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An exploration of the "feeding partnership" between patients with late stage dementia and nursing staff.

Submitted for the degree of
Doctor of Philosophy
by
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Department of Language and Communication Science

February 2003

Volume One

"Dementia touches everyone."
(Goldsmith, 1996)

Dedicated to my family,
Grandad,
and those who care and support him.

February 2003

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Thank you.

Rachael Henton

October 2002

Declaration

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Abstract

This study explores the nature of feeding partnerships between patients with late stage dementia and nursing staff. Twelve video dyads, consisting of four female patients and three members of their nursing team, were recorded during feeding. All twelve videos were made during the midday meal, within the normal nursing environment of the continuing care ward of a psychogeriatric unit. The videos were transcribed using an adapted conversation analysis technique.

A number of small scale studies were carried out on the data. A correlation was found between the amount and type of speech used by the members of staff and the amount of food successfully fed to the patients. Demarcation of feeding was lost when there were high levels of speech, suggesting that staff members' communication should be task related so as to enable feeding cues to be detected.

The findings were interpreted against a summary model which was then reconfigured into three stages. The roles of the members of nursing staff and the speech and language therapist were conceptualised and three key components of intervention during feeding portrayed. The model emphasises the staff-patient partnership and the direct and indirect influence the speech and language therapist exerts on this.

Suggestions are made for further exploration and future research including communication and feeding profiles, analysis of different demarcation processes and the development of a demarcation hierarchy. Such an intervention would relate equally to other clinical areas such as neurology and learning disabilities.

A number of factors were identified which challenge current speech and language therapy practice, including the link between interaction and successful feeding. It is advocated that dysphagia and communication therapies should be placed on opposing ends of a continuum rather than being viewed as separate constituents to speech and language therapy intervention. By proposing such a continuum it is possible to see how therapy can be targeted at the specific, task related interaction that is necessary for successful feeding.

Chapter One

Chapter One

Background information and problem situation.

This introductory chapter describes how the study was developed. It discusses the role of speech and language therapists in the provision of care for patients with dysphagia and patients with dementia. The researcher's own clinical role involves both disorders, and an interest has been developed in the interactions that take place between patients with dementia and members of nursing staff during feeding. This is referred to throughout the study as the "feeding partnership" and it is the nature of this partnership that the study explores.

1.1 Clinical background to project development.

1.1.1 Speech and language therapists in dysphagia care:

Much of the speech and language therapist's role is concerned with the treatment of swallowing disorders, or *dysphagia*. Speech and language therapists are well suited to take on dysphagia work due to the extensive training they receive in the anatomy, physiology and neurology of the musculature involved in speaking (Enderby and Petheram, 2000; RCSLT, 1996, 1998a). The same musculature is used to swallow, and any neurological damage or developmental disorder which affects the speech mechanism may also affect the swallowing mechanism. The input of such speech and language therapy has been shown to significantly improve health outcomes for patients with dysphagia (Lucas and Rodgers, 1998).

The degree to which speech and language therapists have taken on the role of dysphagia specialist continues to increase, and some districts report more than a threefold increase in the number of patients referred for swallowing assessment (RCSLT, 1998a). Such intervention tends to be prioritised over communication work and many clinicians report little time for communication therapy. This has caused great concern amongst therapists and other professions alike, especially when a dysphagia service is seen to exist at the expense of services for people with acquired communication disorders (Stewart, 2001; Whitworth and Parr, 1998).

> *"Is dysphagia a cuckoo in the nest, displacing speech and language therapists' work with people with communication impairment?"*
> (RCSLT, 1998b, p1-2)

The Royal College of Speech and Language Therapists addressed the issues surrounding dysphagia at a policy review forum in July 1998, and has continued to address them *via* the Professional Standards Board (RCSLT, 1999a). Guidelines are now available for therapists (RCSLT, 1998a) and are currently being reviewed (expected late 2001).

There are also implications relating to training, both of students and qualified therapists. Until recently dysphagia was only trained at postgraduate level. The researcher is aware that it remains difficult to find appropriate postgraduate courses, such as in the specialist areas of learning disability or dementia care. Some of the elements of dysphagia are now taught on undergraduate degree courses and therapists and tutors alike debate what should be included in this training at a practical level (Gray and Hawes, 1999; RCSLT, 1999b). Recommendations for pre- and post-qualification dysphagia training have been issued by the Royal College of Speech and Language Therapists (1999c). It is however becoming more difficult for student placements to be found as therapists spend increasing time with patients who have dysphagia rather than those with communication difficulties (Gascoigne and Marks, 2001). It is argued that pressure on limited speech and language therapy resources could be relieved by nursing staff who are trained in the assessment and management of dysphagia (Davies *et al.*, 2001; Heritage, 2001; Magnus, 2001; Parker and Pownall, 2000). Miller and Krawczyk (2001) discuss how training for nurses might have failed in the past due to the procedure based background to nurse training as opposed to the observational training of speech and language therapists. They argue that this observational training needs to be considered when devising education packages for nursing staff.

Miller and Krawczyk (2001) also suggest that dysphagia training should be seen within a whole system of patient care:

> *"Dysphagia training ... should not be offered simply as a solution to the problem of the SLT of too many urgent and inappropriate dysphagia referrals nor to the problem for the nurse of keeping patients nil by mouth unnecessarily for long periods. Rather it should be seen as part of the overall and evolving approach to managing dysphagia in the trust in which all relevant parties are consulted, involved in the planning and aware of the long-term implications of the training for their departments."*
> (Miller and Krawczyk, 2001, p381).

Such a multi-agency approach is advocated by the Royal College of Speech and Language Therapists (1998c) and the Health Advisory Service (1998).

So, whilst speech and language therapists have taken on the role of carrying out dysphagia intervention, some advocate the training of other professionals to relieve the pressure on speech and language therapy services and in order for speech and language therapists to focus more on communication.

1.1.2 Speech and Language Therapists in dementia care:

Provision for speech and language therapy services for older people with mental illness is variable and depends on the local health authority. Some services provide comprehensive speech and language therapy in a number of settings whilst others have no speech and language therapy provision at all (Maxim and Timothy, 2001). The principal aim of a speech and language therapy service for patients with dementia is assessment of and intervention into communication and swallowing function. The therapist is expected to offer support to the patient and carers, and to enable the carers and other professionals to understand the abilities and needs of each client (RCSLT, 1996).

Communication.

The primary aims of the speech and language therapist, with regard to communication, are assessment, diagnosis and management (Zabihi and Bryan, 1996). Diagnosis is particularly important where language skills help to differentiate different dementia types (Bryan, 1999). Few specific assessments are available other than the Arizona Battery for Communication Disorders in Dementia (*ABCD* - Bayles and Tomoeda, 1993) and the Barnes Language Assessment (Bryan *et al.*, 2001) which is currently being developed. Therefore therapists often use assessment material designed for other patient groups, often in a piece-meal fashion. Management may consist of direct intervention, indirect therapy involving carers (Muir, 1996) or creative work, such as life books (Baker, 2001). Personal Construct Psychology (*PCP* - Kelly, 1995, 1991) has also been used to help people with dementia make sense of their illness (Morris, 2000a).

Dysphagia.

Within the field of dementia care the speech and language therapist working with dysphagia has a slightly different role to colleagues who work in an acute setting. The management of swallowing problems is very different as in the majority of cases the condition in degenerative and the patient cannot therefore be rehabilitated. Therapists working in the field are disadvantaged in assessment techniques and it is the researcher's experience that objective methods such as videofluoroscopy are frequently difficult to access for this client group. Consequently the use of alternative feeding is infrequent (Barratt, 2000; Henton *et al*, 2000). Speech and language therapy practice used to require that dysphagia referrals were made or authorised by members of the medical team. The Royal College of Speech and Language Therapists now argues that clinicians do not require this *"protection"* from doctors (RCSLT, 1998b), but that speech and language therapists should be working as integral members of a multi-disciplinary team. It frequently remains the case however that referrals to radiology clinics or external specialists need to be made by members of the medical team, and cannot often be made by speech and language therapists.

The emphasis of speech and language therapists working with dementia patients who have dysphagia is the continuous modification of textures and safe feeding techniques. In stroke care there is often an emphasis on avoiding oral feeding until it is safe (Clarke, 1999) whilst in dementia care the focus is on enabling the patient to continue eating orally for as long as possible.

1.1.3 Development of project:

Speech and language therapy, by its very nature, brings about change via intervention. The researcher had observed patients being fed by nursing staff in silence or with minimal communication, by different members of staff for each meal, by nursing students and auxiliary staff, or by staff with no formal training in feeding. Clinical recommendations are often made to nursing staff, to socialise with the patients more, to talk about the meal and the task of eating (Layne, 1990). This helps to make the meal time experience more 'normal' for the patient. It is however widely accepted by speech and language therapists that following advice such as that given by Buckley and colleagues (1976, p71), to "*encourage the patient to talk during the feeding process*" could be dangerous for the patient. Intervention in the partnership between the member of nursing staff and the patient during feeding could bring about better results in terms of nutrition, meal enjoyment, and ease and safety of feeding both for the patient and for the member of staff.

A double base-line study was planned whereby the “feeding partnership” would be examined before and after intervention, this intervention taking the form of staff training. The design involved measuring change, designing intervention and applying the intervention consistently to different staff groups. It was first necessary to obtain baseline measurements of the partnership between the member of staff and patient, for which there was no readily accessible method. The researcher had therefore proposed to intervene in, and bring about change to, a relationship which had not even been measured. It was this that brought about the shift in emphasis for the study. Rather than *change* the partnership, there was first a need to *measure* it.

1.2 Theoretical background to project development.

For independent people there is a direct relationship between themselves and the meal they are eating. For dependent people the relationship is more complicated as they are dependent upon another person to help them to eat the meal. The range of support needed may range from minimal assistance to complete dependency. For patients in the late stages of dementia there is the likelihood that they are totally reliant on another person to meet their nutritional requirements. This section defines and describes the role of the patient, the member of nursing staff and the speech and language therapist. A summary model is used to capture the key elements of current dysphagia service.

1.2.1 The patient with late stage dementia:

Dementia is a debilitating and degenerative disease for which the Royal College of Physicians offers the following definition:

> *"Dementia is the global impairment of higher cortical functions including memory, the capacity to solve the problems of day to day living, the performance of learned perceptuomotor skills, the correct use of social skills, and control of emotional reactions in the absence of gross clouding of consciousness. The condition is often irreversible and progressive."* (Royal College of Physicians, 1981).

The characteristics of dementia are distinct from those of normal ageing. The concept of a dementing process has been written about since 3000 BC when Prince Ptah-Hotep gave the first account of an abnormal ageing process. In 30 AD Aulus Celsus first used the terms "*delerium*" and "*dementia*" in an encyclopaedia, whilst the Oxford English dictionary first included "*dementia*" as a noun in 1806. The concept of dementia as we understand it today only emerged at the end of the 19th and the start of the 20th century, due to the work of Kraeplin, Nissl, and Alzheimer. See U'Ren (1987) for more detail.

Dementia is defined as a change in organic neurological material in the brain which results in cognitive changes (Tomlinson, 1992). It is associated with severe destruction or disorganisation, particularly of the cerebral cortex and its connections. One common symptom of dementia is dysphagia, or difficulty in eating.

All older people are at potential risk of developing difficulties eating and swallowing due to a number of anatomical and physiological changes associated with normal ageing (Feldman *et al.*, 1980; Logemann 1990; Patel *et al.*, 1983; Sheth and Diner, 1988), although one controversial study suggested that changes in functional oral-motor skills were related not to age but to whether dentures were worn or not (Fucile *et al.*, 1998; Gisel *et al.*, 1999; Kenny and Judd, 1999). All senses are known to be affected by age including those of taste and smell (Morley and Silver, 1988; Schiffman, 1997; Simons *et al.*, 1999) which contribute to the eating process. Any type of dementia will increase the likelihood and severity of a feeding difficulty.

One of the primary causes of death in patients with dementia is bronchial pneumonia (Burns *et al.*, 1990; Horner *et al.*, 1994; Knelb *et al.*, 1989) and one of the known contributing factors is aspiration of foreign particles into the airway (Gavriely, 1989). In most cases this occurs during feeding when particles of food or liquid are inhaled and not expelled from the lungs, as a result of dysphagia. Dysphagia is common by the latter stages of dementia (Horner *et al.*, 1994), although it sometimes presents in the early stages. It has been suggested that many cases of aspiration dysphagia in dementia are not detected and that the problem is underestimated (Bloem *et al.*, 1990; Feinberg *et al.*, 1982). Dysphagia in dementia is associated with organic changes in the brain due to the dementing process and with some medications used in the management of the illness. See Groher (1992) and Logemann (1983) for in-depth discussion of dysphagia and the normal swallow. Dementia is discussed in more detail in the literature review, Chapter Two.

Dysphagia can result in reduced food intake and is directly related to weight loss in dementia (Gilmore *et al.*, 1995; Keller, 1995). In addition, the dementia itself can result in decreased appetite and changes in eating patterns (Priefer and Robbins, 1997; Steele *et al.*, 1997). People with dementia often prefer sweet foods and avoid savoury foods which are higher in protein and other nutrients (VOICES, 1998). Some common features of dementia are food refusal, retention of food in the mouth without swallowing, and the consumption of unsuitable things (such as flowers, cigarette butts or tissues). Some of these behaviours are a result of cognitive impairment, rendering the patients confused as to what is happening or unaware of food in their mouths, or are based on fear following experiences of choking or discomfort when eating. Some patients are delusional or paranoid and may refuse to eat in the belief that they are being poisoned. Others may find refusing to eat a successful attention seeking device, whilst some may just not want to co-operate. See Alzheimer's Dementia Care and Research (2000a) and Tate *et al.* (2000) for summaries of eating and feeding difficulties.

It has been shown that as many as half of all older people have nutritional problems that require intervention (Posner *et al.*, 1987), although the exact causes of these problems are often unclear (Wolf Klein and Silverstone, 1994). Even if patients receive an intake that would normally be sufficient to maintain body weight it may not be enough to sustain them through episodes of illness or injury (Prentice *et al.*, 1989; Wolf Klein *et al.*, 1995). Figures for malnutrition among the institutionalised elderly range between 12% and 70% (Cooper and Cobb, 1988; Kolasa *et al.*, 1989; Sandman *et al.*, 1987), but the number of cases is often underestimated (Hunt, 1997).

Patients with dementia are at increasing risk of malnutrition due to a number of factors:

- they may be dependent on others to feed them;
- dysphagia can make it difficult to feed them, or difficult for them to take food;
- chest infections, resulting from dysphagia, may make them weaker and therefore exacerbate the dysphagia;
- modified diets such as purée, often given to patients with dysphagia, are lower in nutritional value;
- the nutrition received may not be sufficient when the patient is suffering from an additional illness, such as a chest infection; and
- being nursed in bed can exacerbate the dysphagia and increase the risk of aspiration.

Patients with both dementia and dysphagia therefore often follow a cyclic pattern of feeding difficulties leading to decreasing independence and loss of weight, which in-turn result in further feeding difficulties. The further down this spiral a patient descends, the greater the risk of becoming malnourished.

Food and being fed are basic requirements of all human beings (Maslow, 1954) and are part of every day life. Thoughts, images, ideas, feelings and emotions are evoked by food, both consciously and subconsciously (Lyman, 1989). It is therefore important that the significance of meal times for patients with dementia is considered and that a patient is supported to enable as normal a meal-time as possible (Malone, 1996).

One of the many skills lost in dementia is the ability to use utensils appropriately to feed oneself. This results in dependence on staff or carers and an increased risk of malnutrition (Du *et al.*, 1993). Eating or being fed, particularly for patients with dementia, is a complex activity which the person needs to understand and be motivated to perform. There are five components to eating, as outlined by Siebens *et al.* (1986):

- the behavioural/cognitive ability to recognise that food is present and is to be eaten;
- the physical function of transferring food from plate to mouth;
- the pre-oral stage (chewing/mastication) and oral stage of swallowing (trigger of swallow reflex);
- the pharyngeal stage of swallowing (bolus carried through pharynx); and
- the oesophageal stage of swallowing (bolus carried into stomach).

Breakdown in the first of the above components is common in dementia, where patients fail to recognise food or 'forget' how to eat. Physical impairments which result from dementia such as hemiplegia, spasticity, tremours etc., make it difficult for a patients to feed themselves. Impairment to any of the latter three stages will result in dysphagia. Deficits in any of these areas will result in the patient requiring assistance when eating.

1.2.2 The member of nursing staff:

In the chronic care setting 19-24% of patients require total feeding assistance while 50-66% require some degree of help (Dwyer *et al.*, 1987; Siebens *et al.*, 1986; Silver *et al.*, 1988). It is estimated that feeding someone who is totally dependent requires an average of 30-45 minutes a day (Hogstel and Robinson, 1989; Morley and Silver, 1988). This is likely to be an underestimate. For example a video recorded for this study revealed that one meal took 27 minutes to complete.

This study examines the mealtime process for patients who require feeding. For ease of reference, the person feeding the patient is referred to throughout the thesis as the '*feeder*' and the person eating as the '*eater*'. This enables semantic transparency and avoids confusion with the term 'recipient' which is used in descriptions of conversational interaction. The feeding process is two way and therefore provides an opportunity for interaction between the eater and the feeder. Eaters respond to the feeding sensations and feeders learn to recognise such signs as pleasure, annoyance, difficulty, amusement and satiety (Satter, 1986; Shishmanian and Tomlinson, 1989). A range of limited behaviours may be regarded as meaningful requests for a reciprocal action (Athlin and Norberg, 1987; Satter, 1990; Shishmanian and Tomlinson, 1989). Feeding is recognised as being more than the simple mechanical process of putting food or drink in a person's mouth. It is dyadic in nature, synchronised and a collaborative process with both partners having a role (Satter, 1986, 1990).

> *"The ... ability to ingest an appropriate amount of food and maintain a nutritionally adequate diet depends on a positive feeding interaction with the primary care provider."* (Satter, 1990, p s188).

Patients in the latter stages of dementia suffer from severe feeding problems and, in addition to a lack of purposeful behaviour, there are many primitive reflexes evident. Carers often report that they do not know how to interpret such patients' behaviour and that they feel uncertain as to whether the patients are able to understand their attempts at interpreting them. Such difficulties in the synchrony of feeding result in feelings of helplessness and guilt, and may lead to the carer choosing not to feed that patient in the future. Athlin and Norberg (1987) showed that as a result of feeding the same patient on a number of occasions the carers felt they understood the patients better, and the majority of them felt that their communicative attempts were understood and that a synchronous partnership had been developed.

The behaviour of the feeder can be described as a continuum from positive and supporting to inappropriate control and insensitivity. Feeders and eaters who develop synchrony are successful with each other. The eaters learn that they are able to convey what they want and trust that someone is willing to provide it for them. The feeders need to identify both the problem and the solution in a consistent way in order for the eaters to have self awareness and understanding of their sensations. But where feeders and eaters develop asynchronous partnerships they are unsuccessful and this can be detrimental to both of them.

Either partner may impede or facilitate the synchrony (Thoman, 1975). Eaters may be faced with feeders who do not meet their needs for food preferences, timing, amount, pace or capabilities; whilst feeders may be confronted with dissatisfied, overly passive or overly active eaters.

For many dementia sufferers who live at home, the spouse or family members become primary carers and take on the role of feeder. Patients in hospital however are dependent upon nursing staff. With the risk of malnutrition being so great, staff often find themselvs under pressure to ensure that patients are fed and receive an adequate daily intake, and may be accused of *neglect* if they fail (Daily Mail, 2000). For many patients with dementia however, adequate intake is near impossible.

The care offered to older patients by nursing staff is often criticised and debated (Age Concern, 1999; Daily Telegraph, 1999; Kingston and District Community NHS Trust, 2000; Shepherd, 2000). A recent survey showed that much of what we consider to be good practice in supporting older people with dementia to eat is not widely applied (Alzheimer's Dementia Care and Research, 2000a). Although the quality of elderly care has been given more attention recently (Philp, 2000; Tune and Bowie, 2000), some authors are critical of the delay to reforms for elderly services (Moor, 2000). The launch of the National Service Framework for Older People (Department of Health, 2001a) was hoped to signal a change in direction toward higher standards of service.

Staff who support older patients are often undervalued and attributed with poor caring attitudes (Wade, 2000). The care of older patients actually involves a lot of skill as such patients often present with unusual or atypical symptoms which require careful and often complicated interventions (Herbert, 1992). As well as nursing the patient the members of nursing staff are key to communication between ward staff, the medical team, therapists and friends or relatives. Learning the skills for good communication with patients who have dementia is not easy. Where communication breaks down it is often easier for people to attribute the problem to the patient than it is to identify their own part in the breakdown (McConkey *et al.*, 1999).

Thomas (1994) noted that although staff recognise the importance of forming relationships and communicating with patients, this was not observed within the nursing environment. As a result of work pressures, interactions between staff and their patients with dementia have been found to be mostly task orientated (White, 1999) and nurses' verbal cues are often vague (Edberg *et al.*, 1995). If the care staff do not try to interpret and understand the patient then no meaningful communication can take place.

In video analysis work with adults who have learning disabilities, Couchman (1996) demonstrated that staff often ignore non-verbal cues when there is no accompanying speech. If non-verbal cues of the dependent person with dementia are ignored the results can be detrimental to the patient. Richter *et al.* (1995) suggest that once people are placed in an institutional environment their physical and safety needs become a priority whilst communication needs are often overlooked. Yet how can patients' needs be fulfilled if staff are not able to understand what they are communicating? If behaviours are not interpreted then patients may be left in a *"social and emotional vacuum"* (Dewing and Garner, 1998, p14).

Norberg (1996) identifies a connection between the way a nurse views the person they are caring for and the way they view the care they are providing. Those who view the patient as an unique and valuable person experience their task of caring as an important responsibility rather than a burden. As dementia progresses, physical and emotional barriers become increasingly evident and staff can find it more difficult to relate to their patient (Richter *et al.*; 1995). Some find it difficult to see the patient as a person as a result of the poor communication and fragmented facial expression (Asplund and Norberg, 1993; Athlin *et al.*, 1990). Others may feel that there is somebody behind the 'mask' of dementia, *"... a healthy human being imprisoned by the damaged brain."* (Norberg, 1996, p105).

The role of the nursing staff is therefore critical to the care a patient with dementia receives. They are pivotal to any discussion surrounding patient care and spend more time than any other staff group (or family member) with them. A good understanding of a patient's communicative cues is therefore crucial.

1.2.3 The speech and language therapist:

A speech and language therapist may have two roles, working with impaired communication and difficulty swallowing. Both are discussed here with relation to patients who have dementia.

The primary role of a speech and language therapy service is to intervene when speech and language, or in the wider sense communication, become impaired. Increasingly speech and language therapists are focusing on the total communication environment, and are intervening to enable asymmetrical communication relationships become more symmetrical. The speech and language therapist's role may be to help the patient with dementia to use compensatory techniques (such as describing objects they have forgotten the name for) and to work with the patient's primary communicative partner (e.g. spouse, child) to encourage them to look for and accept the message the patient is trying to say rather than pursuing accuraccy.

Interactions become asymmetrical when one of the partners has an authoritative role (such as parent-child, doctor-patient or teacher-student interactions) or when one partner relies on compensation by the other partner(s). This happens in dementia from the early stages when the patient presents with mild aphasia, right through to the late stages where the patient is mute and interacts via limited behaviours only.

One of the primary reasons why nursing staff have great difficulty relating to such patients is the communication difficulties that are associated with dementia. A language disorder is always a symptom of dementia and communicating with someone with dementia can therefore be difficult. This is particularly true in the early and mid-stages when cognitive skills are often more impaired than language skills and carers therefore assume greater comprehension than actually exists (Richter *et al.*, 1995). Many language problems are a result of, or are compounded further by memory problems (Morris, 2000b; Ramanathan, 1997). The problems identified in the communication of people with dementia, and the wider field of interaction, are reviewed in detail in Chapter Two.

Although the speech and language therapist has a recognised role both in communication and dysphagia, the two are rarely viewed together. Instead they are viewed as two separate aspects of a speech and language therapy service.

Within a dysphagia service the speech and language therapist has two roles, direct intervention and indirect intervention. Direct intervention would include specific speech and language therapy assessments, swallow rehabilitation and clinical decisions around the management of the patient. Indirectly the speech and language therapist could influence the caring context for the patient by devising feeding programmes, training staff members and other carers, and offering advice and guidelines.

Some speech and language therapists have an indirect role in the provision of meals for patients. Meals provided by hospitals have been criticised both for their poor quality and their limited variety (Daily Telegraph, 1999). The researcher's experience is of a hospital catering service striving to meet the needs of a wide cross section of different patients on a very limited budget. The food preferences and needs of the elderly are very different to the preferences and requirements of children, yet the catering staff are expected to produce menus that appeal to both patient groups. In many cases the result is that the menu neither pleases nor meets the needs of any of the patients receiving it. Like many other hospitals, dietetic advice is provided to ensure a nutritionally well balanced meal, but this is only of benefit to the patient if the food is actually consumed. Improvements are expected with the introduction of new NHS menu and recipe standards (NHS, 2001).

