 - 'Why do you think they thought support was required?'
 - 'Where did this occur?'
8. 'Could you tell me who you think offered you support with eating?'
 - 'Can you tell me why you think this is?'
 - 'Is this the same for support with drinking?'
 - 'If not, then how did this differ?'
9. 'Could you tell me if different members of the stroke unit team supported you to eat?'
 - 'If yes, then who and how?'
 - 'Can you tell me why you think this was?'
 - 'Is this the same for drinking?'
 - 'If not, then how did this differ?'
10. 'Did anyone other than the members of the stroke unit team support you to eat?'
 - 'If yes, then who and how?'
 - 'Can you tell me why you think this was?'
 - 'Was this the same for drinking?'
 - 'If not, then how did this differ?'
11. 'Could you tell me how you felt during those experiences?'
 - 'Can you tell me why you felt that way?'
 - 'Did you feel the same when supported to eat as when you were supported to drink?'
 - 'If not, then how did this differ?'
12. 'Could you tell me if you think you ate enough whilst in the stroke unit?'
 - 'If yes, then why?'
 - 'If no, then why?'
 - 'Was this the same for drinking?'
 - 'If not, then how did this differ?'
13. 'Could you describe an experience where you felt encouraged to eat whilst on the stroke unit(s)?'
 - Functionally, Emotionally, Socially, Environmentally
 - 'If yes, then why?'

- 'If no, then why?'
 - 'Was this the same for drinking?'
 - 'If not, then how did this differ?'
14. 'Could you describe an experience where you felt discouraged to eat whilst on the stroke unit(s)?'
- Functionally, Emotionally, Socially, Environmentally
 - 'If yes, then why?'
 - 'If no, then why?'
 - 'Was this the same for drinking?'
 - 'If not, then how did this differ?'
15. 'What do you know about the organisation of food delivery on the stroke unit(s)?'
- 'Is this the same for drinks?'
 - 'If not, then how does this differ?'
16. 'Was food available at times that were appropriate to you?'
- 'If yes, then why?'
 - 'If no, then why?'
 - 'Was this the same for drinks?'
 - 'If not, then how did this differ?'
17. Was the food available appropriate for you?'
- 'If yes, then why?'
 - 'If no, then why?'
 - 'Was this the same for drinks?'
 - 'If not, then how did this differ?'
18. 'Can you think of any other issues that may have affected how you could have been supported to eat on the stroke unit(s)?'
- 'If yes, then how?'
 - 'Is this the same for drinking?'
 - 'If not, then how does this differ?'
19. 'Is there anything else you would like to ask or tell me about support with eating and drinking whilst you were a patient in the stroke unit(s)?'
20. 'Is there anything else you would like to ask me about the study you are participating in?'

Close session with thanking the patient. Offer the opportunity to ask any further questions.

Interview topic guide – Informal carer

Preparation

Ensure private room with enough space to accommodate the informal carer and the interviewer comfortably - not encroaching on each other's personal space. Ensure that there are no barriers between the informal carer and the

interviewer. Ensure recording equipment is prepared and spare batteries are available.

Introduction

- Welcome the informal carer to the interview and express thanks for agreeing to participate
- Check written informed consent.
- Outline the aim of the study and the interview session.
- Explain that the interview will be recorded and the interviewer may take written notes.
- Explain again that the interview can be stopped at any time.
- Explain again that the informal carer does not have to answer questions they do not want to.
- Explain that if it becomes apparent during the discussions that they are at risk of harm, or have experienced professional malpractice, the researcher will follow the University of Leeds Safeguarding Adults Procedure. The researcher will talk to them about their views and wishes, including whether they wish any action to be taken. There may be circumstances when the researcher is obliged to act and breach confidentiality, including: if they lack capacity and it is in their best interests; if there is a life-threatening situation; if they are subject to coercion; or if there is risk to others.
- Provide an opportunity for the informal carer to ask any questions.

Questions

This is a guide to questions that may be asked during the interview. Further questions may be developed from observation sessions and documentary analysis.

If not initiated by the informal carer, the interviewer opens questioning by asking:

(Bullet points denote sub-questions and prompts)

1. 'Could you tell me about how your relative/ friend's stroke has affected them?'
 - Functionally, Emotionally, Socially
2. 'Could you tell me if your relative/ friend's stroke has affected their ability to eat?'
 - Functionally, Emotionally, Socially
3. 'Could you tell me if your relative/ friend's stroke has affected their ability to drink?'
 - Functionally, Emotionally, Socially

4. 'Could you describe a time when you supported your relative/ friend to eat whilst in the stroke unit?'

- Functionally, Emotionally, Socially

5. 'Could you describe a time when you supported your relative/ friend to drink whilst in the stroke unit?'

- Functionally, Emotionally, Socially

6. 'Could you tell me how you felt during those experiences?'

- 'Can you tell me why you felt that way?'
- 'Did you feel the same when you supported them to eat as when you supported them to drink?'
- 'If not, then how did this differ?'

7. 'Could you tell me how you think your relative/ friend felt during those experiences?'

- 'Can you tell me why you think they felt that way?'
- 'Did they feel the same when you supported them to eat as when you supported them to drink?'
- 'If not, then how did this differ?'

8. 'Could you tell me who decided your relative/friend needed support to eat or drink?'

- Functionally, Emotionally, Socially
- You; relative/ friend; member of the MDT
- 'Why do you think they thought support was required?'
- 'Where did this occur?'

9. 'Could you tell me who you think offered your relative/ friend support with eating and drinking whilst on the stroke unit?'

- 'Can you tell me why you think this was?'
- 'Was this the same for support with drinking?'
- 'If not, then how did this differ?'

10. 'Could you tell me if different members of the stroke unit team supported your relative/ friend to eat and drink whilst on the stroke unit?'

- 'If yes, then who (profession) and how?'
- 'Can you tell me why you think this was?'
- 'Was this the same for drinking?'
- 'If not, then how did this differ?'

11. 'Could you tell me if you think your relative/ friend ate enough whilst in the stroke unit?'

- 'If yes, then why?'
- 'If no, then why?'
- 'Was this the same for drinking?'
- 'If not, then how did this differ?'

12. 'Could you describe an experience where you felt encouraged to support your relative/ friend to eat?'

- Functionally, Emotionally, Socially, Environmentally
- 'If yes, then why?'
- 'If no, then why?'
- 'Was this the same for drinking?'
- 'If not, then how did this differ?'

13. 'Could you describe an experience where you felt discouraged to support your relative/ friend to eat?'

- Functionally, Emotionally, Socially, Environmentally
- 'If yes, then why?'
- 'If no, then why?'
- 'Was this the same for drinking?'
- 'If not, then how did this differ?'

14. 'What do you know about the organisation of food delivery on the stroke unit(s)?'

- 'Was this the same for drinks?'
- 'If not, then how did this differ?'

15. 'Was food available at times that were appropriate to your relative/friend?'

- 'If yes, then why?'
- 'If no, then why?'
- 'Was this the same for drinks?'
- 'If not, then how did this differ?'

16. 'Was the food available appropriate for your relative/friend?'

- 'If yes, then why?'
- 'If no, then why?'

- 'Was this the same for drinks?'
- 'If not, then how did this differ?'

17. 'Can you think of any other issues that may have affected how your relative /friend could have been supported to eat whilst on the stroke unit(s)?'

- 'If yes, then how?'
- 'Was this the same for drinking?'
- 'If not, then how did this differ?'

18. 'Is there anything else you would like to ask or tell me about support with eating and drinking whilst your friend/relative was in the stroke unit(s)?'

19. 'Is there anything else you would like to ask me about the study you are participating in?'