For patients with dementia it is common for meals to be modified and this often takes the form of the meal being purêed. Depending on how it is done, the result can be an unappetising concoction of different food types being minced together. At the other end of the spectrum purêe food can be presented in a pleasing way that maximises the effects of different colours and keeps separate the different flavours. Some commercial thickener companies advocate the use of 'cook-chill' techniques to reproduce purêe in food shapes using moulds (Fresenius Kabi, 2000; Novartis, 1998; Nutricia, 1998).

The presentation, taste and smell of the food is crucial to make it appetising for the patients. There is no need for a meal to be unappetising just because it has been puréed. Such training for both catering and nursing staff often falls to the speech and language therapist in conjunction with a dietitian.

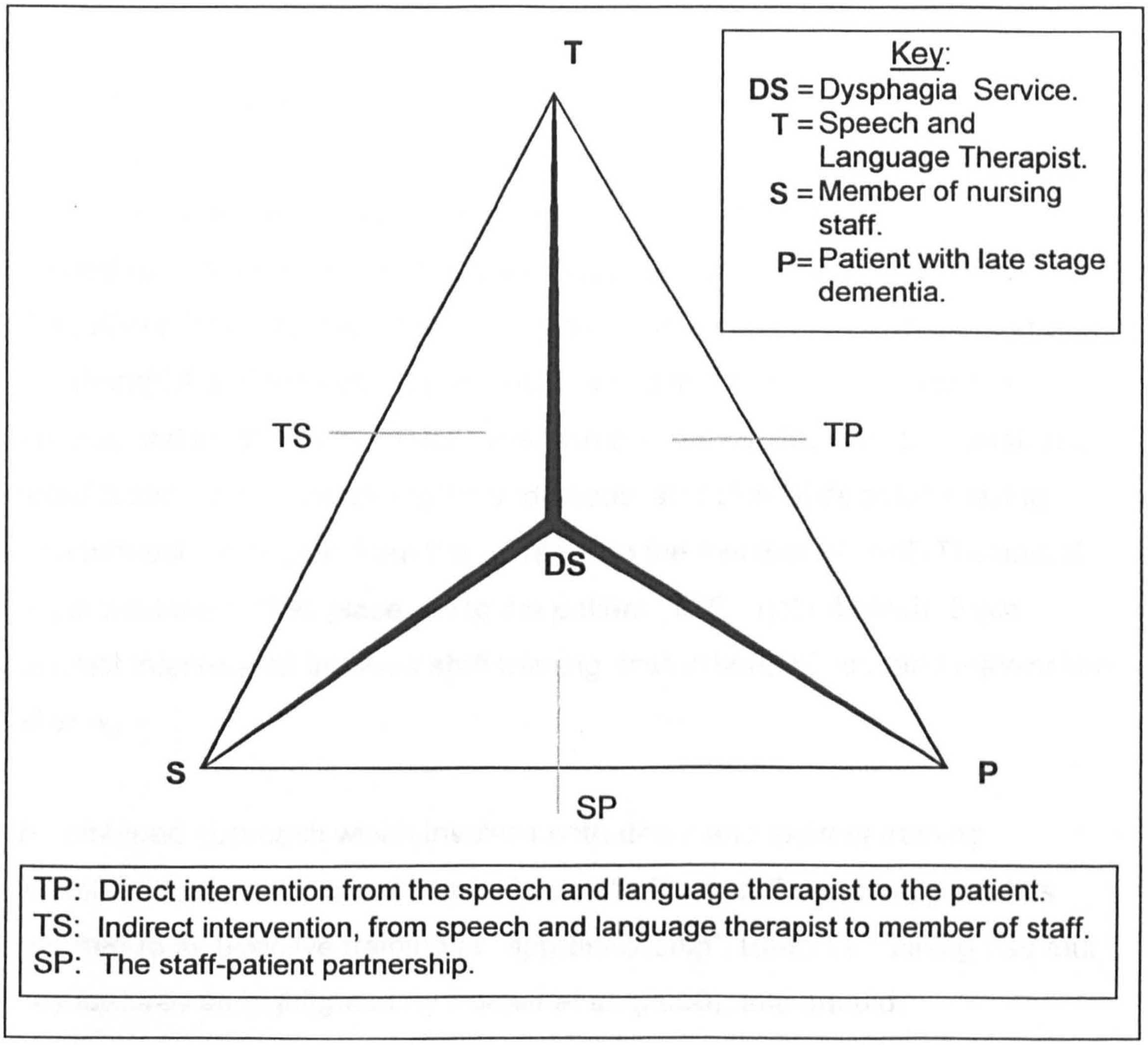
1.2.4 The dysphagia service:

Taking each of the key components discussed so far the researcher produced a model to summarise the dysphagia service being offered to patients with late stage dementia in the research setting. This is shown over the page in figure 1-1. A glossary of terms is provided in table 1-1.

Term	Definition
Pyramid.	The 3 dimensional shape of the model.
Apex.	The top point of the pyramid, the element formed by the three components.
Components.	The corner points of the pyramid.
Faces.	The three solid sides, rising to meet at the apex of the pyramid.

Table 1-1 Glossary of terms for model structure.

The model is pyramidal in shape with three faces (and a base that will be discussed later). It is three dimensional with the apex coming out of the page toward the reader. The three corner components contribute to the element represented at the apex of the model. Letters are used to represent the main element of the model and the components. These are also further explained within the text. The faces of the model are formed from two adjacent components rising up to the apex point. Letters are used to label these and a more detailed description is provided underneath the model. In figure 1-1 the dysphagia service (DS) can be seen at the apex of the model, formed from three components: the speech and language therapist (T), the member of nursing staff (S) and the patient with late stage dementia (P). The sides are labelled as indirect therapeutic intervention (TS), direct therapeutic intervention (TP) and the staff-patient partnership (SP).



Key:
DS = Dysphagia Service.
T = Speech and Language Therapist.
S = Member of nursing staff.
P= Patient with late stage dementia.

TP: Direct intervention from the speech and language therapist to the patient.
TS: Indirect intervention, from speech and language therapist to member of staff.
SP: The staff-patient partnership.

Figure 1-1. Model of the components contributing to a dysphagia service for patients with late stage dementia.

The role of the members of staff and the patients can be discussed in terms of service provision. Nursing staff are employed to provide a service to the patients. Within the task of feeding they physically carry out the feeding process, they communicate with the patient and they provide care to enable well-being in the patient. The patients play a reciprocal role in that they eat the meal fed by the member of nursing staff, have a role in interaction (although a lesser role than the nursing staff) and have needs which need to be met for them to achieve well-being. In simple terms the nursing staff may be seen as a service provider and the patient as the service consumer.

The role of the speech and language therapist is less easy to define. The therapist is not employed with the same purpose as the members of nursing staff and there is no direct provision of care. Instead the therapist has a distinct role to provide both direct and indirect intervention for the benefit of the patient. The direct route of intervention can be seen in the model between the therapist and the patient (TP). Such direct intervention includes the speech and language therapist's assessment, data collection, data analysis, identification of clinical strengths and needs, and clinical decision making. The indirect route goes from the therapist to the member of staff (TS) and, if implementation takes place, on to the patient (TSP - not labelled). Such indirect intervention involves staff training, instruction, advice, and information sharing.

A combined approach which involves both direct and indirect training simultaneously has been shown to be most effective. Such an approach is referred to as effective training or "apprenticeship". Effective training has four key features as highlighted by Purcell *et al.* (2000), and should:

- be carried out in the care environment, involving situations and contexts which are familiar to the staff;
- focus on patients with whom the staff most commonly interact;
- be guided by a more experienced colleague who knows the needs of the patient and has opportunities to work alongside the members of staff; and
- consist of an action-research strategy (critical assessment in a range of settings and over time).

The SP face of the model also needs to be defined. This can be referred to as the staff-patient partnership. Such a partnership is based on experience and familiarity, how long the patient has been known to the staff member, what the staff member's expectations are, and the staff member's knowledge base. The partnership between the staff member and the patient contributes towards the physical process of feeding, ascription of meaning in interaction between the patient and the staff member, and decision making with regards to the needs and care provision for the patient. The staff member also offers feeding support to the patient by physical modifications to the environment, the meal, and the patient (e.g. positioning).

The dysphagia service is delivered by the multi-disciplinary team and involves other professions such as dietitians, physiotherapists, occupational therapists etc. This multi-disciplinary team is represented by the point DS. One role of the much larger multi-disciplinary team is that of ethical decision making for the patients. One common scenario is refusal to eat. The health care team wish the patient to be fed, but alternative feeding methods are not considered appropriate (Norberg and Hirschfield, 1987; Oliver *et al.*, 1996). This raises issues between members of staff who feel they should continue to feed the patient and those who feel that feeding should be stopped. Continuing to feed patients in this situation could be considered to be force feeding but stopping could be construed as starving them (Carter, 1999; Harris, 1999; Tonks and Bennett, 1999). Either response is likely to evoke feelings of guilt (Justice, 1995; Norberg *et al.*, 1980). Such dilemmas and feelings may result in staff distancing themselves from their patients (Åkerlund and Norberg, 1985), the very antithesis of person-centred care which forms the philosophy of today's dementia care.

> *"When everything you do is wrong, you feel guilty."*
> (Norberg *et al.*, 1980, p848).

At times the decision about whether to feed a patient or not appears to be synonymous with decisions to withhold medication (Burgess, 1994; Miskovitz *et al.*, 1988; Sheth and Diner, 1988) and other life sustaining processes (Groher, 1990; Justice, 1995). Intravenous hydration is used to *ensure the patient's comfort* (Penn, 1992) even though there is evidence to suggest that it has the opposite effect (Dresser and Boisaubin, 1985; Malone, 1994; Printz, 1988; Zerwekh, 1983). Differing opinions within the multi-disciplinary team as to what is and is not ethical make such decisions even more difficult.

In some cases the debate is widened by not only considering *whether* to continue feeding a patient but *how*. The multi-disciplinary team may want to consider alternative methods of feeding such as naso-gastric (NG) or percutaneous endoscopic gastrostomy (PEG). Whilst it is common for this latter procedure to be used in the United States of America it is rarely used for this client group in Britain (Grimley Evans, 1992). Guidelines are available to aid doctors, nursing staff, therapists and relatives in this decision making process (British Association for Parenteral and Enteral Nutrition; Rice, 1999).

The debate on the efficacy and ethics of tube feeding patients with dementia (Alzheimer's Dementia Care and Research, 2000b; Chouinard *et al.*, 1998; Ciment, 2000) and comparisons to other life sustaining procedures is ongoing (Bliss, 1991; Burgess, 1994; Grimley Evans, 1989; Groher, 1990; Michaelsson *et al.*, 1987; Miskovitz *et al.*, 1988; Sheth and Diner, 1988; Teno *et al.*, 1997). Alternative feeding has been criticised for prolonging the death process (Chouinard *et al.*, 1998; Grimley Evans, 1989), but for some patients alternative feeding methods may be appropriate and the only viable option to prevent death from malnutrition (Barratt, 2000; Henton *et al.*, 2000).

End-of-life decisions are an important part of feeding considerations, particularly for patients who have dementia. They do not only affect the patient and immediate family but also the therapist and members of nursing staff. Within the above model such issues can be seen to be shared as an intrinsic role of the Dysphagia Service.

Summary:

This chapter has presented a summary model which is representative of the dysphagia service offered to patients with late stage dementia. The role of the therapist, member of nursing staff and patient have all been defined and the role of the dysphagia service has been discussed. The model, being triadic, encompasses the diverse role of the speech and language therapist, involving both direct and indirect intervention.

The partnership between the member of staff and the patient (the "feeding partnership") will be discussed further. This study utilises a number of exploratory methods to describe and define this partnership.

1.3 Structure of the thesis.

This first chapter has described in detail the summary model the researcher used to conceptualise the problem area. Describing the "feeding partnership" in terms of this model is useful for visualising the different components of the partnership between the member of nursing staff and patient and the role of the speech and language therapist.

The model gave direction for the literature review which is found in Chapter Two. The chapter examines the disease process of dementia in more detail, as well as discussing previous and current dementia care philosophies. The communication of patients with dementia is discussed further in the second section of Chapter Two, in terms of language disorder, non-verbal communication, functional communication and the communication environment. The third and fourth sections of Chapter Two offer an expansion of communication and look at partnerships and collaboration. Different models of communication are explored as well as how participants actively take part in discourse. Asymmetrical communication partnerships develop when one participant is required to compensate for the lack of development or acquired deficits of the other. A developmental framework is used to examine parent-infant interactions and parallels are drawn with adult asymmetrical interactions such as those observed with people who have dementia. The fifth section of the chapter explores methods of analysing such partnerships, such as conversation analysis or measuring states of engagement. The chapter ends with an introduction to the research questions and hypotheses which grew from this literature review. The literature review was carried out prior to commencement of the data analysis and thus the thesis is presented as a 'learning journey'. Further literature, which substantiates the analyses and findings of later chapters, is introduced in Chapter Five.

Chapter Three introduces the project design and methodology. The chapter is divided into two sections: the process of designing the project and ethical considerations which needed to be explored, and then how the project was actually carried out. The chapter closes with a critique of the methodologies utilised in the study.

The fourth chapter reports on each of the analyses carried out, the methods used, and the main findings. The findings are presented with the original research questions and hypotheses and a critique of these analyses.

Chapter Five firstly reiterates the summary model presented in Chapter One. Then over the next four sections the model is reconfigured in three stages, drawing together the findings from Chapter Four and additional literature. The final stage of the model conceptualises the roles of the speech and language therapist and the members of nursing staff, and portrays three key components of intervention during feeding. In the sixth section suggestions are made for further exploration and future research, including communication and feeding profiles, an analysis of different demarcation processes and the development of a demarcation hierarchy. In the final section the researcher then challenges current speech and language therapy practice. The researcher advocates that dysphagia and communication therapies should be placed on opposing ends of a continuum rather than being viewed as separate constituents to speech and language therapy intervention.

The study is summarised in Chapter Six and closes with the researcher's concluding remarks.

Chapter Two

Chapter Two

Literature review

This second chapter builds upon the main components and considerations of the summary model discussed in Chapter One. Dementia and associated communication deficits are examined and then communication is expanded to incorporate interaction and collaborative partnerships. Research questions are presented at the end of the chapter.

This study pulls together a number of different themes and taps into many areas of literature and research. The literature review has been written as an ongoing 'work in progress' throughout the six year duration of the study. The researcher therefore wishes to explain the inclusion and exclusion criteria for this review.

References and literature used in this chapter relate to background information:

- about the medical condition the patient subjects present with;
- about the communication difficulties as a result of it;
- about how communication is collaborative and how patients therefore rely on others to compensate for their cognitive and communication impairment;
- and about ways in which communication can be analysed.

It highlights the complexity of the study and the vast area it encomposses. The literature review therefore serves to provide a backdrop against which the study is discussed in future chapters. The reader will notice that new literature is introduced in the final chapter, much referring to the socio-political context of care of the elderly services. The researcher felt it inappropriate to include this literature in the review here in Chapter Two. Rather the reader is asked to treat the layout of the thesis as a ‘learning journey’ and to recognise that areas not discussed in this section may be referred to in later chapters.

2.1 The patient with dementia - in context.

2.1.1 Dementia, its causes and its prevalence:

Surveys identify the prevalence of dementia in the developing world as approximately 5% of over 65's and 20% of over 80's (Terry and Katzman, 1983). Other authors identify 2.3% of people aged 65-74, 7.2% of aged 75-84 and 21.9% of aged 85 and older (Ely *et al.*, 1996). In real terms these figures equate to 15,000 - 20,000 people aged between 40 and 45; 200,000 - 250,000 aged under 80; and 300,000 - 350,000 aged over 80 in the UK (Goldsmith, 1996). On average the prevalence of dementia doubles with every five year increase in age after the age of 65 (Cheston and Bender, 1999; Jorm *et al.*, 1987). The population of people with dementia aged 75 to 100 years is mostly women. This is due to two factors, the first being the longer life expectancy of women. Secondly many men from the generation currently in this age group were killed during war. The figures do not indicate a greater risk of dementia in women (Goldsmith, 1996).

It is generally thought that there are around 670,000 cases of dementia in the UK (Cheston and Bender 1999), whilst Goldsmith (1996) cites 500,000 with a definite diagnosis. Predictions for this early part of the twenty first century suggest that the overall number of people with dementia could rise by 11%, more than three times the expected percentage increase in world population (Melzer *et al.*, 1997). This is partly due to the expected increase in the number of elderly people. It has been estimated that there will be around 37 million people with dementia in the world by 2020, with 6 million in Europe alone (Tomlinson, 1992). These figures are vast, and present a huge 'burden' for hospital and care organisations (Hargreaves, 2000; Petrie *et al.*, 2000; Stern, 2000; Wong, 2000).

It is worth noting that whilst for many the term 'Alzheimer's disease' has become synonymous with any dementing process, this is inaccurate.

Alzheimer's disease is recognised scientifically as just one of the types of dementia, which was originally described by Alzheimer (1898, 1977 translation). Alzheimer's disease as we currently know it accounts for 50% of dementia cases (Tobiansky, 1993) and is characterised by plaques and tangles in the neurones of the brain and by neuronal cell loss (Tomlinson, 1992). It can only be diagnosed at post-mortem, so a working diagnosis of Dementia of the Alzheimer's Type (DAT) is often used.

There are great variations in what is known as *dementia* and it is still not really known whether it is a syndrome with many subtypes or many different but similar diseases. What is known is that there are a number of different presentations of dementia:

- *pseudo dementia* - such as that associated with severe depressive illness;
- *reversible dementia* - such as that associated with vitamin B_{12} deficiency, some tumours, subdural haematoma, hypothyroidism, hydrocephalus and other coexisting diseases (Heckmann *et al.*, 2000; Hurley *et al.*, 1999); and
- *degenerative dementia* - such as Alzheimer's disease, Lewy body dementia, Pick's disease and multi-infarct dementia.

The degenerative dementias are by far the largest group. Some degenerative dementias have known causes, such as the human immunodeficiency virus infection (AIDS) (Rostasy *et al.*, 1999), vascular disease (de Deyne *et al.*, 1999) and those dementias associated with specific neurological disorders such as Parkinson's disease, Huntington's disease and multiple sclerosis. The causes of other dementia types are less clear but there are a number of theories:

- genetic causes (Butcher, 2000; Corder *et al.*, 1993; Edwardson and Morris, 1998; Goate *et al.*, 1991; Hardy *et al.*, 1998; Highfield, 2000; St George Hyslop *et al.*, 1990);
- causative links with smoking (Brayne, 2000; Doll *et al.*, 2000; Launer *et al.*, 1999; Merchant *et al.*, 1999; Wang *et al.*, 1999);

- alcohol consumption (Marsden, 1984);
- aluminium (Edwardson, 1991; Neri and Hewitt, 1991);
- brain inflammation (Marsden, 1984); or
- tumours and other brain traumas (Mortimer *et al.*, 1985).

More in-depth studies have been published by Marsden (1984), Pitt (1987) and Tomlinson (1992). They provide very detailed descriptions of senescent neurological changes and the different dementing processes. A poor or limited social network has been shown to increase the risk of dementia by 60% (Berkman, 2000; Fratiglioni *et al.*, 2000; Plattner and Ehrhardt, 2000), whilst there is also evidence to suggest that the use of some cholesterol lowering drugs may reduce the likelihood of developing dementia (Jick *et al.*, 2000).

From now on only the degenerative dementias will be discussed. A 'stage-model' of dementia describes it as occurring in three stages: the *forgetfulness* stage, the *confusional* stage and the *dementia* stage (Schneck *et al.*, 1982). The person may initially present with subtle memory problems, such as misplacing objects or difficulty recalling names, as well as changes to behaviour and language. Cognitive deterioration is more marked in the second stage with personality changes and confusion. The final stage is characterised by severe disturbances to cognitive functioning and dependence on others.

This model is challenged by Bell and McGregor (1995). They caution that using such a theory presents a number of dangers such as making the decline of dementia a self-fulfilling prophecy, labelling or classifying people with a syndrome and dehumanising the person. They make a comparison to people who are in a coma. They point out that whilst we recognise that people in a coma can often understand what is happening around them and can understand what is being said about them, we fail to offer people with dementia the same degree of dignity. This may result from the assumption that a person may wake from the coma, whilst people with dementia are viewed as being permanently damaged. For all the arguments against it, the stage theory does allow the carers and relatives of people with dementia to understand the process and progress of the illness. There is surely scope to work within the stage-model whilst also seeing people with dementia as individuals.

Whatever model is used to discuss dementia it is undeniable that as the illness progresses the sufferer becomes more dependent on other people to fulfil daily activities until they become totally dependent (Janicki *et al.*, 1996). Most patients will die between four and twelve years after the onset of the disease (Tobiansky, 1993). Death usually occurs due to decline in general health rather than the dementia itself and the difference between dying *from* dementia and dying *with* dementia should be recognised (Kitwood, 1997a).

The types of dementia are thought to present differently in the beginning stages (Bryan, 1999; Holden, 1995). Early changes in the brain could be used to predict the pattern of future decline (Larkin, 1999) and there are some recent reports identifying very early symptoms, such as loss of the sense of smell (Burns, 2000). There is currently no cure for dementia although interventions for prevention are being studied (Breitner, 1999) as are drugs to help reduce cognitive impairment (Birks *et al.*, 1999; Bullock, 2000; Highfield, 2000; McKeith *et al.*, 2000; Wilcock *et al.*, 2000). Diagnosis of different dementias is expensive and time consuming. Recent advances in drug treatments and a clearer understanding of potential therapeutic intervention for different dementia types means that differential diagnosis is now beginning to be considered more cost effective (Bryan, 1999; Copeland, 1998; Hopker, 1999; Kmietowicz, 1998).

Current dementia care attempts to keep people with dementia in their home environment for as long as possible (Department of Health, 1990), but despite this the elderly suffering from dementia constitute the largest population of admissions to nursing care (Philp *et al.*, 1997). Before the NHS and Community Care Act (HMSO, 1990) many people with dementia would have been cared for in long stay psychiatric hospitals, but the vast majority of such institutions have now been closed and as many as 90% of dementia patients live in the community (Tomlinson, 1992). Some individuals will however still need to be admitted into or remain in hospital.

2.1.2 Dementia care philosophy:

The philosophy of dementia care has changed greatly over recent years. Foucault (1967) outlined three main phases of care philosophy for people with mental illness:

- *bestialisation,* where inmates were treated much like zoo animals;
- *moralisation,* when in the 19th century asylums were re-created as a place for re-education; and
- *medicalisation*, where non-conformity was classed as a disease.

The latter part of the 20th century and this first part of the 21st century has seen us moving into a fourth phase, that of *person-centred-care* (Kitwood, 1995a; Kitwood, 1995b; Kitwood 1997a; Morton, 2000a; Morton, 2000b). This was heralded by the introduction of Dementia Care Mapping (Innes *et al.*, 2000; Kitwood and Bredin, 1994) and the work of the late Tom Kitwood and colleagues (Kitwood, 1993a; Kitwood 1997b).

The differences between old and new cultures of dementia care are marked (Kitwood, 1995a; Morton, 2000a; Morton, 2000b; Tobin, 1995; Woods, 1995; Woods, 1999), the new culture very much focusing on values, the environment and individualisation.

> *"... much of the ill being experienced by people with dementia is not the result of their disability, but of negative attitudes and care practices which surround them."* (Innes *et al.*, 2000, p20).

Kitwood (1990, 1993b) provides an equation for understanding people with dementia (D). He urges the examination of the interaction between five main components, personality (P), biography (B), physical health (H), neurological impairment (NI) and social psychology (SP).

$$D = P + B + H + NI + SP$$

He argues that people should be valued not for what they can do but for who they are and that who they are can only be understood by examining all of the above factors. This is crucial if the experience of dementia is to be viewed as *"a troubled person rather than a diseased brain"* (Cheston and Bender, 1999, p17).

Dementia Care Mapping has become an internationally recognised method of dementia care theory. There is still however an imbalance between training and actual implementation (Innes, 2000; Packer, 2000a; Packer 2000b). Many authors are concerned about the lack of general care provision for such patients and eagerly await service reforms for older people with mental health needs (Moor, 2000). It is hoped that the National Service Framework for Older People (Department of Health, 2001a) will vastly improve services (RCSLT, 2001).

2.2 The communication of patients who have dementia.

2.2.1 Language:

As mentioned in Chapter One, a language impairment is always associated with dementia. A stage model of language functioning throughout life has been proposed (Albert, 1980):

- acquisition and then continued development of language skills throughout life;
- cognitive deterioration associated with normal ageing;
- strategies used by normal elderly people to overcome their cognitive deterioration; and
- specific deficits as a result of dementia.

The language deficits that result from dementia are described in terms of a three stage model, parallel to the stages of the progression of the illness discussed in section 2.1.

- In the early stage a person may have memory problems and subtle language difficulties such as object naming. The person may develop strategies to compensate for the difficulties, at least early on in the disease process, and be able to mask them. The person may be disorientated in time but will be orientated in place and person.
- By the middle stage the person will present with marked naming deficits and his discourse may be circumlocutive and vague. His communication will be less interactive and will show comprehension difficulties. The person may be disorientated in both time and place.
- By the late stage the person will lack conventional communication means and be unaware of other people attempting to interact with him. Any verbalisations will be repetitive and jargonistic, before becoming echolalic. The person will eventually become mute. He will be disorientated in time, place and person.