Close session with thanking the informal carer. Offer the opportunity to ask any further questions.

Interview topic guide – Multidisciplinary team members

Preparation

Ensure private room with enough space to accommodate the participant and the interviewer comfortably - not encroaching on each other's personal space. Ensure that there are no barriers between the participant and the interviewer. Ensure recording equipment is prepared and spare batteries are available.

Introduction

- Welcome the participant to the interview and express thanks for agreeing to participate
- Check written informed consent.
- Outline the aim of the study and the interview session.
- Explain that the interview will be recorded and the interviewer may take written notes.
- Explain again that the interview can be stopped at any time.
- Explain again that the participant does not have to answer questions they do not want to.
- Explain again that confidentiality will be maintained unless the researcher has concerns that the participant is describing abuse or medical malpractice. In this case confidentiality will be broken in order to alert relevant hospital services.

- Provide an opportunity for the participant to ask any questions.

Questions

This is a guide to questions that may be asked during the interview. Further questions may be developed from observation sessions and documentary analysis.

If not initiated by the participant, the interviewer opens questioning by asking:

(Bullet points denote sub-questions and prompts)

1. 'Could you tell me about your experience working on the stroke unit?'

- Profession
- Length of time on this unit
- Previous experience caring for stroke patients

2. 'What do you know about the organisation of food delivery on the stroke unit(s)?'

- 'Is this the same for drinks?'
- 'If not, then how does this differ?'

3. 'Do you think that food is available at times that are appropriate to the patients?'

- 'If yes, then why?'
- 'If no, then why?'
- 'Is this the same for drinks?'
- 'If not, then how does this differ?'

4. 'Do you think the food available is consistently appropriate for the patients?'

- 'If yes, then why?'
- 'If no, then why?'
- 'Is this the same for drinks?'
- 'If not, then how does this differ?'

5. 'Could you tell me whose role you think it is to support stroke patients to eat on the stroke unit?'

- 'Who (informal carer, MDT member) and how?'
- 'Can you tell me why you think this is?'
- 'Is this the same for drinking?'

- 'If not, then how does this differ?'
7. 'Could you tell me who initially decides that there is a need for support to eat or drink?'
- Functionally, Emotionally, Socially
 - Yourself; patient; relative/ friend; another member of the MDT
 - 'Why do you think this is so?'
6. 'Could you tell me who you think offers support to stroke patients with eating on the stroke unit?'
- 'Who (informal carer, MDT member) and how?'
 - 'Can you tell me why you think this is?'
 - 'Can you tell me what you think about this?'
 - 'Can you tell me how you feel about this?'
 - 'Is this the same for support with drinking?'
 - 'If not, then how does this differ?'
7. 'Could you describe a time when you supported a stroke patient to eat on the stroke unit?'
- Support may have been functional, emotional, and social
 - 'Could you tell me how you felt during that experience?'
 - 'Can you tell me why you think you felt that way?'
 - 'Is this the same for support with drinking?'
 - 'If not, then how did this differ?'
8. 'Could you tell me how you found out that the patient needed support to eat or drink?'
- Functionally, Emotionally, Socially
 - Patient/ relative; Own assessment; Instruction from another MDT member (when?); looking at care records.
 - 'Can you tell me what you think about that?'
 - 'Can you tell me how you feel about that?'
9. 'How do you usually find out if a patient needs support to eat and drink?'
- Functionally, Emotionally, Socially
 - Patient/ relative; Own assessment; Instruction from another MDT member (when?); looking at care records.

- 'Can you tell me what you think about that?'
 - 'Can you tell me how you feel about that?'
10. 'How do you usually communicate to others that a patient requires support to eat or drink?'
- Functionally, Emotionally, Socially
 - To whom: patient; informal carer; other MDT members
 - Verbally (when); Written (when and where)
 - 'Can you tell me what you think about that?'
 - 'Can you tell me how you feel about that?'
11. 'Could you describe an experience where you felt encouraged to support a stroke patient to eat?'
- Functionally, Emotionally, Socially, Environmentally
 - 'If yes, then why?'
 - 'If no, then why?'
12. 'Could you describe an experience where you felt discouraged to support stroke patients eat?'
- Functionally, Emotionally, Socially, Environmentally
 - 'If yes, then why?'
 - 'If no, then why?'
13. 'Could you describe an experience where you felt encouraged to support a stroke patient to drink?'
- Functionally, Emotionally, Socially, Environmentally
 - 'If yes, then why?'
 - 'If no, then why?'
14. 'Could you describe an experience where you felt discouraged to support a stroke patient to drink?'
- Functionally, Emotionally, Socially, Environmentally
 - If yes, then why?'
 - If no, then why?'
15. 'Could you tell me if you think patients requiring support eat enough whilst on the stroke unit?'
- Functionally, Emotionally, Socially
 - 'If yes, then why?'

- 'If no, then why?'
- 'Is this the same for drinking?'
- 'If not, then how does this differ?'

16. 'Can you think of any other issues that may affect how patients are supported to eat whilst on the stroke unit(s)?'

- 'If yes, then how?'
- 'Is this the same for drinking?'
- 'If not, then how does this differ?'

17. 'Is there anything else you would like to ask or tell me about support with eating and drinking for patients during the stroke unit(s) stay?'

18. 'Is there anything else you would like to ask me about the study you are participating in?'

Close session with thanking the participant. Offer the opportunity to ask any further questions.

Appendix Q: Documentary Data - Data collection guide

1. TYPE OF DOCUMENT e.g., Case notes; MDT record; assessment proforma.	
2. UNIQUE PHYSICAL CHARACTERISTICS OF THE DOCUMENT e.g., hand written, fully completed	
3. DATE(S) OF DOCUMENT:	
4. AUTHOR (OR CREATOR) OF THE DOCUMENT: POSITION (TITLE):	
5. FOR WHAT AUDIENCE WAS THE DOCUMENT WRITTEN?	
6. DOCUMENT INFORMATION (a-f)	
a. List things the author said that you think are important:	
b. Why do you think this document was written?	
c. What evidence in the document helps you know why it was written? Quote from the document.	
d. List things the document tells you about support with E and D at the time it was written.	
e. Write any questions that are left unanswered by the document	
f. Any further notes or comments	

Appendix R: Example of code book from NVivo 12

Codes\\Site A patients 5th attempt Nov 18

Name	Description
Adapting to E and D with stroke deficit	How patients say they manage to eat, how have they adapted
Drinking less	Patients describe drinking less so that they do not need to ask to go to the toilet as often.
Negative views about eating and drinking	Patient's comments about how they feel about eating and drinking since stroke.
Patient Choosing different foods since stroke	Discuss changes to food choices such as soft foods, and comments as to why this was doing. Chewing issues or cutting up issues. Eating or drinking less.
Require preparation of food and drink different to pre stroke	Comments about needing food preparing e.g., cutting up, mashing
Appearance of modified diets	comments about how puree meals etc. look and if this had any effect on the patient
taste of modified diets	did these taste any differently to normal food?
Thickened drinks	comments about having to use thickener in drinks
Changes to hand since stroke affecting E and D	Comments about stroke affecting hands and therefore ability to eat and drink.
Communication of requirements	Comments about patients' requirements were communicated to others MDT and ICs

3rd attempt same notes to see if get 10/5/18
Same groupings.

What is Support

Physical support - 'doing'

Whose job

Staff's emotional ~~response~~ response supporting

Ward culture

Patient rapport

Patient's experience from staff perspective
psychological effects

Where

Resources

DRUGS

FOOD

Quality of food

Availability

Delivery perceived

MISSING MEALS + attempts to manage medication

100 BUSY

MDT nutritional awareness

Monitoring E+D

Informal carers supporting

MDT experience with stroke

Risk Perception

What would help?