See Bayles (1984), Obler and Albert (1984), and Overman and Goeffrey (1987) for more detail. Hamilton (1994) tracks these three stages in her longitudinal study of one patient with Alzheimer's disease.

There is much debate about whether to call the language of dementia a *language disorder secondary to dementia* or the commonly used term *aphasia* (Maxim and Bryan, 1996; Walker, 1988). Using the former helps to distinguish between language disorders of sudden acute onset (such as a result of cerebro vascular accidents) and those attributable to dementia. The distinction becomes less clear in conditions such as multi-infarct dementia where dementia occurs as a result of a series of small vascular accidents. The language of patients with dementia tends to present differently to other aphasias (Stevens, 1992). The characteristics of language impairment seen in dementia suggest that Jakobson's Regression Hypothesis (Jakobson, 1941) may better fit the language of dementia than aphasia to which it was initially applied (Emery, 1986; Obler, 1981).

Studies examining the language of dementia are varied and include detailed accounts of many different types of dementia (Boles, 1996; Garcia and Orange, 1996; Griffiths, 1991; Lee, 1991; Nespoulous, 1996; Orange and Purves, 1996; Ramanathan, 1997). Many studies examine early language disturbances as a differentiating diagnostic factor (Armstrong, 1996; Bryan, 1999; Maxim and Bryan, 1994; Maxim and Bryan 1996). This is only possible in the early stages of dementia for as the disease progresses the language difficulties become more alike, converging in *"a final common path"* (Walker, 1988, p175). Such language changes will not be discussed here.

At a conversational level, turn taking is thought to be preserved in dementia (Ripich *et al.*, 1991), even in the late stage (Golper and Binder 1981; Hamilton, 1994; Sabat, 1991). Patients with generally incoherent speech may still manage conversation structure (Sabat *et al.*, 1984). However, patients often require longer to respond than is generally given in normal conversation (Causino *et al.*, 1994). Obler (1981) suggests that such latency may be partly responsible for the characteristic muteness of some patients with Alzheimer's disease.

2.2.2 Non-verbal communication:

Non-verbal aspects are an important part of effective communication (Couchman, 1995; Hargie, 1997; White *et al.*, 1996) and particularly so for people with dementia. Studies have examined changes in the facial expressions of people with dementia (Bartlett *et al.*, 1999; Cohn *et al.*, 1999; Jansson *et al.*, 1992), some using computer technology such as the Facial Action Coding System (FACS - Ekman and Friesen, 1978). In other studies gaze and body orientation were shown to demonstrate a readiness to communicate (Couchman, 1995), whilst eye blinks, head movements and movements of the mouth, lip and jaw were the most commonly observed communicative behaviours (Jansson *et al.*, 1992; Norberg *et al.*, 1986). In one study facial movements were shown to increase in response to feeding (Asplund *et al.*, 1991). These findings are supported by the theory that a dementing disease affects the higher nervous functions first, leaving the subcortical and brainstem functions, such as involuntary movements, more intact for longer (de Ajuriaguerra, 1968; Tomlinson, 1992).

Not only are people with severe dementia found to be using facial movements expressively, they are also thought to rely on them for basic understanding. The information portrayed in the human face contributes to the recognition of other people as well as emotional state, race, age, health and mood. Emotions are perceptually easier to recognise than most other properties conveyed by the face (Roudier *et al.*, 1998; Sergent *et al.*, 1994). The net of emotional expressions is far smaller than that of identity so people with dementia are more likely to recognise how a person is feeling rather than who they are.

Disturbed or disruptive behaviour is often seen in dementia and is increasingly thought of as communicative. Behavioural disturbances in the early stages may result from the person being unable to come to terms with the illness (Morris, 1999b) or may be the only means available to the person to express their fear and frustration. Direct correlation between behaviour disturbances and the nursing environment has also been identified (Bowie and Mountain, 1997). Some authors recommend that the management of behaviour needs to include an increased awareness of the limited means patients have to express their emotion (Norberg, 1996; Roberts *et al.*, 1996).

2.2.3 Sensory impairment:

Hearing loss is common in the normal ageing population and there is evidence that hearing loss has a huge impact on quality of life due to social isolation (Norris and Cunningham, 1981; Thomas, 1981; Weinstein and Ventry, 1982), disorientation (Ohta *et al.*, 1981) and depression (Herbst and Humphrey, 1980; Jones *et al.*, 1984). The solution may be for carers to be aware of the hearing loss and adjust communication appropriately, although it has been shown that nurses often lack the adequate training to recognise hearing impairment in the elderly (Heron and Wharrad, 2000). Many people will benefit from the use of a hearing aid, but a common problem for hearing aid users is that all sounds, not just speech sounds, are amplified. Also an aid that is not working, because it is broken or the battery is flat, is worse than not wearing an aid in the first place as it blocks the ear and impedes hearing (Morris, 2000c).

Patients with dementia are just as, if not more likely to suffer from sensory deficits as non-dementing people of a similar age. People with dementia, particularly of the Alzheimer's type, are twice as likely to have impaired hearing (Uhlmann *et al.*, 1989) and the disease process will contribute to an acceleration of the consequent disability. In addition, people with dementia may misperceive what they do hear. Whilst wearing a hearing aid will help some people, it may cause additional problems for people with dementia who may have greater difficulty separating speech sounds from ambient noise. This is particularly so if the person also has auditory perceptual difficulties which will reduce the meaning of what is heard further. In addition, many people will have problems remembering where their hearing aid is, what it is for and how to use it (Nursing Times/Emap Health Care Open Learning, 2000).

The loss of sight can be equally as disabling to communication as the loss of hearing. It is known that lip-reading is an integral part of comprehending speech, as is interpretation of facial expression, body language and gesture. Visual impairment is known to contribute to complex visual hallucinations in dementia in general (Morris, 2000d) and to specific dementing syndromes such as Charles Bonnet syndrome (Terao and Collinson, 2000). Impairment to visual perception can result in fluctuating visual deficits and people with dementia may be unsure whether what they can see is real or distorted (Morris, 1999a). Many patients believe that what they see is real and this contributes to the feelings of fear and paranoia often associated with dementia (Burns *et al.*, 1990).

Whilst many problems are common for all older people with sensory deficits, the person with dementia will require additional support from carers. They will require help to look after a hearing aid and spectacles and in many cases will be reliant on carers to remember to provide them and care for them on a daily basis.

2.2.4 The communication environment:

It is well acknowledged that an institutional setting is not conducive to communication (Bryan and Maxim, 1998; Kaakinen, 1995; Kenny, 1997;

Lubinski *et al.*, 1981; Maxim and Bryan, 1996; Packer, 1999). Patients are often seated round the outside edges of a room with little opportunity for interaction and socialisation. It is not unusual to find a television or radio, or both, playing in the background. The choice of music or programme is often that of the nursing staff rather than patients. Frank (1995) discusses how people with dementia can communicate with those around them so long as people are willing to listen, but in many caring environments these opportunities are just not made. This is a theme also expressed by Packer:

> *"In order to hear, we must learn to listen, and this involves learning to 'listen' with our eyes and intuition as well as ears."*
> (Packer, 1999, p730).

Goldsmith (1996) suggests that many barriers to communication arise from false assumptions and understandings about dementia. He states that...

> *"... once the label of 'dementia' was given to someone, a great many people assumed that they had nothing to contribute and that their views or expressions were almost certain to be distorted and unintelligible."*
> (Goldsmith, 1996, p49).

The disability of dementia is not just about how people communicate but also how they are spoken to by other people. *Elderspeak* (characterised by a simplified speech register, exaggerated pitch and intonation, simplified grammar, limited vocabulary and slow rate of delivery) is acknowledged as a parallel to 'baby talk' (Kemper *et al.*, 1998). Elderspeak is found being used in a number of care settings. Whereas baby talk is thought to teach language to developing children, elderspeak is thought to carry a deprecatory message and effect which indicates the helplessness of the person being addressed (Caporael, 1981; Caporael *et al.*, 1983). It has been argued that the use of elderspeak contributes to the development of an 'old' identity (Harwood *et al.*, 1995; Ryan *et al.*, 1986). There is a risk that this can lead to a negative downward spiral causing loss of self esteem and social isolation. The behaviours or responses of older adults may prompt the use of elderspeak, or the speakers may use elderspeak based on assumptions and stereotypes about communication problems of the elderly (Kemper *et al.*, 1996, 1998). The use of elderspeak may communicate expectations and result in dependent behaviours (Caporael, 1981; Caporael *et al.*, 1983). Denying the possibility of communication or appropriate communication increases the staff members' control over the patients and disempowers them (Goldsmith, 1996).

There are many ways in which the communication of patients with dementia can be maximised. Speech and language therapists working within this field are likely to have produced their own guidelines for staff and carers. There are clear guidelines on reducing noise levels, establishing contact and communicating face-to-face, speaking clearly and directly, and using objects to cue understanding (Bryan *et al.*, 1998a; Enderby, 1990; Morris, 1999c, 2000c; Packer, 1999). Communication can take place in many modes and may involve poetry, metaphor, storytelling, drama therapy, dance or music (Cheston, 1996; Chrichton, 1997; Crimmens, 1998; Killick, 1994).

It is acknowledged that unless staff change their own attitudes and approaches then communication with a person who has dementia will be difficult, if not impossible. Goldsmith (1996) views such communication difficulty as a challenge to be overcome. He states that this kind of attitude results in communication with people who have dementia being possible for much longer than expected. Some training programmes have indeed demonstrated how staff are able to change their communication styles across different contexts (Couchman, 1995, 1996; McConkey *et al.*, 1999).

2.2.5 Functional communication:

Many authors refer to the difficulty of separating out linguistic changes from cognition and memory changes (Walker, 1988) and promote the use of more functional assessments (Chapey, 1992; Frattali, 1992). There are some assessments already designed for this specific purpose for patients with aphasia (Glindemann and Springer, 1995; Holland, 1980; Lomas *et al.*, 1989; Sarno, 1969).

Deficits of speech and language are common in dementia but are not always focused on during therapeutic intervention, particularly in the more advanced stages of the disease. Patients who are formally assessed tend to do badly, even though the assessment process indicates that the patient is able to interact at some level. Because such interaction is not being directly assessed, there is a danger that it gets ignored (Crisp, 1993). Speech and language therapists working with these patients work to maximise functional communication in any way possible. The important factor is not whether a person with dementia can communicate, but whether they can communicate with a significant other about a relevant topic. There is little emphasis on saying things properly but the therapist, patient and carers work together to accentuate understanding of the patient's limited communicative ability (Maxim and Timothy, 2001).

2.3 Communication partnerships.

2.3.1 Models of communication:

Communication models have been devised to help explain the nature of communication and conversation. The concept of conversational rules were proposed by Grice (1975) as a series of principles and maxims. To converse, a speaker produces utterances which are governed by a set of conventions. Rules specify the intent of the speaker, the beliefs that the speaker has about the situation, the propositional content of the utterance etc. The conventions enable the recipient to interpret the meaning, which is often different to the conventional meaning of the utterance (Clark and Schaeffer, 1989; Nofsinger, 1991). This is described as the 'Speech Act' theory (Searle, 1969). Communication has long been discussed and described in terms of models. There are three major models of communication, the *code model*, the *inferential model*, and a combination of the two, the *continuous process* model.

The code model.

Communication may be thought of as a physical stimulus which brings about a similarity in thought between two speakers. For centuries theories of communication have been based on the linear code (or signal) model, whereby communication is achieved by the encoding and decoding of messages, by *"packing a content into words and sending it off to be unpacked by the recipient at the other end"* (Sperber and Wilson, 1986, p1). A message (thought) is encoded into a signal (language) and the signal travels to the recipient (speech) where it is received (heard) and decoded (comprehension). Interference or noise in the channel of transmission can distort the signal.

The code model of communication may have come to be seen as a fact rather than a hypothesis (Sperber and Wilson, 1986), but whilst it may be used to describe telecommunications (such as fax or telex machines, email etc.), it is insufficient to describe human communication. The major assumption of the code model is that language is a code and that the sounds are associated with thoughts (Saussure, 1974; Shannon and Weaver, 1969; Vygotsky, 1962, 1978). Despite many attempts neither assumption has been proven (Sperber and Wilson, 1986). It is argued that the missing factor which results in the code model being insufficient is that of inference.

The inferential model.

Whilst the code model may consider a sentence to be a symbolic representation of thoughts it is unable to explain the different uses of the same sentence, the role of the utterance. The semantic meaning of a sentence will have a common core of meaning whereas each utterance of that sentence is likely to differ in its interpretation of that semantic information. This is referred to as pragmatics. Interpretation of pragmatic meaning is not possible in the code model and requires inference. It is only through pragmatics that references such as "I", "him", "there", "tomorrow" etc. can be understood. Utterances do not only convey thoughts but also reveal the speaker's attitude or beliefs.

> *"The same sentence, used to express the same thought, may sometimes be used to present this thought as true, sometimes to suggest that it is not, sometimes to wonder whether it is true, sometimes to ask the hearer to make it true, and so on."*
> (Sperber and Wilson, 1986, p10).

Whilst there have been attempts to add a pragmatic level to the code model, it is argued that an inferential model is a separate entity. Whereas the code model is based on the recovery of a message from a signal by an underlying code, the inferential model is based on a set of premises which lead to conclusions being formed. For pragmatics to be accepted as a part of the code model it must be shown not only how the speaker and hearer have a common language but also that they have a common set of premises to make the same inferences (Sperber and Wilson, 1986).

Neither the code nor the inferential model alone is sufficient to explain human communication and interaction. Instead, the two theories compliment one another and are both needed for a full, structural description of communication.

Continuous process model.

Fogel (1993, p11) describes such a combined model as *"a continuous process of mutual social co-ordination"*, or "*co-regulation*". The two dimensions of every communication act are identified as linguistic encoding/decoding and inference. The encoder and decoder perspectives interface, not only with each other but within the particular context in which an utterance is made.

In a continuous process model both participants are continuously active, modifying and responding to each other's behaviour in a way which can make it difficult to tell who is the sender and who the receiver at any one point (Fogel, 1993; Stamp and Knapp, 1990). Recipients consensually agree the *frame* of the discourse, such as its scope, location, setting and the acts which are significant and those which are irrelevant (Fogel, 1993). Behaviours occur on multiple levels of organisation and are related to other behaviours by the same person whilst also being affected by the simultaneous behaviours of the other person. The validity of an interpretation may depend on its circumstances (Grove *et al.*, 1999) and can only be understood within the particular interaction taking place. Five communicative goals have been identified (Winograd, 1977):

- to stimulate the hearer into performing a particular action;
- to encourage the hearer to make a particular inference;
- to convey information;

- to create new conceptualisations; and
- to direct a person's attention to a particular event or object.

Attribution of such communicative intent requires an interactional model. Stamp and Knapp (1990) argue that intent cannot be explained by an encoder-decoder model and that scholarly thinking has tended to put the two perspectives in opposition rather than combination. The problem with an interactional perspective such as the continuous process model, is that it assumes that true intentions can be known and that the concept of 'intention' remains the same at all levels of interaction. See for example the elaborate work of Platts (1979) and his account of *'shades of meaning'*.

Whilst it is acknowledged that the true intent behind a behaviour may not be discernible, even to the person himself, some intentions can be reliably recognised. Stamp and Knapp (1990) refer to the work of Schutz (1970), the social phenomenologist, who identified two motivators of social action: *'in-order-to motives'* and *'because-of motives'*. The former involves an intention to bring about a particular state whilst the latter is the reason behind a person's actions. The person will not be conscious of their *'in-order-to motives'* at all, and only conscious of their *'because-of motives'* in retrospect. Schutz states that even an observer may be able to reconstruct a person's *'because-of motives'* from an accomplished act and argues that this makes them more objective. It could be argued that observers make more impartial interpretations of a speaker's intended meaning, as they have no personal agenda to contribute to the interaction.

2.3.2 Contributions to discourse:

One example of a continuous process model is that proposed by Clark and Schaeffer (1989). The model is an elaboration of the theories of turn taking and collaboration. For a person to contribute to conversation they must do more than utter the right words at the right time. Rather, interaction consists of collective acts performed by participants working together. The model is based on interpretations of the London-Lund corpus (Svartvik and Quirk, 1980) and defines contributions as being different to other linguistic units, primarily because they cannot be formulated autonomously following a predetermined plan. Instead contributions emerge as the discourse participants collaborate and act together.

There are two distinct types of intentional act, *individual* acts and *collective* acts (Clark and Carlson, 1982; Grosz and Sidner, 1989; Searle, 1989). In the process of conversing with another person we perform a collective act. Within that collective act there are three distinct acts:

- the collective act of conversing;
- the first participant's individual act as their part of the collective act; and
- the second participant's individual act as their part of the collective act.

Both of the individual acts (the second and third acts above) are *participatory* rather that *autonomous*. That is, they cannot be achieved on their own. Clark and Schaeffer (1989) refer to these participatory acts as "contributions" and these can only be created by the participants acting collectively.

Clark and Schaeffer stipulate two requirements for contribution:

- that the contributor tries to specify the content of their contribution and the other participant(s) try to register that content; and
- that the contributor and participant(s) mutually believe that the contribution has been understood.

The process of contributing can be divided into two concepts, the *presentation* phase and the *acceptance* phase. These emerge during the discourse as a hierarchical structure reflecting the recursive process by which they are created. Definitions of the presentation and acceptance phases are taken directly from Clark and Schaeffer:

> *"Presentation Phase: A presents utterance* 'u' *for B to consider. He does so on the assumption that, if B gives evidence* 'e' *or stronger, he can believe that B understands what A means by* 'u'.
>
> *Acceptance Phase: B accepts utterance* 'u' *by giving evidence* 'e' *that he believes he understands what A means by* 'u'. *He does so on the assumption that, once A registers evidence* 'e', *he will also believe that B understands."*
> (Clark and Schaeffer, 1989, p265).

In other words, the first participant will say something to which the second participant will reply in such a way that he provides evidence of having understood what the first participant meant. The first participant is also then required to offer evidence that he has understood the second participant's evidence. The response is therefore another presentation phase, and the first participant's response to it a second acceptance phase.

Evidence of understanding can be provided in five ways, graded from weakest to strongest:

- *continued attention*, to indicate satisfaction with the first participant's presentation phase;
- *initiation* of the next contribution which would be relevant at a level as high as the current one;
- *acknowledgement* of the presentation phase by nodding or saying 'uhu, 'yeah' etc.;
- *demonstration* of all or part of what the first participant is thought to have meant; or
- verbatim *display* of all of the first participant's presentation phase.

Generally, the more demanding the purpose the more evidence will be required to convince the first participant that the second participant has understood. So if evidence of understanding has to be accepted by further evidence of understanding, how do conversations ever move on? Clark and

Schaeffer discuss the *strength of evidence principle* which states that the evidence required to accept a second presentation phase must be weaker than the evidence to accept the first presentation phase. This ensures that an exchange of presentation and acceptance phases draws to an end and the next exchange can begin.

The commonest form of contribution is that of a turn. Turn taking is fundamental to exchange structures and often takes the form of adjacency pairs. Adjacency pairs are two utterances long, they are produced successively by different speakers, they are ordered and they are strictly related (Sacks, 1963, 1964-72). First pair parts include questions, greetings, offers, requests, and complaints etc. Second pair parts include answers, reciprocal greetings, acceptance/refusals, actions, and apology/justifications. Adjacency pairs are basic structural units which enable the turn taking system to function. See Levinson (1983) for an in-depth discussion of adjacency pairs and preference organisation.

The adjacency pairs used to open and close conversations are those of greeting and closing. Sacks (1964-72) suggested that greetings are mostly universal in conversation and that when they do not occur they are conspicuously absent. Greeting sequences always occur at the very beginning of conversation and cannot be performed elsewhere. They allow all speakers to contribute right at the start. There are only a few examples when greetings might not occur, such as when the conversational partners are strangers, and during telephone conversations (Coulthard, 1985; Sacks, 1964-72; Schegloff, 1968).

A greeting sequence normally consists of a single exchange of greeting followed by the introduction of the topic, as shown in figure 2-1:

a	hello	greeting exchange
b	hello	
a	what are you doing here?	(introduction of topic)

Figure 2-1 Example of a greeting sequence.

Likewise closures are a collaborative and easily identified exchange (Button, 1991; Schegloff and Sacks, 1973). There are three identifiable components of closure: closing down the topic, pre-closing the conversation, and a closing exchange, as shown in figure 2-2.

a	you have had a busy day	(closure of topic)
a	I'd better let you get on	(pre-closure of conversation)
b	thanks bye	(closing exchange)
a	bye	

Figure 2-2. Example of a closing sequence.

All of the models examined thus far assume that all communicative partners are able to communicate at the same level, that interactions are symmetrical. The interaction observed in asymmetrical partnerships is very different.

2.4 Asymmetrical communication partnerships.

There are many examples of asymmetrical communication partnerships. Some arise due to one speaker having a more authoritative role (teacher/pupil, parent/child, doctor/patient etc.) whilst others develop due to one speaker having superior language skills than the other (speech and language therapist/patient, parent/infant etc.). One of the most widely studied asymmetrical partnerships is that of parent and infant.

2.4.1 Parent-infant asymmetrical partnerships:

It is now widely accepted that the minutiae of behaviours exhibited by very young babies can be communicative (Munro, 2000). Caregivers cannot explain communication to infants yet infants typically demonstrate an understanding of the rules of communication (Brazelton and Koslowski, 1974; Brazelton *et al.*, 1975; Brazelton and Als, 1979; Papousek and Papousek, 1997). Theories of child language acquisition vary.

Hirsh-Pasek and Golinkoff (1996) distinguish the main theories of language acquisition as being either *inside-out* or *outside-in*. Inside-out theories emphasise the innateness of language and view its acquisition as a linguistic process, whereas outside-in approaches emphasise learning procedure and cognitive/ social development.

There is a school of thought that suggests children acquire language through imitation. Whilst imitation plays a crucial role, much of the language produced by children will not have been produced by an adult. For exaple, *"my teacher holded the baby rabbits and we patted them"* (Cazden, 1972, p92). Imitation does not account for the grammatical errors observed in child language. Similarly it does not account for how children with speech disorders are able to acquire and understand language they have never spoken (Bruner, 1983).

Another theory suggests that children acquire language by positive reinforcement of correct utterances and negative reinforcement of incorrect ones. Behaviourists such as Skinner (1957) view language as a product of associations between stimuli (events) and reinforcers (consequences). Such an argument has been widely disputed (Chomsky and Lightfoot, 1990) and was disregarded by Brown (1973) who found little evidence of reinforcement except to correct mispronunciation and inaccurate facts.

Neither of these two theories account for non-random errors, the speed at which language is acquired and the fact that it is acquired without formal instruction. Children appear to be born with a pre-requisition to learn the language to which they are exposed (Chomsky, 1965). This has become known as the *innateness hypothesis*. Such a theory is supported by universal patterns of development, critical periods for development and early sensitivity to language (Golinkoff, 1983; Hirsh-Pasek and Golinkoff, 1993, 1996; Lust *et al.*, 1994; Singleton, 1989).

The social constructivism model (Bruner, 1983; Harris, 1993; Lenneberg, 1967; Smith *et al.*, 1988; Snow and Ferguson, 1977; Vygotsky, 1962, 1978) recognises the interaction between innate language skills and learned behaviours, and the role of *apprenticeship* (Vygotsky, 1978). It is argued that adults provide *scaffolding* for the infant's limited communication repertoire, reinforcing and supporting non-conventional communicative behaviour. Adults make interpretations and attribute meaning even to very minimal behaviours. Dimitracopoulou (1990) and Smith (1998) however argue that some responsibility is carried by the child and suggest that at a very young age a child has pragmatic behaviour to which the adult responds and which shapes the child's development. Some pragmatic skills, such as 'showing', 'requesting' or 'sharing' are so well formed at ten months that they may be used to predict communicative competence at two and three years of age (Smith, 1998).

Language is driven by cognition and is one manifestation of symbolic function (Piaget, 1979). A child's cognitive system learns to process information in different ways and make connections between related elements (Messer 1992). The effect of context and interaction style (Harris, 1992; Messer 1992), role of gaze and joint attention (Bates *et al.*, 1979; Coupe and Goldbart, 1998), and the emergence of intention (Coupe and Goldbart, 1998; Camaioni, 1993) have all been identified as key components to language development.

Child language development is thought to occur in stages:

- *Pre-intentional reflexive level:* a small range of behaviours, sounds, reflexes and changes in state of arousal may be produced in response to stimuli (Prechtl, 1969);
- *Pre-intentional reactive level:* behaviours may be elicited by an adult and are seen as being participatory (Brazelton *et al.* 1975), the emergence of a smile and shared attention are important developments;
- *Pre-intentional proactive level*: purposeful action on objects, people and events observed (Coupe and Goldbart, 1998);
- *Intentional primitive level*: early meanings and intentional behaviours develop; and
- *Intentional conventional level*: communication becomes more sophisticated and uses recognisable symbols such as speech, non-verbal behaviours etc.