Training E+D issues.

Who needs what support?
What An staff know?

Appendix T: Thematic analysis Phase 5: Example of a theme narrative.

MDT interviews site A

Theme 1. Who needs support with eating and drinking?

All members of the MDT interviewed made some response that was included in this theme. The theme explores how a need for support with eating and drinking is identified and how this requirement is communicated to the relevant people.

Ten nodes supported this theme divided into two subthemes *1.1 – Identifying a need for support* and *1.2 – Communicating a need for support*.

1.1 – Identifying a need for support with eating and drinking

A range of formal assessments performed as part of hospital protocol were discussed by the participants that when completed may indicate a need for support. These including an initial swallowing screen...

All participants thought of direct observation usually during mealtimes as being the most frequent method of identifying an initial need for support. Specific members of the MDT were thought to identify needs with HCAs and RNs being the staff groups most likely to identify an initial need for support, as they are the staff around at mealtimes.

Identification of a need to support eating and drinking is therefore dependent on the knowledge and skill of the RNs and more so the HCAs to be able to do this.

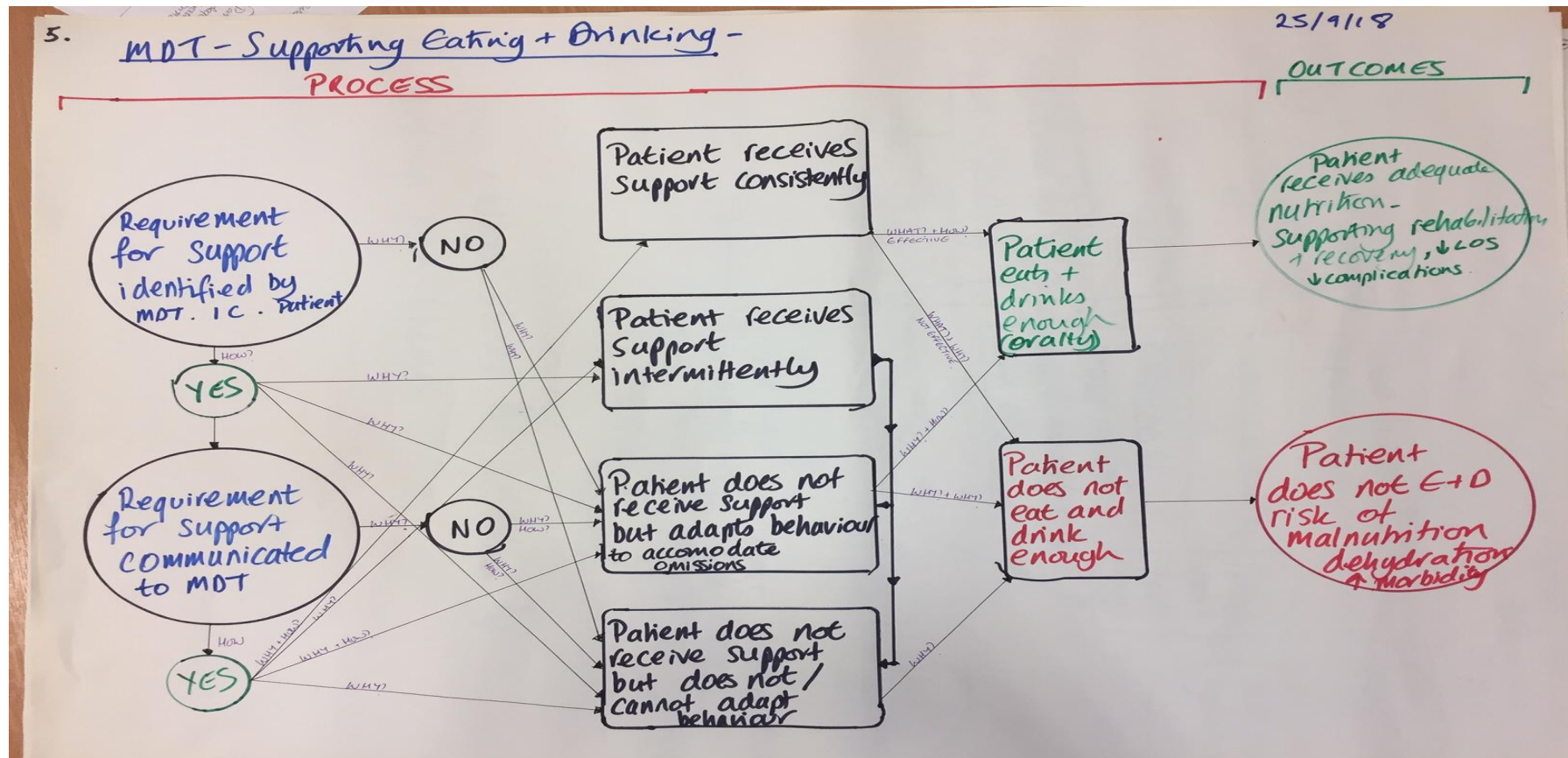
Alternatively, a need for support may not be identified for other reasons.