Throughout the first three stages, communication can be said to be affective (Thoman, 1981) and can be observed in infants and children or adults of arrested development (Coupe *et al.*, 1985). Affective communication can be defined as external and internal emotional responses to changes in the environment and the people within it. Meaning can be attached to such behaviours and may be responded to as if they are communicative signals (Coupe and Goldbart, 1998).

Some authors (Brazelton *et al.*, 1975; Bates *et al.*, 1979; Coupe and Goldbart, 1998; Wetherby and Prizant, 1989) argue that intentional communication is developed during the fourth of the above stages, with the critical indicator being the development of shared attention. Camaioni (1993) however argues that shared co-ordination does not signal intentional communication but is a milestone on the way. She argues that real communicative intent requires subjectivity, the ability to view the human being as a subject...

> *"...who not only perceives/acts but also selectively attends and in general possesses independent psychological states such as interest in objects/events."* (Camaioni, 1993, p93).

This may help explain why co-ordinated attention is thought to indicate intentionality in prelinguistic children (Wetherby and Rodriguez, 1992) but not in students with severe and multiple disabilities (Iacono *et al.*, 1998). The latter group may be less likely to develop the subjectivity that Camaioni (1993) states is required for the development of intention.

The asymmetrical partnership seen in the early infant months gradually develops into a symmetrical one once the child is able to perform independently on an activity or task. Kaye (1982) refers to four levels of parent-infant interaction: *shared regulations, shared intentions, shared memories* and then eventually *shared meaning.*

Schaffer (1997, 1996) and Lewis and Rosenblum (1974) discuss the parent-infant interaction in detail.

2.4.2 Adult asymmetrical partnerships:

A similar partnership to that of parent and infant is seen between carers and people with learning disabilities and between carers and people with dementia, to name but two examples. The role of the competent communicator is however very different to that of an adult communicating with a child. There is no 'modelling' or 'apprenticeship' for language development, but rather a struggle to understand and express ideas with limited communicative function. When the capabilities of one communicative partner are delayed or impaired, pleasurable interaction is no longer spontaneous (McCollum, 1984) and in such cases communication is reliant on interpretation of intention, based on a very limited repertoire of behaviours. The competent communicator must work harder to determine communicative intention on the part of the less competent partner. However, not all people are willing to suspend the basic rule of discourse, that communicative partners have equal function, and so communication in these circumstances often fails (Adamson *et al.*, 1987).

The less explicitly encoded information that is available, the more inference must be used (Grove, *et al.*, 1999). Interpretation of behaviour has a number of steps (Hyche *et al.*, 1992):

- awareness of signalling behaviours;
- selection of salient cues from a stream of behaviour;
- attribution of intention and meaning;
- decision making regarding what response is required; and
- delivery of the appropriate response.

An adult asymmetrical partnership which has received much attention is that of nurses and their patients.

2.4.3 The nurse-patient partnership:

Patients, such as those with dementia, are vulnerable both to misinterpretation and to deliberate abuse. Not attending to cues from patients and therefore not responding to their needs has been likened to a form of neglect or abuse (Forte, 1990; Malone, 1996). 14% Of the nurses struck off the register in a single year had failed to attend to the basic needs of their patients (Harris, 1999). Studies show that such abuse occurs because the staff involved tend not to recognise it as such (Neal, 1999). The majority of complaints from the mental health sector focus around the autonomy of patients and paternalistic attitudes of staff (White, 1999).

Whilst major changes to philosophy need to come from management (Shepherd, 2000), subtle yet significant changes can be made by individual members of staff. The attitudes of staff toward their patients can be improved and this is one of the aims of the Dementia Care Mapping method discussed in section 2.1.2 (Innes *et al.*, 2000; Kitwood and Bredin, 1994). Training alone however is not sufficient to alter practice, unless it results in changed attitudes (Lintern *et al.*, 2000).

The vulnerability of the nurse must also be considered. If the needs of patients are assessed by inference of their behaviour then one person's interpretation may be different to another's. For example, staff who interpret a behaviour as refusal may be accused of neglect by other people who do not view the behaviour in the same way. Likewise, staff who continue to persevere with a task may be accused of forcing patients to do something against their will if another person interprets the behaviour as refusal. In an era of accountability and blame culture, staff need to make decisions based on multi-disciplinary discussion and with the involvement of relatives. Decisions made jointly by a team are less likely to result in allegations of abuse but in satisfactory patient care.

In a parallel to people with dementia, children with Down's syndrome are known to have a lower vocal output, to smile and vocalise less frequently, to have less intensity in expression or affect, and to be delayed in developing functional eye contact when compared to age matched non-handicapped children (Berger and Cunningham, 1981; Hyche *et al.*, 1992). The mothers of children with Down's syndrome were shown to be far more responsive to non-verbal behaviours. With regard to communicating with people with dementia, it could be suggested that the relatives of people with dementia develop a similar heightened sensitivity to cues as the mothers of children with Down's syndrome. Many of the issues of conflict between relatives and care staff result from each having a different starting point. Nursing of this kind, by its very virtue, tends to centre around loss of skills and function. Relatives, on the other hand, tend to look for skills and functions that have been retained. Relatives often want to see communicative behaviour as this helps preserve the person they know.

Janson *et al.* (1992) suggest that if we all work from the pre-understanding that the patient with dementia is trying to communicate with us, then it should be possible for us to infer intention in the behaviours of people even with very severe dementia. There is a cautionary *sting-in-the-tail* however. We must remember that just because inferences can be made does not necessarily mean that those inferences are accurate (Norberg, 1996).

Grove *et al.* (1999) and Camaioni (1993) express particular concern about advocates, facilitators and interpreters, within the field of language impairment. One therapy technique, "facilitated/assisted communication" (Crossley, 1997; Crossley and McDonald, 1980; Crossley and Remington-Gurney, 1992; Crossley, 1992) is a good example of this as there is no empirical evidence that the observed act is from the sender rather than the facilitator (Bunning, 1995, 2000; Von Tetzchner, 1997). The technique has been widely criticised although it is suggested that the technique has been successful in enhancing some communication skills in naturalistic settings (Emerson *et al.*, 2001).

Models of communication, how participants contribute to conversation, and specific communication partnerships have been discussed. The following section examines methods for measuring these communication partnerships.

2.5 Methods of analysing collaborative partnerships.

2.5.1 Conversation analysis:

There are many methods of analysing interaction but most tend to start with some form of conversation analysis. Conversation analysis has been used to study conversational turns in aphasia (Perkins, 1995), help couples adapt to aphasia (Lock *et al.*, 2001; Wilkinson *et al.*, 1998), examine reminiscence in the elderly (Boden and Bielby, 1983) and to maximise care staff awareness of gaze and body orientation in adults with learning disabilities (Couchman, 1995, 1997).

Conversation analysis has grown out of the field of ethnography and was developed initially by three sociologists Sacks, Schlegoff and Jefferson (1974). Ethnography assumes people act according to cultural rules or norms to make their actions meaningful to each other. Ethnomethodology attempts to identify the methods people use to establish these shared meanings. Sacks (1984) describes two different ways of doing analysis: looking for order among random events (discourse analysis) or allowing the events to suggest an order (conversation analysis). The former may be referred to as a 'top down' approach whilst the latter may be referred to as a 'bottom up' approach. Conversation analysis uses categories that are *"demonstrably orientated to by participants rather than superimposing the analyst's categories".* (Lesser and Milroy, 1993). Sacks, Schegloff and Jefferson viewed conversation analysis as the first step toward achieving a discipline of naturalistic observation.

Conversation analysis is a data driven approach and describes observable behaviour. It is designed to give a visual representation, or script, of the spoken conversation - to look to the eye as it sounds to the ear (Schenkein, 1978). Full analysis captures all talk, paralinguistic features, timings, overlaps, pauses and the precise sequence of the conversation. It can therefore handle the most common type of discourse, people interacting within their social setting. It uses real interactions and therefore offers high validity and insight into communication. It treats conversation as a collaborative achievement (Perkins, 1995; Ripich *et al.*, 1991; Schegloff, 1982).

Conversation analysis is qualitative and trying to apply quantitative measures to it results in taking communication out of context (Lesser and Milroy, 1993). Having said that, quantitative methods may be applied to conversation analysis data providing it is interpreted within the qualitative framework. See for example Perkins' (1995) study of the sharing of the conversational floor by three aphasic patients.

Conversation analysis allows study of the patient and caregiver interaction, recognised as being crucial to the management of dementia (Bayles and Kaszniak, 1987; Dodd *et al.*, 1990; Orange, 1991). Past studies of people with dementia have tended to focus on pragmatic abilities (such as picture description, story telling, procedural discourse and clinical interviews) in isolation from the social contexts in which everyday communication takes place (Perkins *et al.*, 1998). Conversation analysis not only examines communication within context but focuses on abilities rather than deficits.

However, by only examining the spoken conversation itself we are only looking at half the story. Recent studies have expanded the use of conversation analysis to non-verbal behaviours (Bryan *et al.*, 1998b; Goodwin, 1997). Whilst this seems contradictory, it is achieved by employing the same principle that successful communication can be identified through how conversational partners respond to each other. In this context it matters not whether the communicative attempt is verbal or non-verbal.

2.5.2 States of engagement:

Conversation analysis allows much of the interaction to be captured. However, because of the lack of a formal linguistic code and as a result of sensory and motor impairments, it is difficult to examine asymmetrical interactions in the same way as symmetrical ones. One way of examining such interactions is to look at non-verbal behaviours as discussed above, but another method is to examine an individual's state of engagement, the place or person or object to which attention is being paid. This method was utilised by Bunning (1996, 1998) in her study of interactions in learning disabled adults. The level and type of interactive behaviour can be observed in the individual's natural environment, and these are categorised in table 2-1.

Bunning was able to show a reduction in self-active engagement with the creation of individual sensory environments. Whilst the aetiologies of learning disability and dementia are different, some of the same observations may be made, that people in institutional environments exhibit stereotypical behaviour and that such behaviours increase the more severe the cognitive impairment. Bunning concluded that a deliberate approach to interaction may help people with severe-profound and multiple disabilities to engage, and the same is thought to be true for people with severe dementia (McNamara and Kempenaar, 1998).

Term	Definition
Self-intimate engagement.	Personal or private activities which may take place in secluded areas. The behaviour is not viewed in order to preserve the respect and dignity of the patient. e.g. engaged in personal hygiene, engaged in toilet routine etc.
Self-neutral engagement.	Routine tasks, doing nothing specifically. Usual body actions are observed and passive responding to the actions of others. e.g. engaged in usual body actions, engaged in routine tasks etc.
Self-active engagement.	Personally or socially maladaptive. Non purposeful movements characterised by repetition, environmental independence and irrelevance to ongoing activity, e.g. fine and gross motor movements which are repetitive and non-purposeful such as rocking, hand flapping etc.
Person engagement.	Interpersonal relations with others. Interactions mutually influence each other. e.g. shows notice of another person in clear, overt way or displays appropriate adaptive response directed to an identified person etc.
Object engagement.	Manipulative schemes applied to objects and their relations in space. Visual pursuit, fixation, tracking and other active engagement with object. e.g. attending, exploring, tracking an object etc.
Person-object engagement.	Emits movement or sound whilst eye contact is alternated between person and object. Co-ordination of individual actions to produce an effect on the environment. e.g. performs action on object whilst looking at person, alternating gaze between person and object etc.

Table 2-1. Glossary of terms for types of engagement (Bunning, 1996).

2.6 Summary and aims of project.

2.6.1 Summary of literature review:

Both the number of cases of dementia and thus the proportion of the population who have the illness are increasing. The field of dementia is currently enjoying a surge of interest and research. Whilst much is known about the apparent causes of dementia there are still many questions requiring answers, and as yet there is no cure. Person-centred-care has brought about a shift in attitude and patients with dementia are receiving an improved level of care as a result. Facilitation of communication is of primary importance, where staff and carers may be able to help people with dementia communicate their needs if they focus more on communicative function than accuracy.

Patients with severe dementia rely totally on carers and staff members to provide for their everyday needs. In order to provide this care the staff members need to be able to interpret what the needs of the patients are. They are required to compensate for the diminished communicative skills of the patients and to infer meaning from weak communicative cues. Staff may enable patients to communicate by ascribing meaning to their behaviours, in much the same way as an adult will ascribe meaning to the behaviour of an infant. Staff may provide scaffolding for the patients' behaviours and maintain the shape of the interaction. How staff compensate for the communication deficits of their patients is explored in Chapter Four.

The care of people with severe dementia tends to be provided in a hospital environment. Such care tends to be task orientated and no task has a greater emphasis than feeding. Ensuring that the person with dementia receives adequate nutrition is often impossible and many patients with dementia suffer from malnutrition. The decision whether or not to feed a person with dementia is often an ethical minefield and one in which there is as yet no clear guidance.

2.6.2 Research questions:

The nature of this study required that the research questions reflect the exploratory nature of the research. The researcher wished to extrapolate key areas for analysis from the literature and examine them within this study. Many areas examined had not previously been analysed with patients who have dementia and there was therefore a need to establish whether the findings of studies carried out with different subjects could be applied to the researcher's sample group. Areas highlighted from the literature review were combined with the researcher's own questions regarding the data collected in the video pilot study (see section 3.2.5). Together these gave direction for where to look for behaviours or events that could be (a) measured and (b) used to indicate feeding success.

Each of the research questions below are discussed with reference to the literature. Hypotheses were drawn up based upon some of these questions. The questions, and where relevant the hypotheses, are shown in table 2-2. at the end of this chapter.

Question 1:

What are the identified differences in staff-patient interactions over the twelve dyads?

There is a question as to whether the type of interaction observed between members of staff and patients is a reflection of the patient's communicative ability or of the member of staff's communicative style. Literature suggests that it is more likely to be the latter. Staff compensate for the communication deficits of patients differently (Grove *et al.*, 1999), and therefore view and treat patients differently (Norberg, 1996). Interactions between staff and patients tends to be task orientated (White, 1999) and staff often find it difficult to relate to the patient in any meaningful way (Richter et al., 1995). It should be possible to identify differences in interaction style across members of staff by examining both the amount of speech and the type of utterances used. It is anticipated that there will be a statistically significant difference in the amount of speech used by each member of staff, which is not dependent upon which patient they are feeding. Likewise, a statistically significant difference is anticipated in the type of utterances used by each member of staff. The null hypothesis is that such differences are due to chance alone. This question is discussed in detail, in terms of methodology and findings, in section 4.1.

Question 2:

What patterns of normal turn taking can be identified during the interaction between members of staff and patients?

Turn taking is thought to be preserved in dementia (Ripich *et al.*, 1991) even in the latter stages (Hamilton, 1994; Golper and Binder, 1981; Sabat, 1991). However, patients often require longer to respond than is generally given in conversation (Causino *et al.*, 1994). Obler (1981) suggests that such latency may in part result in the characteristic muteness of some patients with Alzheimer's disease. It should be possible to identify the key turn taking components, adjacency pairs, in interactions between members of staff and patients. The findings relating to this question are discussed in section 4.2.

Question 3:

How are patients able to indicate an understanding of it being their turn?

Hamilton (1994) argues that the minimal vocalisations made by patients are in response to questions or utterances from their conversational partner. Whilst the patient in the latter stages of dementia is unable to produce lexical items, Hamilton argues that the very nature of the vocalisations indicate an understanding of it being their turn. This theory is further explored using the conversation model of Clarke and Schaeffer (1989). The analysis and findings for this question are presented in section 4.2.

Question 4:

What components of normal greeting and closing sequences can be identified in the interaction of staff and patients?

This exploratory study expands on the previous question. Greetings are inherent to normal conversation and occur throughout different cultures (Button, 1991; Levinson, 1983; Ripich *et al.*, 1991; Sacks, 1968; Sacks et al., 1974; Schegloff and Sacks, 1963). They are expected to be preserved in the interactions between members of staff and patients. It is unlikely that recognisable lexical items will be produced by the patients, but if they are able to preserve turn taking then there should be some indication that they realise a response is expected of them (Hamilton, 1994). The methodology, findings and discussion relating to this question are presented in section 4.3.

Question 5:

How does the patients' engagement status change when the members of staff begin to interact with them?

As the patients are sitting in chairs or in bed ready for their meal to start, it is assumed that their state of engagement will primarily be self-neutral. In some cases the patient may be asleep. When the member of staff arrives and begins to interact with the patient it is anticipated that there will be a change in the patient's state of arousal and engagement (Bunning, 1996, 1998). See section 4.4 for discussion relating to this question.

Question 6:

How do members of staff attempt to elicit engagement from the patients?

If each member of staff interacts differently with the patients then it is feasible that their methods for eliciting engagement from the patients will also differ. By examining the behaviours of the members of staff it should be possible to identifiy differences between them and to establish which methods result in the most effective engagement with the patient. The discussion for this question is presented in section 4.4.

Question 7:

What differences can be measured in the way the meals are fed and in feeding success?

Feeding is synchronised and collaborative (Athlin and Norberg, 1987; Satter, 1990, 1986; Shishmanian and Tomlinson, 1989) but the members of staff can be seen to have the more active role. Quantitative measures will be used to identify differences in the amount of food fed to each patient and feeding success will be measured. It is anticipated that the members of staff will be the influencing factor in observed differences. The null hypothesis is that the differences are due to chance alone. See section 4.5 for discussion relating to this question.

Question 8:

How do patients display a preference for sweet foods?

Patients with dementia are known to prefer sweet foods to savoury ones (Alzheimer's Dementia Care and Research, 2000a; VOICES, 1998). This is explored by examining feeding rate and meal completion in a comparative study. The methodology, findings and discussion are presented in section 4.5.

Question 9:

What are the antecedents to staff members giving the patients a drink?

If members of staff are sensitive to the needs and minimal behaviours of the patients they are feeding, it should be possible to identify the antecedent behaviours which result in the patient being given a drink. The discussion relating to this question can be found in section 4.5.

Each of these questions and hypotheses, as summarised in table 2-2, are addressed in turn in Chapter Four and discussed in Chapter Five.

Research questions and related hypotheses.	
Question 1. What are the identified differences in staff-patient interaction over the twelve dyads?	Hypothesis 1.1. There will be a difference in the amount of speech used by each member of staff which is not dependent on which patient they are talking to. Hypothesis 1.2. There will be a difference observed in the type of utterances used by each member of staff.
Question 2. What patterns of normal conversation can be identified during the interactions between members of staff and patients?	
Question 3. How are patients able to indicate an understanding of it being their turn?	
Question 4. What components of normal greeting and closing sequences can be identified in the interaction of staff members and patients?	
Question 5. How does the patients' engagement status change when the members of staff begin to interact with them?	
Question 6. How do members of staff attempt to elicit engagement from the patients?	
Question 7. What differences can be measured in the way meals are fed and in feeding success?	Hypothesis 7.1. It will be possible to identify differences in the amount of food fed to each patient, influenced by the members of staff. Hypothesis 7.2. It will be possible to identify feeding success from measurements of meal length and the amount of food consumed.
Question 8. How do patients display a preference for sweet foods?	
Question 9. What are the antecedents to staff members giving the patients a drink?	

Table 2-2. Research questions and hypotheses.

Chapter Three

Chapter Three

Methodology

3.1 Project design and development.

This section describes the methodology of setting up and carrying out the project. It does not describe the specific methodologies used for data analysis. It is acknowledged that this format is different to what would be expected in such a thesis. The researcher felt that the structure of this chapter and that in Chapters Four and Five should again reflect the exploratory nature of the study (as with Chapter Two).

When the design for the study was presented to the Local Research Ethics Committee the researcher was unable to specify how the data would be analysed. Although some attempts had been made at analysing the data from the pilot study, the true analysis was exploratory and partially grew from studying the video data. The methodology has therefore been divided into two parts: the *project design* and the *project execution*. The aim of this chapter is to outline in detail how the project was planned.

The researcher felt it would be more appropriate to discuss the methodology for each analysis of the data within Chapter Four. This was felt to make the information more readily available to the reader rather than it being presented in disparate units. Therefore rather than all the methods being discussed here and all findings being discussed in the next chapter, each analysis is discussed in terms of both methodology and findings in Chapter Four. The advantage to this format is that each of the analyses can be examined separately if desired. The disadvantage for the reader is that not all methodology is accessible through one chapter. It is however hoped that this format makes the journey through the project easier for the reader to follow.

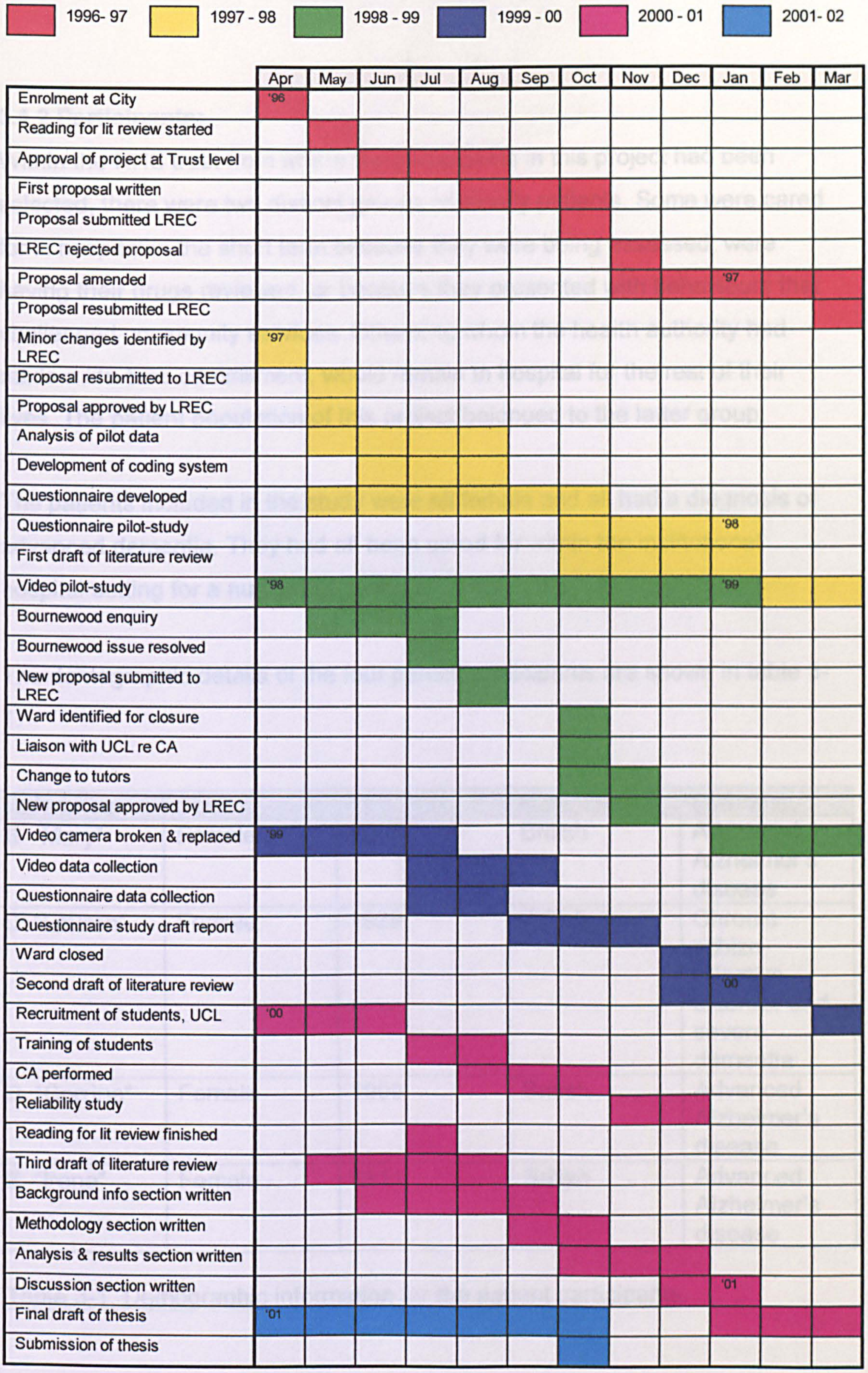
Chapter Three therefore explains how approval was obtained from the Local Research Ethics Committee and how the project was developed throughout this process; it describes the participants and how their consent was obtained; and it discusses confidentiality. For reference the development of the project over time is shown in Figure 3-1. The final part of this chapter then offers a critique of the methodology used and makes recommendations for future research in this area.

3.1.1 Local Research Ethics Committee approval:

A research proposal was first submitted to the Local Research Ethics Committee (LREC) in October 1996. At that stage the aim of the project was to classify the characteristics of swallowing disorders observed in the institutional hospital setting. The proposal was not approved by the LREC for a number of reasons but primarily because it involved the use of videofluoroscopy (modified barium swallow), which uses radiation, on a group of participants who could not give informed consent. It was felt that using videofluoroscopy on a non-dysphagic control group of similar participants would also be unethical. A similar study to the one proposed has since been completed (Chouinard *et al.*, 1998) and such ethical issues were avoided by the use of clinical records from patients diagnosed with dementia who had died, rather than the presenting symptoms of patients still living.

A new proposal was submitted in March 1997. The project had been redesigned to examine the "feeding partnership" (the interaction between carer and patient during feeding) and the effect that training might have on this relationship. It involved a double base-line design which allowed for a period containing no intervention to be compared to a period which contained intervention. After clarification of a number of points the LREC approved the project in May 1997.

Few details had been finalised at the proposal stage as both the methodology for measuring the relationship and the intervention itself were dependent on LREC approval before feasibility and pilot studies could commence. By the following year it was apparent that the project was overly ambitious to be completed on a part-time basis and that the method for defining and measuring the feeding partnership needed much more thought. This then became the focus of the project, a proposal for which was submitted to the LREC in October 1998 and approved in November that same year.



🟥 1996- 97 🟨 1997 - 98 🟩 1998 - 99 🟦 1999 - 00 🟪 2000 - 01 🔷 2001- 02

	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	Jan	Feb	Mar
Enrolment at City	🟥 '96											
Reading for lit review started		🟥										
Approval of project at Trust level			🟥	🟥	🟥							
First proposal written					🟥	🟥	🟥					
Proposal submitted LREC							🟥					
LREC rejected proposal								🟥				
Proposal amended								🟥	🟥	🟥 '97	🟥	🟥
Proposal resubmitted LREC												🟥
Minor changes identified by LREC	🟨 '97											
Proposal resubmitted to LREC		🟨										
Proposal approved by LREC		🟨										
Analysis of pilot data		🟨	🟨	🟨	🟨							
Development of coding system			🟨	🟨	🟨							
Questionnaire developed		🟨	🟨	🟨	🟨	🟨	🟨					
Questionnaire pilot-study							🟨	🟨	🟨	🟨 '98		
First draft of literature review							🟨	🟨	🟨	🟨		
Video pilot-study	🟩 '98	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩 '99	🟨	🟨
Bournewood enquiry		🟩	🟩	🟩								
Bournewood issue resolved				🟩								
New proposal submitted to LREC					🟩							
Ward identified for closure							🟩					
Liaison with UCL re CA							🟩					
Change to tutors							🟩	🟩				
New proposal approved by LREC								🟩				
Video camera broken & replaced	🟦 '99	🟦	🟦	🟦						🟩	🟩	🟩
Video data collection				🟦	🟦	🟦						
Questionnaire data collection				🟦	🟦							
Questionnaire study draft report						🟦	🟦	🟦				
Ward closed									🟦			
Second draft of literature review									🟦	🟦 '00	🟦	
Recruitment of students, UCL	🟪 '00	🟪	🟪									🟦
Training of students				🟪	🟪							
CA performed					🟪	🟪	🟪					
Reliability study								🟪	🟪			
Reading for lit review finished				🟪								
Third draft of literature review		🟪	🟪	🟪	🟪							
Background info section written			🟪	🟪	🟪	🟪						
Methodology section written						🟪	🟪					
Analysis & results section written							🟪	🟪	🟪			
Discussion section written									🟪	🟪 '01		
Final draft of thesis	🔷 '01	🔷	🔷	🔷	🔷	🔷	🔷			🟪	🟪	🟪
Submission of thesis							🔷					

Figure 3-1 Project development 1996 - 2001.

3.1.2 Participants:

Within the NHS trust from where the participants in this project had been selected, there were two distinct groups of elderly patients. Some were cared for in hospital in the short term because they were being assessed, were having their drugs reviewed, or because they presented with behaviours that challenged community services. Others, to whom the health authority had made a life-time commitment, would remain in hospital for the rest of their lives. The patient population of this project belonged to the latter group.

The patients included in the study were all female and all had a diagnosis of advanced dementia. They had all been cared for within the institutional hospital setting for a number of years.

The demographic details of the four patient participants are shown in table 3-1.

Reference	Sex	Year born	Nationality	Diagnosis
B "Mary"	Female	1910	British	Advanced Alzheimer's disease
C "Lauren"	Female	1929	British	Chronic schizo-affective disorder and severe dementia
D "Corrine"	Female	1909	British	Advanced Alzheimer's disease
E "Irene"	Female	1911	British	Advanced Alzheimer's disease

Table 3-1. Demographic information for the patient participants.

Pseudonyms are used for all of the patients. Patient "A" is missing from the table as the videos made with this patient were only used for some of the pilot studies.

The staff participants were all volunteers from the ward on which the patient participants were cared for. They had worked within the hospital for many years and knew the patients well. The demographic details of the three staff participants are shown in table 3-2. Pseudonyms are again used.

Reference	Sex	Age	Nationality	Nursing experience
03 "Simon"	Male	50-60	Mauritian	17 years
05 "Ellen"	Female	40-50	British	20 years
06 "Alan"	Male	40-50	Mauritian	28 years

Table 3-2. Demographic information for the staff participants.

The combination of four patients and three staff members resulted in twelve partnerships to be examined. The four patients and three members of staff were all from the same ward.

It would have been useful to know how long each member of staff had known each of the patients as this may have had a bearing on how they interacted with them. This information was not collected however.

3.1.3 Video:

For this project video was considered an appropriate and relevant method of data collection, primarily because the analysis stage for a part time degree would be a very time consuming operation. Secondly all of the patients selected for inclusion in the project were in the latter stages of dementia and had poor life expectancy, and thirdly the ward itself was due for closure. It was therefore important to capture data which could still be analysed at a much later date, even after the closure of the ward, the death of the patients or the departure of staff members.

Both audio and video recordings may be used for data collection in research studies. As with most research methods the use of video is not without its problems. Lighting and background noise are important factors to consider, the participant may be unavailable, or cameras can malfunction and batteries run flat etc. See Gross (1991) and Gross and Conrad (1991) for in-depth discussion. These issues are considered in detail in the critique in section 3.3.

Such problems are outweighed by the contributing value that video recordings make to research. Capturing behaviour on tape can be invaluable as some behaviours are very subtle and difficult to observe live. Some research studies, such as this one, require the same data to be analysed using a number of different methods and by using video the behaviours can be viewed repeatedly. Areas of disagreement can be observed and discussed which results in less biased interpretation.

It is known that participants may demonstrate different behaviours when they know they are being recorded, and especially if they are aware of the behaviours being observed. By filming during mealtimes there was no need to specify the behaviour being observed and the activity proceeded as if the camera was not there. The importance of starting observations part way through the recording has been stressed (Bakeman, 1978; Bakeman and Gottman 1997; Hollenbeck, 1978). Participants (in this case the members of staff) are most likely to display atypical behaviour at the beginning of the recording period, whilst they are conscious about the video being made. The researcher has been unable to find other studies that have used video with patients in late stage dementia. How patients with dementia react to video equipment is therefore not known.

There is much discussion about how long a sample of video should be (Gross, 1991). This ultimately depends on the nature of the behaviour. General behaviour needs random frequent sampling whilst specific behaviours, as in this project, are constrained to the situation in which they are exhibited.

3.1.4 Consent:

Inclusion of staff participants in a project such as this is uncomplicated as they can be classed as healthy volunteers.

> *"A healthy volunteer is an individual who is not known to suffer any significant illness relevant to the proposed study ... and whose mental state is such that he is able to give valid consent to the study."*
> (Royal College of Physicians, 1996, p5).

With regard to patients however, the issue of consent is vast and involves much debate (Alderson and Goodey, 1998; Doyal, 1998; Smith, 1998). All research needs to be examined to ensure that it is ethical and that there is a balance between the potential risks and potential benefits (British Medical Association, 1993). In most cases this is the task of Local Research Ethics Committees (LREC) (Department of Health, 1991; Neuberger, 1992; Royal College of Physicians, 1996). Research involving people with dementia is a controversial area. Research tends to be discussed in two categories - 'therapeutic' and 'non-therapeutic'. Most ethical debate surrounds the latter, which is of no benefit to the person with dementia (Berghmans and Ter Meulen, 1995; Kitwood 1995c). This project may have had an indirect benefit for the subjects involved but could not be said to be truly therapeutic.

The act of placing a person in front of a video camera can cause a degree of embarrassment, and as a camera is not regarded as a scientific instrument it is recommended that informed consent be obtained. The capacity to give this consent, based on appropriate information and the patient's level of understanding, is assessed in the same way as consent for medical treatment (British medical Association and Law Society, 1995).

In medicine, where a patient is unable to give informed consent the treatment of the patient could be considered an assault. Who decides whether a patient can give consent is a debate on its own (Dean *et al.*, 1998; Leung, 1998; The Law Society, 1995). A patient may however be treated under the common law doctrine of necessity, or under the Mental Health Act (HMSO, 1983) if they are suffering from a mental illness. Professionals involved in the care of a patient discuss the case and will proceed with treatment if it is considered to be in the patient's 'best interests' (British Medical Association and Royal College of Nursing, 1995; MENCAP-a). Additionally it is common practice for the carers or relatives of patients to be involved in decisions about treatment even though they are not able to give consent on the patient's behalf (Age Concern Institute of Gerontology and Centre of Medical Law and Ethics, 1988; British Medical Association and Law Society, 1995; Department of Health, 1996; Hooker, 1998; MENCAP-b; Morris, 1998; Surrey Wide Operational Partnership Group in Mental Health, 1999-2000; Teff, 1994).

Surrogate decision making may be used when conducting research, although legal opinion is divided about whether this is lawful consent (Palmer, 1991). Such a procedure is not without its own problems. In one study almost 50% of eligible participants could not be included either due to the absence of a surrogate or because surrogate consent was not given (Baskin *et al.*, 1998). This is seen as a major barrier both to research in dementia and when making medical decisions.

Guidelines are provided by the Department of Health (2001b) and several other organisations. It is advised that consent should be interpreted as an "agreement to co-operate" (Mental Health Act Commission, 1985, section 14.4) and that *"if mentally incapacitated patients do not overly object to a particular measure, then they should not be deprived of its benefits."* (British Medical Association and Royal College of Nursing, 1995, section 3.5).

Research on mentally incapacitated adults and older people remains as yet unregulated by law (British Medical Association, 1993). The British Medical Association and The Royal College of Nursing (1995) consider non-therapeutic measures to be ethical if the research is into a condition suffered by the patient, if there is minimal risk to the patient, if there is appropriate ethics committee approval and if the patient does not appear to object.

An important test of consent issues emerged with the inquiry known as 'The Bournewood Case' (*R v Bournewood Community and Mental Health NHS Trust ex p L. CA [1998] 1A//ER 634*). As a result of this case it was required that all informal patients be assessed for their ability to consent to being in hospital. Those unable to give consent were required to be assessed against the Mental Health Act criteria for hospital admission and detention. Those patients who did not meet this criteria were required to be discharged. The majority of patients unable to give consent to their hospital admission were the elderly with dementia. Although some may have had complex needs which would meet the Mental Health Act criteria, many in the latter stages of the disease did not and would require placement in nursing home facilities. This included all of the patients participating in this project. For the duration of the inquiry their inclusion in this project was therefore suspended. In July 1998 the House of Lords reversed the Bournewood ruling and the Trust permitted this study to proceed. The law lords acknowledged that there is a gap in mental health legislation and that a way of protecting compliant yet incapacitated patients is required (Dyer, 1998). Whilst no final decision has yet been made this issue is due to become a major clinico-legal issue (Eastman and Peay, 1998).

3.1.5 Confidentiality:

Under the Data Protection Act (HMSO, 1984) all information relating to an individual must be obtained fairly, kept up to date and stored securely (Panting and Palmer, 1992; The Royal College of Psychiatrists, 1989). The person has a right to expect that the information will only be used for the purpose for which it was given (Hood *et al.*, 1998; United Kingdom Central Council for Nursing, Midwifery and Health Visiting, 1987). If permission has not been given to use illustrative photographs it is possible to produce computer generated illustrations that cannot be recognised, using techniques such as MorphMan (Pallen and Loman, 1998) or Digital Disguise (Hood *et al.*, 1998). When material is no longer needed it must be destroyed.

It is acknowledged that in health care, medical training and research there is a quantity of illustrative material produced that may have uses beyond that for which it was originally obtained. However, clinical audio-visual records are subject to the same rules of confidentiality as notes, reports and radiographs (The Institute of Medical and Biographical Illustration, 1988).

Viewing of material should be on a need to know basis and any labelling that identifies the patient should be removed or obscured if the material is used outside of the immediate health or research team. All recordings should be clearly marked on the tape and packaging. Under the Video Recording Act (HMSO, 1984) all videos should be marked "Restricted Exhibition" and all recordings should be kept in a locked cabinet when not in use.

> *"It should be possible to guarantee absolute confidentiality of data collected for a research project."*
> (The Royal College of Psychiatrists, 1989, p14).

When a consenting patient dies then the material may only be used for the purpose for which consent was given. Subsequent consent for use in journals, textbooks or presentations must be sought from relatives (The Institute of Medical and Biographical Illustration, 1988). The Code of Practice does not state how to treat material of patients who have not been able to consent, although the guidelines relating to patients who died before consent could be obtained may be followed.

The videos made for the purpose of this project were duplicated. The two copies of each tape were securely stored in different locations. This ensured not only the confidentiality of the tapes but also that there was a back-up should one copy be destroyed. Each of the tapes was marked with an unique identification reference and was marked "Confidential, restricted viewing for research purposes only". They also showed the date each was made and had the researcher's name on them. The tapes have only been viewed by people directly involved in the research project. A request to view the tape by a relative of one of the patients was refused.

The transcription process involved university students (see section 3.2.6). A third copy of each tape was therefore made and given to the students to be transcribed. Each of the tapes was hand delivered to the students (or sent by courier) thus ensuring that they arrived safely. Likewise, after the analysis was complete the students returned the tapes to the university, delivered them by hand to the researcher, or destroyed them. Posting the tapes was not considered to be a safe method of transportation. The students were issued with guidelines regarding the safety of the tapes, to ensure that they were not watched by any person other than themselves and to check that they were kept secure. Each student signed a declaration to say that they agreed to comply with these restrictions.

3.1.6 Summary of section:

This section has discussed how the project developed, including the issues related to gaining approval from the Local Research Ethics Committee. It has described the project participants and explored the difficulties in consent for this client group. Confidentiality and how it was maintained at all stages of the project has also been discussed. The next section goes on to state how the project was implemented.

3.2 Project methodology.

This section describes the methodology used to capture the project data. It refers to the information and consent forms devised by the researcher; how environmental information and quantitative data from the members of staff were collated; the procedure for making the videos; and their transcription.

3.2.1 Information sheets:

The aim of an information sheet is to inform patients about the procedure they are being asked to participate in, and should contain as much detail as considered appropriate for an "averagely prudent person" (British Medical Association, 1993, p207). The use of information sheets is supported by the British Medical Association but they are very much viewed as an addition, not a replacement, to discussing the project in person with the participants.

The information sheets for this project were produced following the examples of a number of different forms (Medical Defence Union Ltd., 1992; Mental Health Act Commission, 1985; Neuberger, 1992). Two variations of the sheet were required, one to be seen by members of staff who were being asked to participate in the study (Appendix 1.1) and one to be seen by the relatives of the patient participants (Appendix 1.2). Although it was not necessary to consult with the relatives of the patients, as they were unable to give consent on their behalf, it was felt both courteous and prudent to do so, particularly as the researcher was already working clinically with some of the patients.

Within the field of cancer research, the requirement to explain fully the limits of medical knowledge is thought to undermine patient confidence, which may make the patients reluctant to participate (British Medical Association, 1993). Similarly in this project, it was thought that relatives might be reluctant for the patient with dementia to participate as there would be no direct effect on the illness itself. In this respect it was gratifying how well the project was received by relatives who felt the patients would want to contribute to the research.

In line with the guidelines for information sheets the staff participants were informed that they were free to *"withdraw without explanation or hindrance at any stage of the procedure."* (British Medical Association, 1993, p206). The relatives of patient participants were advised that they could raise an objection to the patient taking part at any time and that this would in no way affect the care they were receiving.

All details of any risk must be included on an information sheet. In this case, as the risk was seen to be negligible, the relatives were informed that there was little risk to the patient. An early draft of the information sheet advised that the study was in the patients' *"best interests".* The LREC felt that this was inaccurate and the sentence was removed from the final draft.

The forms provided a contact address and telephone number which relatives could ring if they required any further information or if they had any questions. The staff participants were each addressed personally by a research assistant to ascertain that they had fully understood the information provided. Each staff participant was provided with the telephone number and address of the researcher and given the opportunity to ask questions.

3.2.2 Consent forms:

As with the information sheets, two different variations of the consent form were required. In exact terms only one, that designed for the staff participants, was a *consent form* (Appendix 1.3). The other, designed for the relatives of patient participants, did not ask for consent but asked whether there were *objections* to the patient being involved in the study (Appendix 1.4).

Guidelines for consent forms stipulate that they must confirm the following points (Royal College of Physicians, 1996):

- that the person is willing to take part in the study;
- that the researcher has explained the nature and purpose of the study and informed the participant of any risk;
- that the participant has received written information describing essential details of the study;
- that the participant has been given opportunity to question the researcher; and
- that the participant has been told they are free to withdraw from the study at any time and without the need to justify that decision.

Each of these were included on the form for staff participants. On the form designed for relatives of patients, the family members were additionally asked to confirm that they understood that they were not being asked to give consent on the patient's behalf.

A third form was designed and was completed by the consultant under whom the patients were cared for (Appendix 1.5). This form had two purposes, to provide an opportunity for the consultant to object to a patient participating and to confirm that each of the patients did not have the ability to give informed consent.

3.2.3 Environmental information:

Further information was collected by a research assistant on each of the occasions that a video was recorded. This information was requested by the researcher, who was not present during the meals, to provide information about the meal, the environment and the meal time itself.

The information was collected during a brief interview with the member of staff feeding the patient. A quick rating form was used to record the member of staff's answers (Appendix 2). Another copy was also filled in by the research assistant.

3.2.4 Questionnaire:

In the early stages of the project development it was decided that a questionnaire would help establish how much agreement there was between the inferences that staff members made about the patients they were feeding. As a document designed to seek specific information from its respondents the design of a questionnaire is crucial and a number of texts were used in compiling the questionnaire (Bordens and Abbot, 1996; Greene and D'Oliveira, 1982; Polgar and Thomas, 1995; Robson, 1998).

It was decided to ask staff to make comments about the patients they feed, and to elicit answers that required making inferences from observable behaviours. A list of situations used by speech and language therapists in assessing patients during feeding was compiled and from this list a set of draft questions was compiled. Pilot studies for the questionnaire were carried out within the Speech and Language Therapy service and involved staff members who worked with different client groups such as Adult Learning Disability. This was felt important as at the time the researcher intended to compare findings across the mental health and learning disability client groups.

The number of questions was limited to ten, primarily to keep the questionnaire simple but also to take up as little time as possible. Use of basic vocabulary was crucial as the questionnaire needed to be quickly comprehended by nursing staff, many of whom are unfamiliar with speech and language therapy terminology and who may not have English as their first language.

An introductory first page was included, explaining the purpose of the questionnaire (Appendix 3.1). Eight questions asked staff members to rate the occurrence of behaviours as *always*, *mostly*, *sometimes*, *rarely* and *never.* The other two questions asked for quantitative information, about how much food was usually consumed and how long it took to feed the patient (Appendix 3.3). Although the questionnaire was conducted as an informal interview, written questions and supporting statements were also provided (Appendix 3.4). Each member of staff who worked during the day on the ward was interviewed (n=11), and all staff were asked to consider just one patient, subject B.

The final version of the questionnaire is shown in Appendix 3.2 and the results are shown in Appendix 3.5. When the researcher came to analyse the questionnaire, at a much later date, it was clear that it had not captured all the information that was then required. Some of the results are referred to in the discussion section, but fundamentally the questionnaire collated quantitative data when qualitative information was needed. A full analysis of the questionnaire was therefore not carried out. This is referred to later in the critique in section 3.3.

3.2.5 Making the videos:

Video pilot study.

The practicalities of using video with this study population was addressed in an early pilot study. Due to the delays in gaining ethics committee approval for the study the researcher had opportunity to carry out a small scale study on a different ward to the one used for the final study. One patient who was already known to the Speech and Language Therapy service and his wife who was a frequent visitor to the ward were approached and asked if they would participate in the pilot study. The patient's wife was made aware of the fact that the study was awaiting approval from the ethics committee and she agreed for herself and her husband to be videoed during meal times. This gave the researcher opportunity to pilot the research information sheets and the consent forms. Following feedback from the patient's wife the information sheets were modified.

This small study provided the data from which the researcher developed a format for conversation analysis transcription, developed a coding system for utterance types and trialled many of the analyses discussed in Chapter Four. Whilst this opportunity to trial the analyses was vital, the pilot study also allowed the researcher to observe how the patients and staff members responded to having a video camera on the ward. The experience and observations gained contributed towards both the guidelines written for the Speech and Language Therapy Assistant with regards to making the videos (see below) and for the research assistants who carried out the transcription process (see section 3.2.6)

Capturing the data.

The videos were made by a speech and language therapy assistant who was employed as a research assistant for this project. Training was given on how to use the video camera but technical problems with the camera led to it being replaced. A new and more sophisticated video camera was purchased for the purpose of this project and so both the researcher and the research assistant were required to familiarise themselves with how the camera operated.

Training was given to the assistant on important factors when making the tapes. See Appendix 4 for a copy of the instructions provided. In particular she was advised with regard to positioning of the camera so that an equal proportion of both the patient and the member of staffs' face was evident. It was important to limit the possibility of other patients and members of staff walking into shot by mistake. As well as this lighting, noise and positioning all needed to be taken into account. It was however crucial that the video environment be as natural as possible and to this aim it was not always possible to take the most effective shot. For example, one of the patients is always seated in a corner next to the wall. It was felt too disruptive to move her but the camera angle was limited by being too close to the wall.

A number of pilot videos were made which the researcher and research assistant examined together and discussed. From this it was felt that the research assistant understood the type of shots required and the researcher gave approval for the recordings to begin. All of the videos were made during the lunch time period. Each of the three members of staff agreed to feed each of the four patients for the study, providing twelve tapes.

One unexpected delay was the initial problem with the video camera. This resulted in premature termination of the data collection phase whilst the camera was replaced. The primary concern at this stage was whether the data could realistically be collected before the closure of the ward or whether it would be prudent to recommence the project with different staff and patients. Delay to the ward closure programme enabled the project to recommence with the same participants.

The videos made with the original camera were discounted due to the length of time between them being made and the new camera being available. The same dyads were therefore recorded again with the new camera. There were difficulties arranging times for the videos to be made as the members of staff worked shifts and the research assistant worked part time. The staff present on any particular shift often changed at the last minute and recording sessions had to be abandoned, cancelled or rescheduled. In addition the recording sessions eventually took place during the summer, the busiest period for annual leave. The microphone failed to function on two occasions and two tapes were therefore recorded without sound and needed to be repeated. In total it took thirteen weeks to complete the twelve tapes.

In the majority of cases the video was set up and recording before the member of staff began feeding the patient. In three cases the meal had already started when the research assistant arrived on the ward although the tape was then commenced immediately and very little of the meal was lost. This problem arose due to meals arriving early on the ward, members of staff being unsure as to which patient was to be recorded and members of staff forgetting that the videos were to be made. None of these problems were felt to be extraordinary considering that the tapes were being made at one of the busiest periods in the day. Considering the length of time taken to make all twelve tapes, it was questioned whether the amount of time and additional funding required to repeat these three tapes was a good use of resources. The decision was taken out of the researcher's hands as the ward was closed and the patients and staff relocated before the videos could be repeated.

3.2.6 Transcribing the videos:

Transcription design.

The transcription template was based on that suggested by Wilkinson and Beeke (1999). Their format however included nonverbal behaviours within the same line as the text, as shown in figure 3-2.

511	GB	⌈ it's also (.) the (bit-) (.) the blade on it ⌉ ⌊ ((indicates blade, gestures holding knife)) ⌋

Figure 3-2. Conversation analysis transcription conventions: overlapping verbal and non-verbal information (Wilkinson and Beeke, 1999).

Because the majority of data from the project were non-verbal, a different transcription method was required. Two columns were introduced which allowed narratives of staff and patient behaviours to run alongside the spoken information, as shown in figure 3-3.

talk	narrative patient
it's also (.) the (bit-) (.) the <u>blade</u> on it	indicates blade, gestures holding knife

<u>Figure 3-3. Adapted conversation analysis transcription format: separate column for non-verbal narrative.</u>

Such columns were provided for narratives of both the patient and the members of staff. An additional column was provided in which transcribers could make comments or note further information. For a full description of the transcription method see Appendix 5.5.

<u>Recruitment of assistants.</u>

Funding from the NHS Cullyer fund made it possible to recruit research assistants to do the transcription. This was necessary as the researcher would have been unable to complete all transcriptions within the time limitations of the project. The start and end points for each interaction were identified. The transcriptions needed to start immediately prior to the member of staff beginning to interact with the patient and end immediately afterwards. The total of all twelve tapes was two hundred and twenty nine minutes. Working on the principle that it takes one hour to transcribe one minute of tape (Wilkinson and Beeke, 1999), two hundred and twenty nine hours were needed to complete the transcriptions. It was decided that research assistants who were familiar with conversation analysis techniques would be beneficial and to this aim University College London were approached, where conversation analysis is taught as part of the undergraduate degree course for speech and language therapists.