Some participants were initially alerted to concerns about weight loss by relatives...

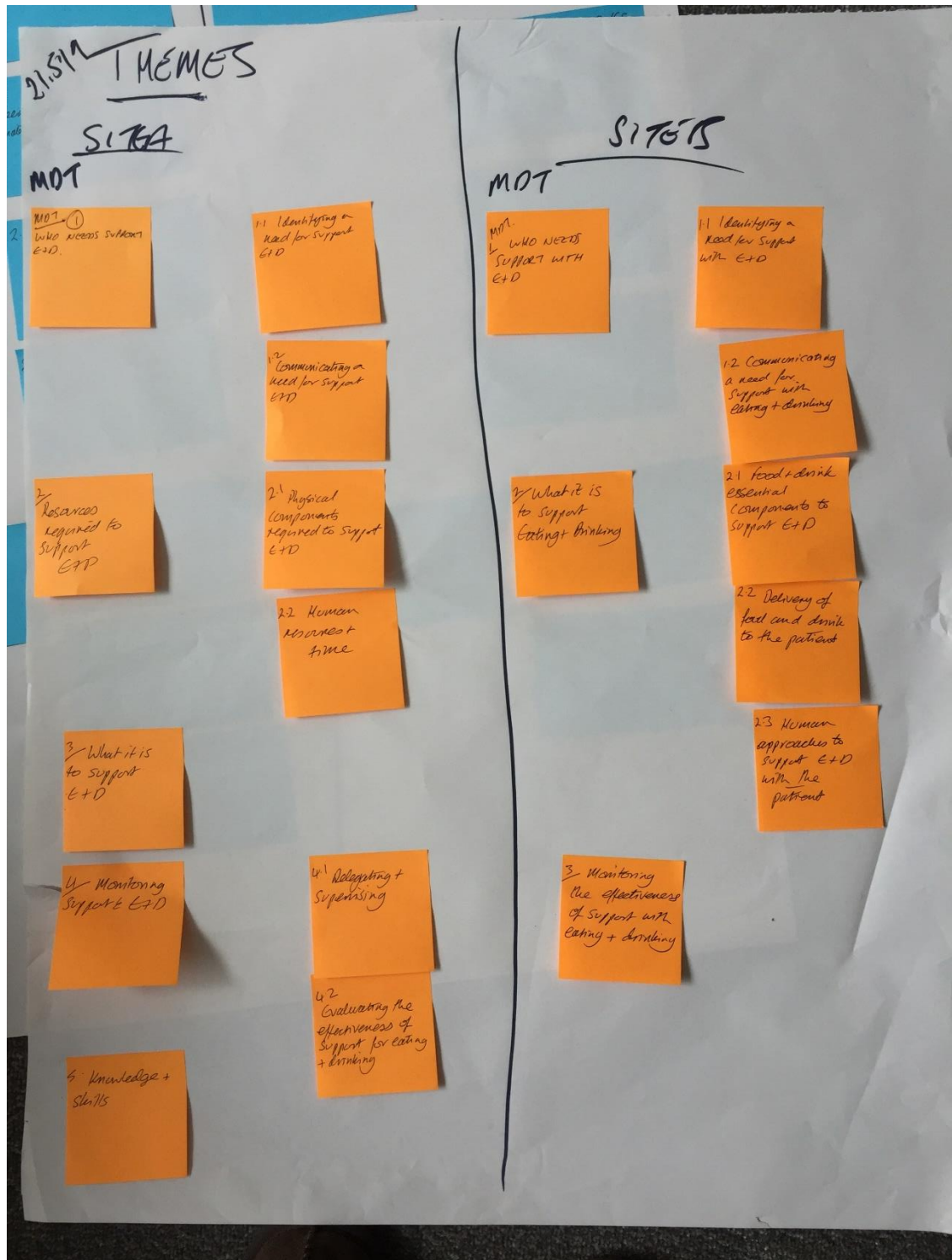
The comments above further support the idea that the MDT are not always identifying a need for support with eating and drinking. The attainment of knowledge and skills to support eating and drinking is further discussed in theme 5.