Seven students responded to an advert placed at University College London (Appendix 5.1). Five were selected on a first-come first-served basis. One of the students requested a full-time equivalent post for the summer holiday and so was asked to transcribe seven of the twelve videos, a total of one hundred and forty two hours work. She was later asked to transcribe one more tape after another student was dropped from the project after failing to complete the training. One student volunteered to transcribe two tapes and two more volunteered to transcribe one each. The four students who did take part were all final year students and were in the process of completing their exams at the time of recruitment.

Training.

Each of the students was contacted by post (Appendix 5.2 and 5.3) and asked to sign a confidentiality agreement and contract (Appendix 5.4). It was essential that confidentiality be obtained before the students entered the training phase as they would be shown actual data during the training session. Once declarations had been received from all of the students a training session was arranged at University College London.

The researcher met with four of the students and presented the video data. The students were told very little about the aims of the project as it was felt that prior knowledge may have influenced their observations. All of the students had prior experience in the use of conversation analysis conventions suggested by Wilkinson and Beeke (1999). The students were shown an extract of tape and this was transcribed as a group to ensure that the same conventions were being used.

The tapes were distributed amongst the four students to ensure that any one student did not transcribe all of the tapes depicting one member of staff or one patient. The distribution is shown in table 3-3.

Member of staff/ patient dyad	Student who transcribed	Member of staff/ patient dyad	Student who transcribed
03/B	JD	05/D	LF
03/C	LF	05/E	LF
03/D	LF	06/B	LF
03/E	CS	06/C	LF
05/B	ED	06/D	LF
05/C	LF	06/E	JD

Table 3-3. Distribution of video tapes to students for transcription.

Each of the students was provided with a copy of the video(s) they were transcribing and a floppy disk for each tape. The disks had been prepared by the researcher and contained a template of the transcription format. In addition, each student was provided with written guidelines (Appendix 5.5) which explained in detail the transcription conventions to be used.

The students were asked to complete the first minute of their tape(s) and send a printed copy of the transcript to the researcher. The researcher and students corresponded by post to complete the training, with corrections and suggestions being forwarded.

Issues raised during training.

During the completion of the first minute of each tape there were a number of problems raised by the students and issues identified by the researcher.

The students had been asked not to download the file onto their hard drives but to work from the floppy disk provided. The reason for this was to prevent transcripts being left inadvertently on hard drives and to retain confidentiality. One student identified a problem early on and contacted the researcher to report a virus on one of the disks. The disk was therefore replaced. However, another student then experienced a similar problem which resulted in the transcript being lost completely. There were no viruses detected on either of the discs. An independent IT service suggested that the problem may be a result of the floppy disks corrupting as they were being used so intensively. The students were therefore contacted and asked to download the disks onto their hard drives after all. They were asked to copy the file onto a new floppy disk when it was completed and to delete the copy from the hard drive. Each student was asked to send written confirmation that this had been completed to ensure confidentiality was retained. Confirmation was received for each of the transcripts. Additional funding was sought to enable the student whose file had been lost to start again.

Because students could not use the templates on disk they each formatted their own transcripts on their hard drives. This resulted in each version being slightly different. Once the disk copies of the transcripts were received they were re-formatted to be identical. Other training issues are represented in table 3-4.

Once the researcher was satisfied with the transcription of the first minute, each student was asked to continue with the rest of the tape.

The finished transcriptions.

The transcripts were sent to the researcher, both as a printed copy and on computer disk. As discussed above, the transcripts were amended for table size, font and font size, corrections to line numberings and formatting.

Destruction of video tapes.

Ten of the twelve tapes were returned to the researcher, after the transcripts were completed. In these cases the tapes were stored in a locked cabinet pending completion of the project. In two cases it was not possible for the tapes to be returned and the researcher requested that they not be posted. In

Issue raised	Advice to students
Errors with line numbering.	Nearly every transcript had some missing numbers which needed correcting. One transcript had numbers increasing by a factor of ten.
Changes to line numbering.	Students were requested to add the line numbers by hand for correspondence purposes and to type them in at the very end of the transcription process.
Capital letters used at start of speech.	Students were requested to use lower case except for pronoun "I" and names.
Diacritic (") used for continuing behaviour.	Students were asked to check which behaviour was indicated and to be more specific.
Silences.	Students tended to attribute all silences to patients. They were asked to consider whether a response was expected by the member of staff.
Use of large brackets.	Students were reminded that these should be lined up in transcript.
Tenses.	Students were asked to write narratives in present perfect tense e.g. *groans.*
Pseudonyms.	Students were reminded to use pseudonyms, particularly when surnames were used.
Eye contact.	Students had difficulty judging eye contact, primarily due to the quality of tapes. They were therefore asked to mark this only where it was possible.
Sound quality.	One tape had no sound at the start. The student was asked to transcribe just non-verbal narratives until the sound began.
Lines of text in column five.	Students formatted their own tables, each with a larger column five. When tables were reformatted the text pushed onto the next line. This was left rather than the researcher altering and renumbering all of the lines.

Table 3-4. Issues students raised during transcription training.

both instances the students were asked to destroy the tapes, either by recording over them or by physically destroying them, and to send written confirmation that this had been done. Confirmation was received from both students.

Reliability.

The robustness of the refined conversation analysis technique was tested by a reliability study. A speech and language therapy assistant was recruited for this. She had no previous experience of doing conversation analysis and her remit was to compare the videos with the written transcripts prepared by the students (inter-rater reliability).

Three of the twelve tapes (25%) were selected for the reliability study, showing each of the members of staff feeding one patient. Each tape had been transcribed by a different student. The assistant was asked to make two types of correction, information that she *disagreed* with and information which she felt was *missing*. The overall results of the reliability study are shown in table 3-5.

The mean level of agreement across the three transcriptions was calculated as 92%. All three transcriptions showed over 70% agreement, which is felt to be an acceptable level of agreement (Bordens and Abbott, 1996), and therefore showed good reliability.

Video dyad	% of lines containing disagreement	% of lines containing missed information	Total % of agreement.
03/E	0.6%	0.6%	98.8%
05/E	6.2%	7.2%	86.6%
06/E	1.7%	7.7%	90.6%

Table 3-5. Results of inter-observer reliability study for conversation analysis transcriptions.

There was a large range of information which the assistant did not agree with. Such instances included speech which was transcribed by the student but not heard by the assistant, inaccurate time references, inaccurate narratives, inaccurate speech transcriptions and attribution of speech/vocalisation to the wrong speaker.

The majority of disagreement however related to information which the assistant felt was missing. In most cases this related to non-verbal behaviours in the narratives and in many cases the assistant had broken the behaviour down into smaller components or been more detailed. All such examples were however classed as disagreements. There were also examples of missing speech and in some cases the assistant had added lines where whole utterances had not been transcribed (these lines were added to the total number of lines in the transcript before the above averages were calculated).

Additionally, many identified disagreements were felt to be due to differences in interpretation or in transcription style. For example, the students transcribed vocalisations phonemically whereas the assistant preferred to just call them [vocalisations]. Similarly, but distinct from the elaborated behaviours described above, the assistant altered some of the narratives but described the same behaviours or confirmed information which the students had queried. These instances were not counted as disagreements. See table 3-6 for examples of types of disagreement.

Type of disagreement	Example from student	Example from assistant
Inaccurate time reference (3/E 186)	12:26:40	12:26:43
Missing line (3/E 648)	648 S okay? 649 (4)	648 S okay? 648.1 bye 649 (4)
Inaccurate speech transcriptions (3/E 534)	drinky winky	wakey wakey
Confirmation (5/E 101)	(XXX) (there you are?)	there you are
Transcribed speech not heard by assistant (5/E 001)	okay	(I can't hear this)
Different transcription style (3/E 014)	hm hm hm hm	vocalisation (variation in pitch)
Inaccurate narrative (5/E 105)	scratches arm	scratches arm and lays doll down
Attribution of speech to wrong speaker (3/E 594)	592 I (coughs) 593 (0.5) 594 okay	592 I (coughs) 593 (0.5) 594 S okay
Assistant provided more detail (5/E 062)	watches I, puts spoon to I's mouth	touches I's lips with spoon x2

Table 3-6. Types of disagreement identified in inter-observer reliability study for conversation analysis transcripts.

3.2.7 Summary of section:

This section has described how the project was carried out in terms of informing the subjects about the project and gaining consent where possible. It has discussed the alternative method used when patients were unable to give consent and how relatives and the consultant were given the opportunity to object to a patient's inclusion. The method for making the videos has been explained, and how they were then transcribed by students using an adapted conversation analysis method. The next section discusses some of the limitations and lessons learned from this methodology.

3.3 Critique of project methodology.

This section offers a critique of the project methodology.

3.3.1 Information and consent:

One of the problems of carrying out exploratory research is that researchers do not know what they are going to find. It is therefore impossible to consider all eventualities when providing information for subjects and gaining consent. This issue arose when the researcher was offered the opportunity of having the video tapes copied digitally so that stills could be used for illustration purposes. To do this the researcher was required to return to the subjects and ask permission to use photographic material in the thesis and any future publication.

Whilst this was not an issue where the staff were concerned, two of the patients had since died. The researcher was uncomfortable about re-establishing contact with the relatives of these patients for this purpose. The advantage of being able to use photographic material is acknowledged, and the provision for such illustrative material should be considered when consent is initially obtained. This is especially the case when the consent process is so complex, such as with patients who are unable to give their own informed consent.

3.3.2 Sample:

The nature of this project was exploratory so the sample was kept relatively small. The sample consisted of three members of staff and four patients. However, for comparative purposes the members of staff were each recorded with the four patients, resulting in twelve video dyads. Although restrictive, this method allowed for a number of different analyses to be employed. This would not have been possible with a larger sample. A small sample does however prevent the findings being generalised. Any future work needs to involve a large number of subjects for a quantitative analysis of these exploratory findings.

All of the members of staff and patients were recruited from the same institutional setting and the same ward. Earlier designs for the project included staff dyads from other wards but this was not carried out. This was primarily due to the rapid retraction of the hospital, but also because such a design was felt unnecessary for this stage of an exploratory study. Replication of the work should however involve comparisons between wards and different institutions in an attempt to identify whether findings are environment specific of whether they can be generalised. It would also be interesting to compare different patient groups, such as dependent elderly who do not have dementia or adults with learning disabilities, as it seems unreasonable to assume that the issues of feeding and collaboration identified in this study are only relevant to people with dementia. Important variables are therefore the environment, the type of activity, the time of observation and the client group.

3.3.3 Data set:

Video recording.

The data collection technique was video recording. Video was chosen primarily due to the exploratory nature of the study. Video allowed the same data to be observed repeatedly whilst being subjected to a number of different analyses. Additionally the hospital ward where filming was carried out was due for closure so naturalistic observations were limited to the duration of the ward remaining open. The patients were all in the late stages of dementia and their condition was deteriorating. It was therefore crucial to capture data that could be used even after the patient had deteriorated or died. Other advantages of this method included inter-rater and intra-rater reliability (Gross and Conrad, 1991), reduction of observer drift (Kent and Foster, 1977), and greater reliability of behaviour coding (Bakeman and Gottman, 1997).

There are however many disadvantages to using video, one of which is the reactivity of the subjects to the presence of the video camera. Some people become shy and withdrawn when being recorded whilst others become more flamboyant and "show off". The researcher believes this to be the case with the staff subjects filmed in this study. Member of staff 05 appeared more withdrawn than when observed in a natural setting (during clinical assessments of patients), whilst member of staff 06 appeared more active. It is difficult to see a remedy for such reactivity without taking the subjects away from their naturalistic environment and placing them in an artificial one, where they may be observed through one way glass or recorded covertly. The threat of reactivity may be reduced by natural observation and coding. Now that the exploratory phase of the study has been carried out, future work could use less obtrusive observation and coding methods, whilst preserving the natural environment.

Reactivity was evident during the study of greeting and closing sequences. By their very virtue these exchanges took place just as the member of staff arrived in shot and just as the member of staff was about to leave the patient. Reactivity to the camera was anticipated during the greeting sequences but not during the closing sequences. The study identified that whilst the members of staff indicated to the patient that the activity had ended, each member of staff then also turned to camera and spoke to the speech and language therapy assistant. The most natural behaviours of the members of staff therefore occurred outside of the greeting and closing sequences.

It was not clear how the patients with dementia would react to the video camera, although it was suspected that they may be less aware of its presence than the members of staff and therefore react to a lesser extent. The researcher was unable to locate literature where video recording had been used with such patients and the presence of the camera had been discussed. Reactivity was not observed in the patient participants.

One method of reducing the effect of reactivity is to commence coding part way through the video sample. To this aim the researcher planned for video recording to commence prior to feeding taking place. This was not always possible however and a number of videos were started after feeding had already begun. Additionally, the video recording only captured the behaviour of the patient prior to feeding, as the members of staff typically arrived with the meal and then began feeding the patient immediately. Future researchers may wish to consider recording members of staff in a variety of settings, including caring activities and the time between activities. In this way the member of staff, who is more likely to be reactive to the video camera, will become increasingly desensitised to its presence.

Technical difficulties.

The primary problem of the methodology utilised in this study is that the researcher did not make the videos herself and was reliant on another person. This required intensive, basic training in the use of the video camera. There is an issue, pertinent to all health sciences, with regards to using non-technical staff for data collection. Whilst the use of a speech and language therapy assistant was relatively cost effective it had to be balanced against the length of time it took to make the videos. An alternative solution, not available to the researcher for this study, may be to employ a team of personnel experienced in the use of video filming techniques.

Technical problems with the first video camera resulted in it being decommissioned and another bought. Prohibitive prices prevented the purchase of a digital camera, which might have been better suited to the researcher's needs. Digitised film would have enabled the researcher to utilise a software programme known as SignStream (American Sign Language Linguistic Research Project). This would have enabled the different behaviours of staff members and patients to be simultaneously recorded against a time line, rather like sheet music. It would also have been possible to use video editing software to capture video stills for illustration purposes. The use of a digital camera and computer analysis software needs to be considered in the planning stage of future research.

Time frames.

A number of videos had already been made prior to the first camera being decommissioned. During the time taken to replace the camera, changes were made to the staff team on the ward and some of the patients were moved to other wards or discharged into nursing care. Over even short periods of time the patients continue to deteriorate and the researcher feared that the way members of staff reacted and interacted with them would also change. It was therefore important to capture data from the same patient as closely together as possible. The original videos were therefore not used and the data collection phase started again when the new camera was received.

There were still a number of issues related to the time frame of the videos, primarily due to the fact that the speech and language therapy assistant employed to make them only worked part-time whilst the members of nursing staff worked shifts. The recording of videos was therefore dependent on both staff members being on duty on the same day and over the lunch time period. Additionally, the delay with the video camera resulted in the recording taking place during the summer months when many staff members take annual leave. Even when both staff members were present there were delays caused by the meals having arrived early and the patient having already been fed, the patient being fed by a member of staff who was not a subject in the study or visiting relatives feeding the patients instead of the members of staff. Whilst these issues were not insurmountable, the data collection was secondary to the everyday caring routine on the ward. The issues in combination lead to the tapes being recorded over a much longer period than was planned.

Environment issues.

Likewise the ward setting was not always ideal for optimum video recording, but as little change as possible was made to the natural setting. For example, some chairs were positioned next to walls which prevented the required camera angle, whilst another patient was seated next to a fish tank, the pump for which produced high levels of background noise. Future studies may need more in-depth research into the ward environment and discussions with ward managers about how the natural setting can be preserved whilst producing optimal video recordings.

Lighting.

Lighting was also an issue as it proved difficult to illuminate the faces of the subjects for the video recordings. One solution would have been to use additional lighting but this was felt to be too intrusive both for the subjects and other people on the ward. Natural light from windows was utilised where possible, but this fluctuated, and because the ward had a lot of windows it was not possible to prevent the faces of subjects being in silhouette at times. One simple solution would have been to draw the curtains behind the subjects, although the researcher recognised that this would have reduced the natural light further. The quality of the video tapes was adequate to observe gross interaction between the members of staff and patients but was insufficient to capture some minor behaviours. At times the poor lighting prevented facial expressions being observed and it was not possible to identify eye contact reliably.

Sound quality.

Problems with sound quality were evident immediately the new camera was used. The in-built microphone was more advanced than that on the old camera and picked up much more background noise. It was therefore necessary to use a separate microphone which was powerful enough to pick up the vocalisations of the patient and the speech of the member of staff, but that reduced background noise. A battery operated radio microphone was therefore used. This required additional training for the speech and language therapy assistant.

Such problems with the visual and sound quality highlighted to the researcher the importance of adequate training and checking the quality of data recorded in the real setting as well as in pilot settings.

Scope of data captured.

The video captured the patient and the member of staff only. It did not record what was going on around the subjects. Whilst this did not matter for the most part, it would have been useful to know where the patient or member of staffs' eye gaze was orientated when they appeared to look at things out of shot. Naturalistic observation during the recording sessions would have been useful to add this information. The speech and language therapy assistant did keep some records of the meals recorded, such as what the food was, how she felt the recording had gone etc., but her records did not include information about other activities on the ward. The researcher recommends a naturalistic observation alongside video recording. A "narrative" of the meal process as it progresses would contribute additional information missing from this study.

The records kept by the speech and language therapy assistant could also have included information such as how frequently the member of staff fed a particular patient; whether they avoided feeding a particular patient; what their attitudes about feeding patients and caring for them in general were; and whether they had received training about feeding, and if so what form it had taken. Such information needs to be included in future studies to aid interpretation of the behaviours observed.

Transcription of videos.

The difficulties encountered by the students who carried out the conversation analysis have already been discussed in detail above. It became apparent that some of the students had difficulty working out what some of the members of staff were saying. The researcher, who was more familiar with the staff did not find this so difficult and so utterances that the students were unsure about were added after the reliability study had been carried out. This highlights the difficulty of involving people who are unfamiliar with the subjects, especially during the transcription phase of the study. Ideally the researcher would have been best placed to have carried out the transcriptions and the verbal contributions of staff may have been more accurate had she done so. The accuracy of the transcriptions was however balanced against the time it would have taken for the researcher to do all of the transcribing herself. The good reliability score suggests that this balance was achieved.

Questionnaire.

A questionnaire was developed by the researcher which asked staff to rate the patient's difficulties in different areas around feeding, such as choking, positioning, how they communicated their likes, dislikes etc. The questionnaire collected quantitative information such as how often a patient appeared comfortable, whilst qualitative information such as the behaviours members of staff used to infer comfort was actually needed. This discrepancy arose from the questionnaire being devised during the planning of the project when the information required was not clear. The purpose of the questionnaire was not decided upon until the study was nearing completion and after it had already been administered. In hindsight the questionnaire needed to be rewritten and future research needs to focus on staff members' interpretations of behaviour.

3.3.4 Summary of section:

This section has addressed the importance of establishing exactly what information is going to be needed at the start of the research process and the importance of seeking permission for all procedures when during the consent stage. The researcher has also highlighted the difficulty associated with exploratory research where the methodology develops as opposed to being clear-cut from the start. This has particular implications for research with this and similar client groups, where it may not be appropriate to seek additional consent at a later date.

The researcher has also identified some of the limitations and difficulties related to using video data for research. The disadvantages of using video are well documented in the literature. Despite careful planning the video data collection still ran into a number of problems including technical set backs, inadequate lighting, excessive background noise and extended time frames for the data collection. The members of staff were felt to have demonstrated reactivity to the camera, although the same could not be said for the patients.

The researcher highlighted particular difficulties associated with employing other people to carry out parts of the data collection. The importance of adequate training for research assistants was acknowledged as was the requirement for repeated quality checks on the work being produced. Despite the problems, the utilisation of research assistants enabled the project to be implemented and the research to be carried out on a part-time basis, something which would otherwise have been impossible.

3.4 Summary of Chapter.

This chapter has outlined the issues related to research on elderly patients with dementia, and how they may be addressed. It has described how the project data were collected and the problems and limitations associated with the methodology. The next chapter introduces each of the analyses that were carried out as a series of small scale studies.

Chapter Four

Chapter Four

Data analysis and findings

Qualitative health research is aimed at obtaining a realistic understanding of the experiences and views of people who provide or access health services. Qualitative research is open-ended and searches for new questions and meanings, as well as answers (Alderson, 2001). Like most qualitative research, this project combines qualitative questions (what types of evidence are there?) with quantitative ones (how many are there?).

This chapter contains each of the analyses used to examine the data in accordance with the research questions and hypotheses outlined in table 2-2. Each analysis is presented in terms of methodology, results and findings, and where necessary a critique of the analysis methods. As discussed in Chapter Three, this format was deliberately used to make the information more readily accessible to the reader. Each question is discussed in turn with a description of the method used and then the findings. The discussion which examines the interaction between these various analyses is then presented in Chapter Five, pulling the separate components back together.

4.1 Differences in interaction.

Question 1.
What are the identified differences in staff-patient interaction over the twelve dyads?

Introduction:

The transcripts which were prepared by the students can be seen in Appendix 9. From initial observations it was evident that the interaction between members of staff and patients was different across the twelve videos, such as predicted from the literature review in Chapter Two (section 2.2.1). These observed differences in the interactive style of the three members of staff were examined by measuring the amount of speech used and the type of speech used. It was hypothesised that there would be a significant difference in the amount of speech used by each member of staff and a difference in the type of utterances used. The null hypothesis was that the observed differences would be due to chance alone.

Method:

A glossary of terms for this section is provided in table 4-1.

Term	Definition
Dyad.	The combination of one member of staff and one patient, in this case for the purpose of feeding.
Speech units.	Single words or meaningful vocalisations such as “uhu”, “mm” etc. (“it’s” etc. counted as two units.)
Utterance.	A line of speech units as represented on the transcripts.
Main-meal phase.	The food/drink consumed during the main course of the meal only. Does not include additional drinks or dessert.
Speech rate.	The average number of speech units per minute to give an indication of the amount of speech used.

Table 4-1. Glossary of terms for section 4.1.

A measure was taken of the number of speech units used during the main-meal phase of all twelve video dyads. The number of utterances in the whole transcript of three videos was then counted and each utterance was coded as an utterance type using the criteria in table 4-2.

Type.	Definition.
Attention seeking (A).	Utterances used to gain the attention of the patient. e.g. "Mary?", "can you wake up please?".
Preparatory (P).	Utterances used to indicate that feeding is about to take place. Can either be macro level (about the meal process) e.g. "here's your lunch", "look what you got"; or micro level (about an individual spoonful) e.g. "open your mouth", "taste it".
Evaluatory (E).	Utterances used to evaluate the feeding process. Can be either macro level (about the meal process) e.g. "I think you like it", "that's it you doing well"; or micro level (about an individual mouthful) e.g. "that's better", "very good".
Non-related incidental (N).	Utterances directed to the patient that are not attention seeking, preparatory or evaluatory e.g. "let me swap your hands around", "what's this cat doing here?".
Incidental, outside of partnership (O).	Utterances directed to somebody other than the patient being fed e.g. "I'm ready when you are" (to camera operator).
Questionable instances (Q).	Utterances which cannot be coded as any of the above.

Table 4-2. Criteria for coding of utterance type.

The coding system had been developed by the researcher during the pilot stage of the project (see section 3.2.5) using conversation analysis. The codes were developed from the behaviours observed in the videos and grouped together for classification. The coding system was subjected to an inter-rater and intra-rater reliability study. A speech and language therapy colleague was presented with the above coding criteria and asked to code three of the video dyads.

The inter-rater and intra-rater reliability results for utterance type coding are shown in the confusion matrices in tables 4-3 and 4-4. The calculations for Cohen's Kappa are shown in table 4-5. A value of 0.70 was achieved for inter-rater reliability and a figure of 0.80 for the intra-rater reliability.

Observer One	Observer Two						
	A	P	E	N	O	Q	Total
A	**1**	5					6
P		**35**	2	2			39
E		5	**18**	1		2	26
N				**7**	2		9
O			1		**4**		5
Q						**2**	2
Total	1	45	21	10	6	4	**67**/87 77%

Table 4-3. Inter-rater reliability confusion matrix for utterance type codes.

Observer One$_1$	Observer One$_2$						
	A	P	E	N	O	Q	Total
A	**1**	1					2
P	4	**36**	4				44
E		1	**20**				21
N			1	**9**			10
O					**6**		6
Q			1			**3**	4
Total	4	38	26	9	6	3	**75**/87 86%

Table 4-4. Intra-rater reliability confusion matrix for utterance type codes.

	P_0	P_c	K
Inter-rater	0.77	0.24	0.70
Intra-rater	0.86	0.30	0.80

Table 4-5. Cohen's Kappa calculations for inter-rater and intra-rater reliability for utterance type codes.

These are considered by Fliess (1981) to be good and excellent reliability scores respectively.

The number of speech units used by each member of staff and directed to the patients during the main-meal, was then counted. Utterances made to people other than the patients were excluded from the analysis at this stage. Such utterances were however coded, as discussed under hypothesis 1.3 below.

The values were converted to rate of speech by dividing the number of speech units by the length of the main-meal phase. These results are shown in table 4-6.

Member of staff/ patient dyad	Length of main-meal phase (mm:ss)	Number of speech units	Average rate of speech (units per minute)
03/B	4:49	54	11.21
03/C	9:23	236	25.10
03/D	6:27	91	14.12
03/E	6:14	114	18.29
05/B	10:28	11	1.05
05/C	19:20	86	4.45
05/D	6:20	97	15.31
05/E	7:49	28	3.58
06/B	6:13	353	56.60
06/C	8:38	277	32.09
06/D	12:44	919	72.29
06/E	5:51	159	28.30

Table 4-6. The amount of speech used and the rate of speech during the main-meal phase in each dyad.

The mean speech rate was calculated by dividing the total number of speech units used by each member of staff during the main-meal phases of the four meals, by the total length of the main-meal phases of the four meals. These results are shown in table 4-7.

Member of staff	Mean speech rate
03	17.18
05	6.10
06	47.31

Table 4-7. The mean rate of speech for each member of staff (in speech units per minute).

Three dyads were then examined in more detail, 03/B, 05/B and 06/B, for the type of utterances used. These three dyads were felt to be representative of the other recordings and allowed comparison of the members of staff with the same patient.

Results and findings:

Hypothesis 1.1.
There will be a difference in the amount of speech used by each member of staff, which is not dependent on which patient they are talking to.
(Null hypothesis that differences are due to chance alone)

The difference in the rate of speech, just during the main-meal phase of the meal, could be seen clearly. The difference between the speech rate of the three members of staff was significant when examined using the Friedman Test ($p<0.05$) (table 4-8) (Appendix 6.1).

χr^2	p	significance
6.5	0.042	0.05

Table 4-8. Friedman Test for rate of speech during main-meal phase (members of staff as conditions).

There was however no significant difference when the patients were examined as conditions (p>0.05) (table 4-9.) (Appendix 6.2).

χ^2	p	significance
3.4	0.466	>0.5

Table 4-9. Friedman Test for rate of speech during main-meal phase (patients as conditions).

It was therefore clear that the amount of speech used depended on the member of staffs' individual styles of interaction. The null hypothesis, that differences were due to chance, could therefore be rejected. The amount of speech used was not related to which patient was being spoken to. This supports the findings of Grove *et al.* (1999) and Norberg (1996).

The difference between the members of staff is best illustrated as a chart as in figure 4-1.

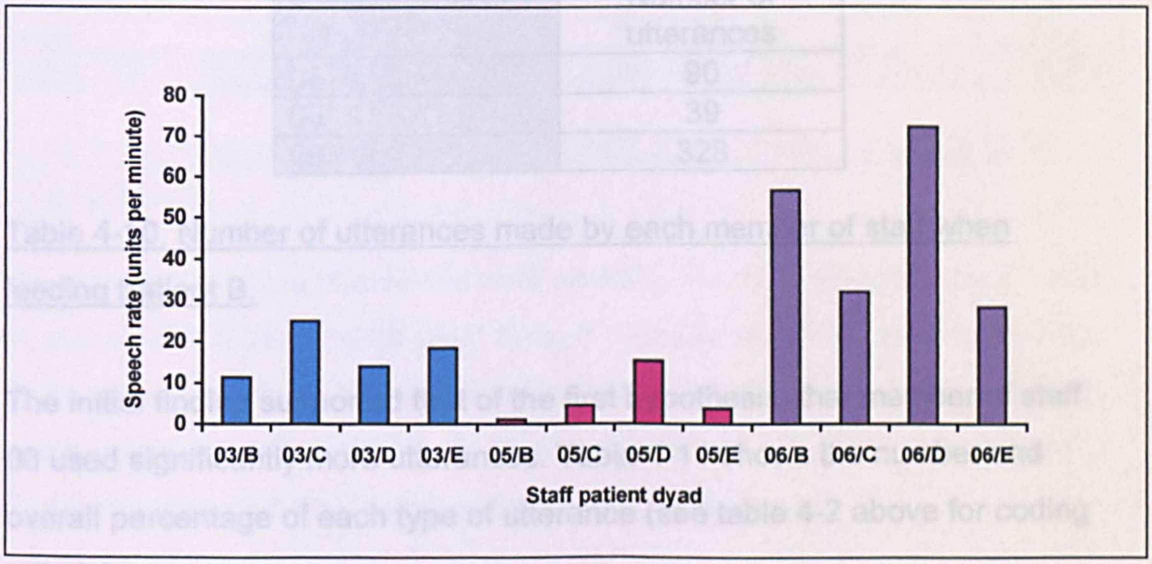


Figure 4-1. Speech rate during the main-meal phase (in speech units per minute).

It was clear that the differences in amount and rate of speech did not correlate with which patient was being talked to. There was a division between each member of staff. Member of staff 06 was by far the most talkative, regardless of which patient he was feeding. He was also observed to speak to people other than the patient during three of the four meals. The other two members of staff only had limited exchanges with other people, such as the camera operator or with nursing colleagues. Had such utterances been included in the analysis it would have increased member of staff 06's speech rate further.

Hypothesis 1.2.
There will be a difference observed in the type of utterances used by each member of staff.
(Null hypothesis that differences are due to chance alone.)

Table 4-10 shows the number of utterances made by each of the three members of staff during the whole of one transcript with patient B.

Member of staff	Number of utterances
03	90
05	39
06	328

Table 4-10. Number of utterances made by each member of staff when feeding patient B.

The initial finding supported that of the first hypothesis, that member of staff 06 used significantly more utterances. Table 4-11 shows the number and overall percentage of each type of utterance (see table 4-2 above for coding criteria).

It was clear from this analysis that over half (63%) of member of staff 06's utterances were not related to the feeding process, but were attention seeking (14.3%), non-related incidental (44.5%) or were made outside of the feeding partnership (4.3%). In comparison 21% of member of staff 03's utterances and 41% of member of staff 05's were not related to the feeding process.

Dyad.	03/B		05/B		06/B	
Utterance type.	Number	%	Number	%	Number	%
Task- related:						
Preparatory (P).	44	50.6%	17	43.5%	45	13.7%
Evaluatory (E).	21	24.2%	4	10.2%	70	21.3%
Subtotals	65	74.7%	21	54%	115	35%
Non-related:						
Non-related incidental (N).	10	11.5%	4	10.2%	146	44.5%
Incidental, outside of partnership (O).	6	6.9%	1	2.6%	14	4.3%
Subtotals	16	18.4%	5	12.7%	160	48.8%
Others:						
Attention seeking (A).	2	2.3%	11	28.2%	47	14.3%
Questionable instances (Q).	4	4.5%	2	5%	6	1.9%
Subtotals	6	6.9%	13	33.3%	53	16.2%
Totals	87	100%	39	100%	328	100%

Table 4-11. Number and percentage of types of utterances for dyads 03/B, 05/B and 06/B.

The attention seeking utterances were removed from this analysis (as it could be argued that these may be used to mark feeding) which showed that 48.8% of the utterances made by member of staff 06 were either non-related or made to someone else. The same could be said for only 18.4% of member of staff 03's utterances and 12.7% of member of staff 05's.

Member of staff 06 could not therefore be said to be task orientated, although the findings from members of staff 03 and 05 do support White's (1999) argument that staff members are task specific in their interaction.

With regard to the utterances that were related to feeding, member of staff 06 used proportionally fewer preparatory utterances. He also used more evaluatory utterances than preparatory ones. These findings are different to the results for members of staff 03 and 05. Whilst both members of staff 03 and 05 said less to the patient, they were more meal and feeding orientated. The null hypothesis, that differences were due to chance, could therefore be rejected.

The researcher considers the preparatory phases, such as "here you are", "are you ready?" etc. to play a crucial role in marking when feeding is about to take place. Because proportionally fewer of staff member 06's utterances were preparatory and because he used the greater number of utterances it is possible that the utterances which were crucial to marking where feeding was about to take place were lost. The members of staff who used fewer utterances were more able to signal when feeding was about to take place.

See for example lines 020 to 022, line 065 and lines 100 to 103 in the transcript for 03/B and lines 020 to 022, line 090 and line 171 in the transcript for 05/B. These examples show how the preparatory utterances used by these two members of staff stand alone. They can easily be picked out. Compare these examples with lines 177 to 195 in the transcript for 06/B. This example is representative of the rest of the sample for member of staff 06 and shows how the preparatory utterances are not easy to find due to the number of other utterances.

It is therefore not only important to use preparatory utterances but also to make sure that they are salient and easily recognised by the patient. In the discussion (Chapter Five) it is argued that the marking of feeding is actually more crucial than what is said. It would therefore not matter whether member of staff 06 was using preparatory utterances or not if the patients were unable to identify that they marked when feeding was about to take place.

Based on the above findings it was hypothesised that member of staff 06 would have greater difficulty feeding than his colleagues as he had marked fewer clear occasions when feeding was to take place. This correlation was indeed discovered when feeding success was studied, as discussed under Question 7.

Critique:

The analysis was not carried out on all video dyads, only one third of them. It has been assumed that the findings can be generalised across the other dyads. Similarly the reliability study was only carried out on one dyad. Whilst the dyads examined were felt to be representative it would have been beneficial to use all twelve dyads for this study.

Summary of findings:

Differences in the interaction of the members of staff could be observed across the twelve dyads (as was represented in figure 4-1 above). This was supported when the total number of utterances were recorded for just three video dyads, showing each member of staff feeding the same patient. From calculating the speech rate and the number of utterances, it was apparent that member of staff 06 used significantly more speech than his colleagues. The types of utterances used by member of staff 06 also differed. He used proportionally less preparatory utterances and many more non-related incidental ones than his two colleagues.

Differences in the amount of speech across the twelve dyads were felt to be the consequence of the individual members of staff and their interactive styles rather than which patient was being fed. Similar conclusions cannot be reached with regard to the type of utterances used as only dyads involving one of the patients were analysed.

4.2 Patterns of normal discourse.

Question 2.
What patterns of normal conversation can be identified in the interactions between members of staff and patients?

Introduction:

Patterns of normal conversation have been discussed in Chapter Two. Turn taking is fundamental to conversation structure. Adjacency pairs form the main components of these turns. Turn taking is thought to be preserved in dementia (Golper and Binder, 1981; Hamilton, 1994; Ripich *et al.*, 1991; Sabat, 1991), and Clark and Schaeffer (1989) discuss how speakers may permit other speakers to contribute to discourse, by accepting their turns. Clark and Schaeffers' model was therefore used to examine the turns that took place between the members of staff and the patients with dementia.

Method:

A glossary of terms for this section is provided in table 4-12.

The conversational transcripts, in conjunction with the video tapes, were examined for evidence of normal patterns of conversation. This type of analysis may be referred to as discourse analysis as it uses pre-determined categories by which to classify the behaviours observed. The transcripts were examined for evidence of preserved turn taking, preserved adjacency pairs, and non-verbal behaviours being used as second parts of adjacency pairs.

Examples are taken from the transcripts and are referenced by the dyad code (e.g. 03/B indicates member of staff 03 and patient B) and the line numbers used in the transcript (e.g. 204). Turns are denoted by P (patient) and S (member of staff). Where a patient's name was used it has been replaced by a pseudonym.

Term	Definition
Turn taking.	Conversation is formed by a sequence of turns by different interlocutors. Turn taking is rule governed.
Adjacency pairs.	Two ordered utterances, the first and second pair parts which are produced by two separate speakers; e.g. question and answer.
Non-verbal adjacency pairs.	One or both parts of the adjacency pair are non-verbal rather than verbal e.g. question answered by nodding the head.
Presentation and Acceptance phases.	Phases of conversation turns, an utterance is presented by one speaker and accepted by another. See Clark and Schaeffer (1989) for full description.
Exchange break-down.	The exchange fails because one of the speakers does not accept the presentation phrase of the other. See Clark and Schaeffer (1989).
Ascription of meaning.	The member of staff responds as if a behaviour or vocalisation is meaningful and in doing so reveals the interpreted meaning of that behaviour or vocalisation.

Table 4-12. Glossary of terms for section 4.2.

Results and findings:

Whilst the patients were unable to produce lexical items, there were occasions when their limited responses appeared to preserve turn taking,

Whether any meaning could be attributed to the patient's (P) vocalisations (shown in square brackets [ ]) is questionable. The researcher based the assumption that vocalisations may not be meaningful on the fact they have been observed to occur in other contexts, such as during other activities with staff and when the patients are on their own. such as the exchange shown in figure 4-2[1].

030	S	Lauren?
031	P	[vocalises]
032	S	hello?
033	P	[vocalises]
034	S	okay

Figure 4-2. Example of preserved turn taking (06/C).

From clinical observations this was particularly the case for patients C and E. In addition to this subjective reasoning, the videos were made to capture the patient prior to the member of staff engaging with them. On occasions when the patients was awake they were all observed to vocalise in the same way as they were observed to do when a member of staff was interacting with them. The researcher takes the view that meaning accorded to such vocalisations was inferred from the way the member of staff responded rather than because the meaning was intended.

The member of staff (S) appeared to respond as if the vocalisations were meaningful. The member of staff therefore ascribed meaning to the vocalisation and in doing so revealed that he had interpreted the patient's vocalisations as appropriate responses. P's vocalisations appeared to act as turns and by responding to them S allowed them to contribute to the exchange and therefore keep the momentum going, preserving the discourse structure. The use of S's "okay" at the end of this exchange may have signalled the end of the greeting sequence, a 'phatic communion token' (Lesser and Milroy,

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[1] In each of the examples diacritics are used, as outlined in Appendix 5.5. The numbers in brackets represent length of pauses in seconds. Pauses of less than 0.1 seconds are represented by (.). Unintelligible vocalisations are represented by (xxx). Large brackets are used to indicate where the two participants overlapped with each other, and the symbol ° ° is used around speech to indicate that it was said quietly.

1993). The same may be said of line 033 in transcript 06/B ("right"), and lines 046 and 066 in transcript 06/C ("right"). With such limited occurrences the researcher acknowledges that these observations are subjective but that they offer an interesting avenue for further analysis.

The most common method for turn taking is the use of adjacency pairs. In line 030 S's request for P's attention was followed by a vocalisation from P. S responded to this by introducing the first pair part of a greeting adjacency pair. He then accepted P's next vocalisation as if it were the second pair part of the greeting.

In everyday conversation a greeting sequence will include a number of 'social' exchanges which act as a pre-amble to the introduction of a topic. Lesser and Milroy (1993) refer to these as 'conventionalised tokens'. Such exchanges rely on both conversation partners understanding the purpose and role of each component. With these patients such a discourse could not be achieved and so S needed to accept P's vocalisation to permit it to contribute to their exchange. P's comprehension level was not sufficient for her to have understood the question (based on speech and language therapy assessment), yet S proceeded as if P had not only understood but also responded appropriately. What is clear is that S continued as if P's vocalisations were the expected second parts of adjacency pairs. By ascribing meaning to P's non-conventional communication he enabled S to contribute to the exchange.

Further examples of the patients' vocalisations being treated as if they were second pair parts of adjacency pairs were identified, such as an offer and an acceptance (figure 4-3), a question and an answer (figure 4-4) and a statement and a correction (figure 4-5).

In figure 4-3, S's responses can be seen to be clarifying P's supposed replies. In figure 4-4, S's responses can be seen to be acknowledging P's supposed replies. In figure 4-5, S's response reveals his interpretation of P's vocalisation as a contradiction of his statement.

196	S	some pudding for you?
197	P	(1)
198		[laughs]
199	S	yeah?

Figure 4-3. Example of an offer and acceptance adjacency pair (03/C).

011	S	I'm going to feed you
012		(1.6)
013	S	is that alright ⌈ (xxx) ⌉
014	P	⌊hm hm hm hm hm⌋
015		hm
016	S	⌈good⌉
017	P	⌊ hm ⌋ (.) hm hm hm hm hm
018		⌈ hm mm: hm ⌉
019	S	⌊alright (.) very good⌋

Figure 4-4. Example of a question and answer adjacency pair (03/E).

244	S	you no like the potatoes? (1.5)
245	P	°[vocalises]°
246	S	you do
247		good

Figure 4-5. Example of a statement and correction adjacency pair (06/D).

Adjacency pairs do not need to consist of two verbal utterances and non-verbal behaviours can constitute either or both of the turns. Many first pair parts of adjacency pairs are answered non-verbally in normal conversations. For example a question may be followed by a shrug, a request may be followed by a directional point, or a request may be followed by another action. Non-verbal behaviours were transcribed as part of the conversation analysis and can be seen in the transcripts in Appendix 9. Members of staff could be seen to be interpreting non-verbal behaviours in the same way that they attributed meaning to the verbal ones. For example, in dyad 06/B the patient was observed to rub one hand across the palm of the other. The member of staff responded to this behaviour by saying "you're writing a cheque".

Within the project data examples were found where a non-verbal response appeared to be sufficient to complete an adjacency pair, as the extract in figure 4-6 shows.

007	S	come on try to eat
008	P	[starts to chew]
009	S	alright

Figure 4-6. Example of a non-verbal adjacency pair (03/D).

Here the patient appeared to respond to the member of staff's instruction to eat. It could be argued that P was likely to have commenced chewing at this point regardless of the member of staff's utterance (food having been placed in P's mouth) although in conversation analysis terms the utterance and the behaviour appear to be linked. It is not possible to say what would have happened had the member of staff not made the utterance at that particular moment. S's response acknowledged P's chewing behaviour and reinforced her contribution. There were however other examples where the non-verbal behaviour exhibited by the patient was not acknowledged as the second pair part of the adjacency pair, such as in the extract shown in figure 4-7.

282	S	is it nice?
283	P	[looks at S]
284	S	is it nice?
285		(2)
286	P	[vocalises]
287	S	yeah?

Figure 4-7. Example where non-verbal behaviour was insufficient to complete an adjacency pair (03/C).

In this case S did not accept the eye contact from P in line 283 as being an adequate response to his question, although he did appear to accept her vocalisation in line 286. A further exchange in lines 106 to 110 shows P breaking eye gaze after being asked a question. Again S does not accept this as a response to the question and asks it again. This time there is no vocalisation, the exchange is not completed and therefore breaks down.

It is a feature of normal conversation that exchanges break down, often to be repaired by the speakers. When a presentation phase is not accepted it results in failure to contribute. An example of this is shown in figure 4-8.

006	S	is it nice Lauren?
007	P	(2)
008	S	you like the food Lauren?

Figure 4-8. Example where the presentation phase was not accepted (03/C).

By not responding to S's question P did not accept his presentation phase. S had therefore not made a contribution to the discourse. Evidence that he realised this to be the case was shown in his re-phrasing of the question in an attempt to elicit a response. In this example P prevented S from contributing. With the group of patients studied this was the most frequently seen exchange observed across all of the dyads.

However, evidence was also found where the members of staff prevented the patients from contributing. In these instances the structure was not maintained and the interaction was not sustained by the member of staff. Take for example the extracts shown in figures 4-9 and 4-10.

In figure 4-9, S did not respond to P's vocalisation and therefore did not reinforce it as having contributed to an exchange.

002	S	hello Irene
003	P	[vocalises]
004	S	(8)

Figure 4-9. Example of exchange break-down? (05/E).

In figure 4-10, S was addressed by the camera operator and her attention was therefore diverted away from P. P's vocalisation was therefore not acknowledged and was not reinforced as contributing to an exchange.

005	S	Irene?
006		ready?
007	P	[vocalises]
008		*(S addressed by camera operator)*

Figure 4-10. Example of exchange break-down (05/E).

There is however an important difference between these two examples. In figure 4-9 it could be argued that both parts of a greeting adjacency pair were present, a 'hello' followed by a response. Structurally there is nothing missing from this exchange as continued attention is accepted as evidence of understanding (Clarke and Schaeffer, 1989). In figure 4-10 however the attention of the first speaker was transferred to the camera operator and so there was no evidence of S accepting P's utterance as having contributed to the exchange.

Some patterns of normal conversation were therefore identified in the exchanges of members of staff and patients with dementia. The patients were shown to use vocalisations or non-verbal behaviours which were treated as second parts of adjacency pairs. Members of staff were shown to accept these minimal responses as being contributions and therefore being conversation turns. The question remains as to whether the patient's turns were active or, as the researcher proposes, they were formed by the way in which the members of staff responded. This is discussed in more detail under Question 3.

Question 3.
How are patients able to indicate an understanding of it being their turn?

To say that patients are taking turns in conversation, as discussed above, is insufficient. If the assumption is made that vocalisations are meaningful then the patients could be seen to be preserving turn taking (Hamilton, 1994). If however it is assumed that the vocalisations are incidental then there is another explanation for turn taking that can be offered. The staff members preserve the turns of the patients by responding to the vocalisations as if they were meaningful. In the majority of cases this works at the level of adjacency pairs, the fundamental building blocks for conversation. If a vocalisation is made following a first pair part of an adjacency pair and the member of staff acknowledges the vocalisation as if it were a response then the patient appears to have had a turn. It was also possible to identify non-verbal behaviours that were treated as if they were first pair parts.

By using the model set out by Clark and Schaeffer (1989) it was possible to make sense of some of the interactions that took place. The members of staff were not just responding to vocalisations, but in doing so were allowing the patient to have an active part in the conversation. By preserving the patient's role in the conversation the staff member attempts to equalise the relationship that they have.

It is also clear that staff members are not comfortable when their utterances are not permitted to contribute to the discourse. To compensate for this they appeared to turn a number of questions into rhetorical ones, so that they did not lose face if there was no answer received. See for example line 034 in transcript 03/B ("you like it? ... I hope") where member of staff 03 added to his original question to make it a statement. See also lines 049 to 053 and lines 196 to 200 in transcript 06/B.

It is interesting to note that member of staff 06 made many references to the fact that the patient was not interacting with him throughout the transcript for 06/B. The researcher concluded that this too was a technique by which the member of staff could appear not to lose face, by implying that the patient was playing some kind of "game" with him (e.g. line 214 "I can see you smiling you know"). In this way her lack of responses became to appear meaningful.

These techniques are often used and have probably been developed over many years of working with such patients. To continually have one-sided conversations would be very poor for morale and so the staff enable two-way conversations, however minor the second role, to take place.

Critique:

This exploration of the data has included examples from the video transcripts. It has been purely qualitative with no attempt to look at the data quantitatively. In conversation analysis terms such quantitative analysis is rejected. Future work could however code the exchanges and compare the strategies used by different members of staff, or extrapolate the behaviours/vocalisations most frequently responded to by staff.

Another area of study which has not been examined here is the role of intonation. Did the staff members respond to the intonation of the utterances made by the patients? Did the intonation of the staff members' utterances reflect the intonation of the patients? This area should be considered for future research.

Summary of findings:

The interactions that took place between the members of staff and patients were less conversational than those to which Clark and Schaeffer (1989) applied their model. The patients were 'passive', as described by Hamilton (1994), and produced no lexical items. Some of the same structures of conversation were however observed, and members of staff could be seen to preserve turn taking by responding to vocalisations and behaviours. The behaviours exhibited by the patient may not have been in response to the members of staff at all but spontaneous acts. Regardless, the fact that the members of staff responded to the behaviours as if they were a response permitted the behaviours to contribute to exchanges.

4.3 Greeting and closing sequences.

Question 4.
What components of normal greeting and closing sequences can be identified in the interaction of staff members and patients?

Introduction:

Two adjacency pairs which appear in all conversations are those of greeting and closing (Button, 1991; Levinson, 1983; Ripich *et al.*, 1991; Sacks, 1963; Sacks *et al.*, 1974; Schegloff and Sacks, 1973). Greetings and closings are collaborative in nature with both communication partners fulfilling their part of a shared ritual. The researcher was interested in examining how these particular adjacency pairs and the ritual of greeting or closing was handled by the project subjects. These exchanges were therefore selected for in-depth discourse analysis and incidences where the members of staff introduced a greeting or closing were identified.

Method:

A glossary of terms used is provided in table 4-13.

A greeting sequence was identified in nine of the twelve videos (table 4-14). It is of course important to note that only the member of staff was truly acting out one of these sequences. This will be discussed further below. In the other three cases the video recording had started after feeding had already commenced. Dyad 06/B contained two greeting sequences as the member of staff left the patient to collect the meal, following a lengthy greeting sequence. A second greeting sequence then took place when the member of staff returned with the meal. Dyad 05/C was also shown to have 2 greeting sequences, although one of these took place within the interaction rather than at the start. This is discussed further below.

Term	Definition
Greeting sequence.	The portion of video in which the members of staff first arrived in shot and engaged with the patients.
Greeting exchange.	Identifiable exchange which acted as the first pair part of a greeting e.g. "hello".
Closing sequence.	The portion of video from when the members of staff completed the meal to when they went out of shot.
Closing exchange.	Identifiable exchange which acted as the first pair part of a closing e.g. "goodbye".
Introduction to meal.	Identifiable utterances in which the members of staff informed the patients that it was meal time, or that feeding was about to start e.g. "here's your meal", "I'm going to feed you".

Table 4-13. Glossary of terms for section 4.3.

Members of staff	03	05	06
Patients			
B	✓	✓	✓✓
C	x	✓✓	✓
D	x	✓	✓
E	✓	✓	x

Table 4-14. Video dyads and whether or not the greeting sequence was recorded.

Results and findings:

Greetings.

There were five different types of greeting sequence identified, as shown in table 4-15 below, and defined in table 4-13 above.