Appendix U: Examples of phase 6: Thematic Analysis

Diagrammatic story of support with eating and drinking from MDT interviews site A



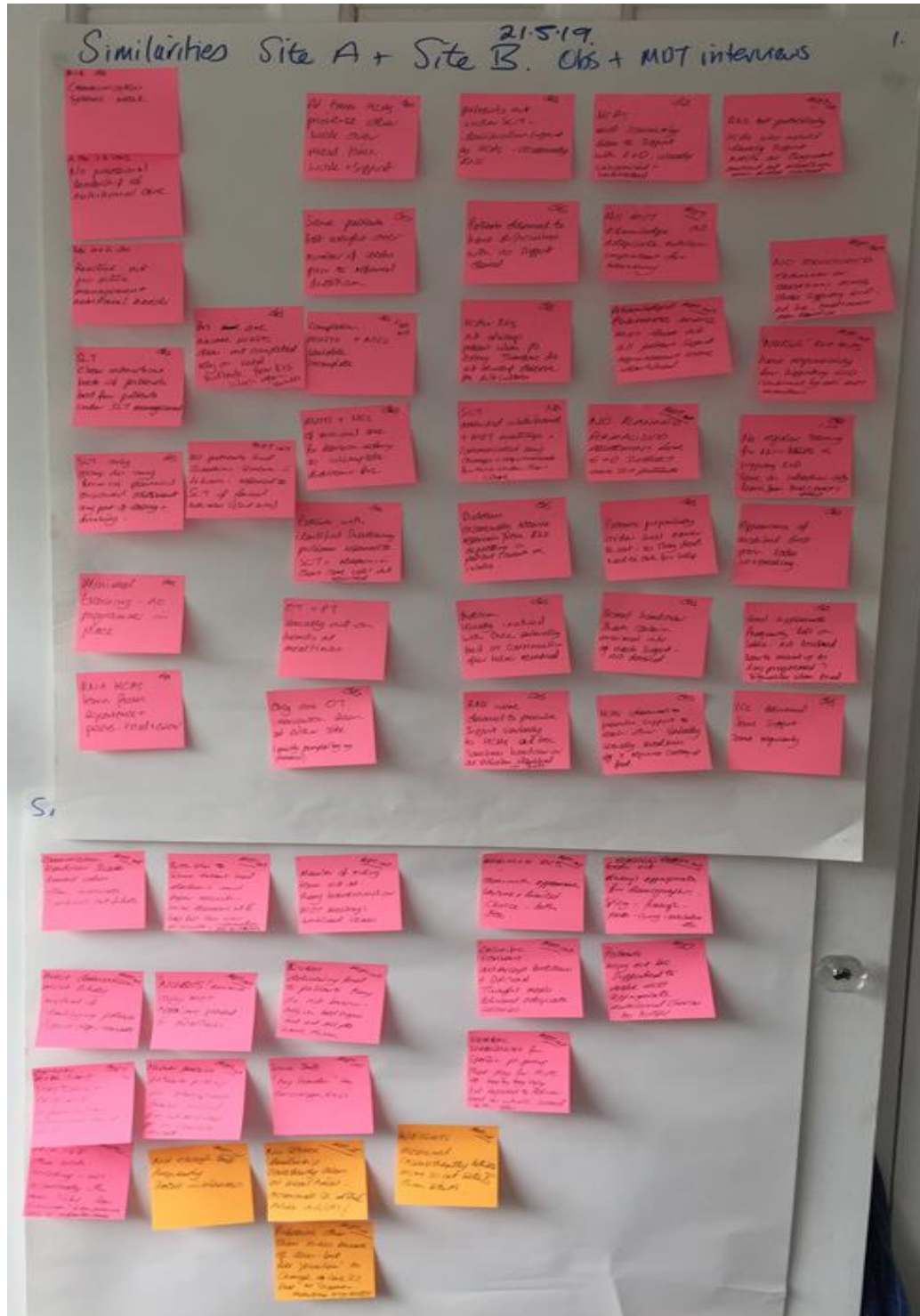
Appendix V: Comparison of themes and subthemes



Appendix W: Synthesis of findings

Example similarities and differences site A and site B

Similarities



Differences

21-5-19 Differences Site A + Site B. Chs, MPT, IC + P interviews

A B

The sticky notes are organized into two main columns, A and B, separated by a red vertical line. Column A (left) contains approximately 15 yellow sticky notes, while Column B (right) contains approximately 25 green sticky notes. The notes are arranged in a grid-like fashion, with some overlapping. The text on the notes is handwritten and appears to be a list of differences or observations related to 'Site A' and 'Site B' across various categories: 'Chs', 'MPT', 'IC', and 'P'. The notes are densely packed and cover most of the page area.

Appendix X: Example consent form (MDT)



UNIVERSITY OF LEEDS

IRAS Number: 208171	Participant ID:
Researcher: Sarah Batt	Centre ID:

STROKE EATING AND DRINKING STUDY

MULTIDISCIPLINARY TEAM (MDT) MEMBER CONSENT FORM

Version 2 (14/10/16)

1.	I confirm that I have read the information sheet dated 14/10/16 (Version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	Initial:
2.	I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason and without my legal rights being affected.	Initial:
3.	I understand that my data will be collected for this study and may be used to help develop new research. I understand that my anonymised data may be used in future research studies other than this one, that data protection regulations will be observed, and strict confidentiality maintained unless there are concerns that I or someone else is at risk of harm.	Initial:
4.	I understand that even if I withdraw consent to take part in the study, the data already collected will contribute to the study unless I specifically withdraw consent for this. I understand that my identity will remain anonymous.	Initial:
5.	I understand that a copy of this consent form will be held at the Academic Unit of Elderly Care and Rehabilitation - Bradford, which is part of Leeds Institute of Health Sciences at the University of Leeds.	Initial:
6.	I agree for the researcher to conduct observations for the purpose of the study.	Initial:
7.	I agree to have an interview and for the interview to be audio recorded.	Initial:
8.	I agree to take part in the above study.	Initial:

MDT member: name in capitals	SIGNATURE:	DATE:
RESEARCHER: name in capitals	SIGNATURE:	DATE:

Original to researcher; 1 Copy to MDT member.