Type of sequence	Dyad sequence found in
First pair part of greeting exchange + introduction to meal	03/E 05/B 05/C$_1$
First pair part of greeting exchange only	05/E 06/C
Use of patient's name as greeting exchange + introduction to meal	05/D 06/B$_1$ 06/D
Atypical greeting exchange	03/B 06/B$_2$
Greetings within interactions	05/C$_2$

Table 4-15. Type of greeting sequence and dyads in which they were found.

The first pair part of a typical greeting exchange accompanied by the introduction of the meal was observed in three of the observed greeting sequences. Such a sequence is illustrated in figure 4-11[2].

002	S	hello Irene
003	P	
004	S	how are you
005	P	
006	S	alright? I got I got some lunch for
007		you here
008		
009	S	alright?
010		
011	S	I'm going to feed you
012		
013	S	is that alright?
014	P	[vocalises]
015	P	'hm:
016	S	good

Figure 4-11. Example of the first pair part of the greeting exchange followed by introduction of the meal (03/E).

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[2] The line numbers are again given for reference to the original transcripts. S represents the member of staff and P the patient. Blank lines indicate that there was no response and square brackets [ ] are used to indicate behaviours.

Member of staff 03 (S) used a number of first pair parts of adjacency pairs. In line 002 he opened the greeting exchange but did not receive a reply from the patient (P). In line 004 S continued with the greeting exchange, still with no response. This one-sided conversation worked due to P's vocalisation in line 014. S appeared to have accepted the vocalisation as if it were a second pair part response to his previous questions.

In the extract in figure 4-12[3], S opened the greeting exchange in line 002. With no response S repeated the greeting in line 007. The meal was introduced in line 018.

002	S	hello Mary
003	P	(6.3)
007	S	hello
008	P	(1.4)
009	S	let me swap your hands around
010	P	(1.0)
012	S	°yes I know I know°
013		(1.0)
014	P	[vocalises]
015	S	there we are
016		(8.3)
017	P	(laughs)
018	S	there's your lunch

Figure 4-12. Example of the first pair part of the greeting exchange followed by introduction of the meal (05/B).

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[3] The numbers in brackets indicate the length of pause, and the ° ° symbols around lines of speech indicate that it was said quietly.

A similar pattern was also observed in figure 4-13[4].

001	S	Lauren
002	S	hello
003	P	
004	S	let's sit you up a little ⌈bit more⌉
005	P	⌊ xxx ⌋
005.1	P	⌈ xxx ⌉
006	S	⌊°I know°⌋
007	S	it's lunch time
008	S	hello?
009	P	
010	P	[vocalises]
011	S	now let's see what you think of this?

Figure 4-13. Example of the first pair part of the greeting exchange followed by introduction of the meal (05/C$_1$).

There were two examples of the first pair part of a typical greeting exchange being used where the meal was not introduced. These are shown in figure 4-14 and figure 4-15.

001	S	okay
002	S	hello Irene?
003	P	° [vocalises] °
004		
005	S	Irene?
006	S	ready?
007	P	[vocalises]

Figure 4-14. Example of the first pair part of the greeting exchange only (05/E).

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[4] The large brackets indicate where speech overlapped and [xxx] is used where speech or vocalisations were unintelligible.

030	S	Lauren?
031	P	[vocalises]
032	S	hello
033	P	[vocalises]
034	S	okay

Figure 4-15. Example of the first pair part of the greeting exchange only (06/C).

The patient's name was used as a greeting in a number of dyads. It is questionable whether these were true greetings or whether they were requests for attention. In section 4.1 these same utterances were coded as attention seeking. In figure 4-16, S's whole greeting sequence consisted of the patient's name and the introduction of the meal.

019	S	Corrine?
020	P	
021	S	some lunch for you

Figure 4-16. Example of the use of the patient's name followed by introduction of the meal (05/D).

P could have been expected to respond at line 020, whether it be through orientation or verbally, which would give the use of P's name the same status as the opening part of a greeting sequence.

Similarly in figure 4-17, S used the patient's name repeatedly as a means of waking her up. It would be hard to argue that this is a greeting as there could be no expectation of a second pair part. Rather the member of staff was using her name as a means of gaining attention.

004	S	ah (.) okay
005		Mary?
006	P	(1)
007	S	Mary?
008		Mary?
009		can you wake up please?
010		look it's lunch time
011		(2)
012		look it's lunch time

Figure 4-17. Example of the use of the patient's name followed by introduction of the meal (06/B_1).

The extract in figure 4-18 likewise contains a number of uses of the patient's name, followed by the introduction of the meal.

006	S	Corrine?
007	P	
008	S	Corrine?
009	P	
010	S	Corrine?
011	P	
012	S	I've got your lunch here
013	S	I've got your lunch
014	S	right?

Figure 4-18. Example of the use of the patient's name followed by introduction of the meal (06/D).

It could be said that these last three examples were more of a summons than a greeting.

The example in figure 4-19 illustrates a different type of greeting sequence which does not fit into the categories already discussed.

003	S	alright Mary?
004	P	(2.9)
005	S	here's your lunch
006	P	(3.0)

Figure 4-19. Example of an atypical greeting sequence (03/B).

The utterance in line 003 appears to have served two functions. Not only was the patient's name used as a means of gaining attention but S also asked a question which required a response. It is unclear whether S was asking as to the status of P's health, her readiness to eat lunch or something else entirely. Similarly the exchange in figure 4-20 is of interest.

035	S	that's okay
036	S	alright
037		(3)
038	P	[laugh]
039		(2)
040	S	are you awake?
041	P	(1)
042	S	are you awake?
043	P	(1)
044	S	good (1)
045	P	[xxx]
046		(3)
047	S	Mary?
048	P	(2)
049	S	you are awake aren't you Mary?
050	P	(2)
051	S	I can't feed you when you're asleep (.) can I ?
052	P	(1)
053	S	no (.) that's it (.) well done

Figure 4-20 Example of an atypical greeting sequence ($06B_2$).

S left the patient following the lengthy first greeting sequence, in order to get her meal. When he returned he again greeted the patient, this time by asking her whether she was awake. This technique can be used to gain attention rather like the phrase “can you talk?” (Schegloff, 1980).

Although greetings only occur at the beginning of normal interactions, there is evidence to suggest that a greeting type utterance may be used within interactions when addressing such patients. This is shown in figure 4-21 where S greeted the patient with an “hello” when eye contact was made.

267	P	[vocalises]
		opens eyes, looks at S
268	S	hello?

Figure 4-21. Example of a greeting used within interaction (05/C_2).

In this instance the greeting is used as the second pair part as if the eye contact were the first pair part.

This may be an example of the member of staff validating the patient's eye contact by the only means available, to assume it to be a re-establishment of contact on the patient's part.

There was only one example of this kind found across the twelve video dyads. This serves to demonstrate either that the patients do not initiate contact very frequently, or that other opportunities to respond as if the patient had initiated a contact had been missed.

Closings.

The closing sequence was recorded for all twelve dyads and again only the members of staff actively participated in the closing ritual. Only three of the dyads contained what would be recognised as a closing exchange, although there were six additional examples in which the meal was closed but a closing of the conversation did not take place. This information is represented in table 4-16 below, and defined in table 4-13 above.

Type of sequence	Dyad sequence found in
No closing.	05/B 05/D 06/E
Closing sequence.	(06/D)
Meal and conversation closed.	05/D 06/C (06/D)
Meal closed but not the conversation.	03/E 03/B 03/C 05/C 05/E 06/B

Table 4-16. Type of closing sequence and dyads in which they were found.

There were no closing sequences observed in dyads 05/B, 05/D and 06/E. There was only one example of a closing sequence that contained all the elements required in such a sequence (closing of topic, pre-closing of conversation, closing exchange). This was found in dyad 06/D, as is shown in Figure 4-22. S closed the meal topic by requesting a naturally occurring turn, thanks.

738	S	say thank you
739	S	say thank you
740	S	okay
741	P	[vocalises]
742	S	okay bye
743	S	I'll see you in a minute

Figure 4-22. Example of a request for the next natural turn (06/D).

It could be argued that this was the pre-closing exchange. When thanks were not received he closed the conversation in line 742. What is interesting is that he then almost re-opened the conversation at line 743 by saying that he would see P again in a while.

In another two dyads there was evidence of topic closing (the meal) and an exchange closing. In figure 4-23, S closed the meal in line 221 and could be argued to have closed the conversation in line 222.

221	S	I think that's you (there?)
222	S	shall we leave you be now?

Figure 4-23. Example where meal and conversation closed (05/D).

In figure 4-24 S closed the conversation at line 499 and it could be argued that his utterance in the previous line indicated the closing of the topic, i.e. the end of the meal.

498	S	okay
499	S	right I think I won't keep you any more alright okay

Figure 4-24. Example where meal and conversation closed (06/C).

S appeared to have difficulty closing this conversation however as he followed the extracted utterances with a series of short utterances, 'there you are', 'okay', and 'alright'. Closings may have a number of turns, such as those cited by Schegloff and Sacks (1973), which may consist of conventional tokens (such as 'okay', 'right', 'well then') and/or phatic communion tokens (such as expressions of solitude or platitude). Lesser and Milroy (1993) discuss the purpose of these pre-closing sequences as *"... clear[ing] the* *ground for and giv[ing] participants an opportunity to delay the imminent closing, the final exchange of* goodbye *tokens"* (p203). What is different about the example cited in 4-24 is that S does not offer any final *goodbye* token after these exchanges. His closing did not therefore really close the conversation at all.

A similar dilemma was observed in figure 4-25 where S appeared to have difficulty closing the conversation. (Only S's turns are shown, hence the missing line numbers.) What S did in this extract was to close down each of the activities as a means of communicating the end of the meal, in lines 635 and 638.

635	S	(wipe you)
638	S	(take your bib off)
642	S	that's it
646	S	alright Irene
648	S	okay

Figure 4-25. Example of difficulty closing conversation (03/E).

The same is seen in figure 4-26.

393	S	let's take your bib off Mary

Figure 4-26. Example of closing activity components (03/B).

In this instance S then closed not with a comment to the patient, but with a final comment to the camera operator, as shown in figure 4-27. In fact in a number of dyads the meal appeared to be closed without final *goodbye* tokens being made. This can be seen in figure 4-28, figure 4-29, figure 4-30, and in figure 4-31.

398	S	okay
299	S	finished

Figure 4-27. Example where closing of activity was directed to camera operator (03/B).

210	S	okay
211	S	it's all done

Figure 4-28. Example where meal closed but not conversation (03/C).

302	S	right all done

Figure 4-29. Example where meal closed but not conversation (05/C).

198	S	last bit
203	S	well done
205	S	that's it

Figure 4-30. Example where meal closed but not conversation (05/E).

497	S	thank you
498	S	well done

Figure 4-31. Example where meal closed but not conversation (06/B).

It was therefore possible to identify both greeting and closing sequences. These were identified as being introduced by the members of staff and were based upon expected first pair parts of adjacency pairs. The one exception was when the member of staff provided a second pair part in response to eye contact from the patient.

The sequences did however appear to have a different status to those found in normal conversation. Because the staff were on the ward for a whole shift and would have had contact with all of the patients during that time, it is wondered exactly what role a greeting sequence would play. One suggestion is that the greetings observed were more of a re-establishment of contact rather than an initial contact. This would make particular sense if taking into account the fact that the midday meal is served at the end of the morning shift and so the staff would have already been working with the patients all morning. In the same vein, the closing sequences that were observed were more about ending the activity and signalling a change rather than an end to any contact.

This could help explain why the greetings and closings did not totally follow the anticipated form and also why there was an example of a greeting found during the meal time as well as at the beginning. The fact that the staff members were responsible for introducing the greeting and closing rituals themselves may also explain why they were not observed in all dyads. Such sequences are collaborative and to introduce them is therefore indicating an expectancy that the other partner will provide the expected response to progress the exchange. When the conversational partner is unable to provide the appropriate second pair part the exchange will break down. By introducing such exchanges the members of staff were creating a situation whereby the conversation was bound to break down. All the exchanges observed for this section were unilateral rather than collaborative. The members of staff were observed to utilise the same techniques discussed previously in this chapter to provide structure and imply meaning to minimal vocalisations and behaviours.

Critique:

Again this analysis has been exploratory and therefore qualitative in nature. Whilst observations can be made from the project data these cannot be generalised. Quantitative analysis of different types of greeting and closing sequences may shed more light on the role of these utterances when interacting with this patient group.

Problems of analysing such sequences from video should be acknowledged. By their very nature the greetings occurred when the member of staff had just arrived with the meal. The members of staff had therefore not become desensitised to the presence of the video camera. Surprisingly the members of staff also seemed to be affected by the camera's presence at the end of the meal. In many closing sequences the member of staff addressed the camera operator to close the interaction rather than the patient. This has been discussed in section 3.3.3.

Summary of findings:

Some form of greeting exchange took place in all of the dyads where the greeting sequence had been recorded. Not all of these greetings contained typical first pair parts of adjacency pairs but instead used the patients' names as a summons to gain their attention. Closing exchanges were used less frequently although there was evidence found of the meal topic being closed.

It must of course be remembered that these were not true greetings or closings as the members of staff had been on duty since early that morning and would have already had a number of interactions with the patients. It was therefore proposed that greetings could be viewed as a means of making renewed engagement with the patient, who may well have fallen asleep since the last contact. Likewise it may be that members of staff do not close a conversation as they will return to continue the interaction with a new topic such as toiletting or changing. The findings may therefore be a reflection of the member of staffs' caring function, as a result of interactions being task based.

4.4 Changes in status of engagement.

Question 5.
How do the patients' engagement status change when the members of staff begin to interact with them?

Introduction:

Engagement can be defined as attending to a person, object or place. Differing levels of engagement have been discussed in depth by Bunning (1996, 1998). At the start of the video tapes all patients were either asleep or doing nothing in particular. It was anticipated that the patients' state of engagement would change when the member of staff began to interact with them. Anticipated changes were for the patient to orientate towards the member of staff and/or to look at the meal being presented to them. The most obvious place to examine change in engagement was when the staff members began to interact with the patient. This took place during the greeting sequences discussed above.

Method:

As discussed in the previous section, a greeting sequence was not recorded for all video dyads. Table 4-17 reiterates the dyads where the greeting sequence was captured.

Members of staff	03	05	06
Patients			
B	✓	✓	✓
C	x	✓	✓
D	x	✓	✓
E	✓	✓	x

Table 4-17. Video dyads and whether or not the greeting sequence was recorded.

As all three members of staff could be examined feeding patient B, these three videos were selected for micro-analysis of the greeting sequence. Bunning's (1996) codes of engagement were used. Unlike Bunning, who used interval coding, event coding was used. This was possible as the greeting sequences were short and the range of behaviours fairly limited. The codes have been defined in Chapter Two and are repeated in table 4-18.

Term	Definition
Self-intimate engagement (SI).	Personal or private activities which may take place in secluded areas. The behaviour is not viewed in order to preserve the respect and dignity of the patient. e.g. engaged in personal hygiene, engaged in toilet routine etc.
Self-neutral engagement (SN).	Routine tasks, doing nothing specifically. Usual body actions are observed and passive responding to the actions of others. e.g. engaged in usual body actions, engaged in routine tasks etc.
Self-active engagement (SA).	Personally or socially maladaptive. Non purposeful movements characterised by repetition, environmental independence and irrelevance to ongoing activity, e.g. fine and gross motor movements which are repetitive and non-purposeful such as rocking, hand flapping etc.
Person engagement (P).	Interpersonal relations with others. Interactions mutually influence each other. e.g. shows notice of another person in clear, overt way or displays appropriate adaptive response directed to an identified person etc.
Object engagement (O).	Manipulative schemes applied to objects and their relations in space. Visual pursuit, fixation, tracking and other active engagement with object. e.g. attending, exploring, tracking an object etc.
Person-object engagement (PO).	Emits movement or sound whilst eye contact is alternated between person and object. Co-ordination of individual actions to produce an effect on the environment. e.g. performs action on object whilst looking at person, alternating gaze between person and object etc.

Table 4-18. Glossary of terms for section 4.4 and criteria for coding types of engagement (Bunning, 1996).

The coding system was subjected to inter-rater and intra-rater reliability studies. A speech and language therapy colleague was presented with the above coding criteria and asked to code the same video dyads. All three of the dyads were used because the number of coded events was so small.

The inter-rater reliability results are shown in table 4-19. The codes are shown in their order of appearance, as coded by each observer.

Dyad	Observer One.	Observer Two.	Agreement.
03/B	Self-neutral.	Self-neutral.	100%
05/B	Self-neutral; object; person; self-neutral.	Self-neutral; object; person; self-neutral.	100%
06/B_1	Self-neutral; person; person; self-active; object.	Self-neutral; person; person; object; (object).	80%
06/B_2	Self-active; person; object; self-neutral.	Object; person; object; self neutral.	75%

Table 4-19. Inter-rater reliability for engagement codes.

A confusion matrix was used, as shown in table 4-20, even though the number of coded events was very small.

Observer	Observer Two						
One	SI	SN	SA	P	O	PO	Total
SI							0
SN		**5**					5
SA					2		2
P				**3**			2
O					**3**		3
PO							0
Total	0	5	0	3	5	0	**11**/13 85%

Table 4-20. Inter-rater reliability confusion matrix for engagement codes.

Table 4-21 gives the Cohen's Kappa results and shows that an excellent reliability of 0.85 was attained (Fliess, 1981). However, the very small number of codes needs to be taken into account.

	P_0	P_c	K
Inter-rater	0.85	0.0046	0.85

Table 4-21. Cohen's Kappa results for engagement codes.

Intra-rater reliability was also tested and 100% agreement was obtained.

Non-verbal behaviours of the members of staff were examined to identify how they attempted to engage with the patients. This was achieved by freeze-frame analysis of the video data. The minutiae of behaviours were recorded as expanded narratives, as shown in Appendix 7.

Results and findings:

In dyad 03/B the member of staff (S) tapped the patient (P) on her arm and used her name in an attempt to gain her attention. S introduced the meal in line 005 and again tapped P on the shoulder to gain her attention. P was observed to be demonstrating *self-neutral engagement*. When feeding commenced P was still demonstrating *self-neutral engagement*. Passively participating in self-care or other routines such as feeding would be classified as self-neutral by Bunning (1996). Both observers agreed that there was no evidence of object or person engagement and it could be concluded that P did not engage with S during this greeting sequence.

In dyad 05/B, P demonstrated *self-neutral engagement* at the start of the sequence. A change in engagement was noted when S showed P her lunch. At this point P appeared to glance at the plate, before looking forward again. This could be classified as *object engagement*. *Person engagement* was also observed when S gained eye contact with P. The eye contact was very brief but was coded by both observers. By the time S introduced the meal in line 018, P was again demonstrating *self-neutral engagement.*

In dyad 06/B there were two greeting sequences, as discussed in section 4.3 above. The first greeting sequence occurred when S woke P. He used her name and physical contact to gain her attention. Unlike his colleagues, S lowered himself so that his head was level with P's. S was observed to physically manipulate P in an attempt to wake her up. P raised her arm which appeared to be a protest at the physical manipulation. This could be classified as *person engagement* as it was an appropriate adaptive response directed to an identified person (Bunning, 1996). Both observers did however feel that the response could have been reflexive. Later S gained eye-contact from P, which was another example of *person engagement.* It was when P broke the eye-contact that S let her hand and head go. S then reduced his contact with P and adjusted the chair positioning. During this period P was observed to stroke the toy cat on her lap. It is unclear whether the behaviour was appropriate and purposeful (object engagement) or whether it was a repetitive behaviour (self-active engagement). The researcher coded this behaviour as *self-active engagement* whereas the second observer coded it as *object engagement.* A few seconds later S left to collect P's meal and in his absence P demonstrated repetitive hand stroking and stroking of the toy cat. The researcher coded the hand stroking as *self-active engagement* whilst the second observer coded it as *object engagement.* When P's attention shifted to the toy cat both observers coded *object engagement.*

The second sequence began when S returned with the meal. P was still demonstrating stroking behaviours which were coded by the researcher as *self-active engagement* and by the second observer as *object engagement.* S greeted P again by asking her if she was awake, as a means of gaining her attention. S again achieved eye-contact with P (*person engagement*) and P glanced at the plate (*object engagement*). This difference in opinion as to whether repetitive stroking behaviours were self-active or object engagement was the only disagreement noted. Even when the two observers watched the videos together a consensus could not be agreed. This was because the second observer felt that the stroking of the toy cat was purposeful whilst the researcher felt it was non-purposeful.

It was anticipated that a change in engagement status would be observed as soon as the member of staff began to interact with the patient, and it was hypothesised that such change would be to person engagement. It was therefore surprising that there was limited change to person engagement noted even though there were a number of different changes in engagement status observed. When feeding or interacting with a child there is evidence of eye contact and orientation toward the adult. It was anticipated that similar behaviours would be seen. Although changes in engagement were noted there were fewer instances of person engagement than anticipated and non of the expected person-object engagement. The researcher offers this as further evidence that the patients were not taking active turns, as discussed in section 4.2. If the patients were not actively engaging with the members of staff then they were unlikely to be actively taking a turn in the interaction.

The limitation of only using one patient for this section (with three different members of staff) is acknowledged and the findings cannot be generalised to the other patients and how they would engage with the three members of staff. Further analysis involving the other patients would have been useful.

One question that still remains with regard to engagement is whether the different members of staff utilised different techniques to elicit engagement in the patients. This is addressed in question 6.

Question 6.
How do members of staff attempt to elicit engagement from the patients?

In addition to the conversational components there were a number of non-verbal behaviours observed. The behaviours observed in the members of staff can be categorised as shown in table 4-22.

Behaviour code	Dyad 03/B	Dyad 05/B	Dyad 06/B
Orientation to patient.	Head and eyes. Leans toward P.	Sits next to P but does not lean any closer.	Head kept level or lower than P's. Eyes and head toward her.
Adjustment to bib.	(Touches bib/taps shoulder?)	Lifts bib, puts own hands under bib to reach for P's hand.	Strokes bib, taps bib to chest.
Places patient's hands under bib.	(Are already under bib.)	Places hands in lap, covers with bib.	Covers hands with bib.
Shows meal to patient.	Moves plate near P. "here's your lunch".	Plate on chair arm. "there's your lunch".	Holds plate up in front of P.
Physical contact - touching.	Taps arm. (Touches bib/taps shoulder?)	Rubs P's arm. Holds P's hands. Pats hands when they are under bib.	Strokes hand/face. Holds P's hands. Strokes under chin. Shaking/rocking? Brushes hand down arm.
Physical contact - adjustment to patient's position.		Repositions P's hands.	Moves head. Pushes shoulders back.

Table 4-22. Summary of staff behaviours observed during greeting sequences.

All staff members were observed to orientate toward the patient, although none was more marked than member of staff 06. The three members of staff were observed to touch or adjust the bib and in each case the patient's hands were covered by the bib. The three members of staff physically showed the meal to the patient prior to commencing feeding. They all used physical contact as a means of gaining attention and giving reassurance. Members of staff 05 and 06 also physically altered the patient's positioning.

The members of staff all orientated themselves to the patient by head movements, eye movements and general body orientation. Member of staff 06 in particular used the position of his head in relation to the patient's to provoke engagement. Whilst member of staff 05 gained fleeting eye contact, member of staff 06 was the only member of staff from the three examples examined to actively pursue and achieve person engagement.

Staff members were observed to use a wide range of non-verbal behaviours to signal the meal time activity. As the beginning of the meal would normally be signalled by the putting on of bibs, it was suggested that the bib adjustments observed across the dyads were to signal the start of the meal.

It was questioned why the patient's hands were placed under the bib by all of the staff members. Staff were adamant that hands should stay under the bib. It was suggested that this might have this increased the feelings of dependency in the patients, but may have also introduced some element of panic and loss of control. Physical contact was used to gain attention and to give reassurance.

Critique:

The duration of the greeting sequences was short allowing only minimal observation of engagement. The greeting sequences of only three video dyads were examined. Further investigation into how the engagement of patients alters is required. The researcher observed that patients did make eye contact or look at the meal and other objects throughout the meal process. These instances were not recorded as part of the above study. The engagement status study demonstrated that Bunning's (1996, 1998) codes of engagement may be used for patients with late stage dementia in addition to adults with learning disabilities for whom they were devised. There is much scope for using these codes as part of staff training and evaluation of whether the patient is able to demonstrate joint attention. The limited manner in which they were used in this study should be taken into consideration when discussing the findings.

Observations of how members of staff attempted to elicit engagement were not developed in the same way as other parts of the project had been. Rather, question 6 grew out of the observations made for question 5. A coding system was not used but the researcher listed behaviours observed when the videos were watched frame by frame. Whilst the findings are interesting there were many issues that were not explored further.

For example the role of specific feeding implements, such as spoons and bibs, was not explored. Some of the patients in this study were observed to hold the bib or attempt to hold the cup or spoon during feeding. It is suggested that such objects might help the patient to understand what is happening. If this is the case then maybe staff should be instructed to encourage patients to hold an object such as a spoon during meal times. Such techniques are often used with young children as a progression towards independent feeding. Maybe with patients with dementia the same method would help preserve the patient's feelings of playing an active role in the feeding process, as well as providing visual and tactile stimuli for what is happening. Further investigation into this area would be interesting, particularly as loss of concept is known to occur in dementia. Could it really be said that such objects hold any meaning for patients in the latter stages of dementia?

Summary of findings:

There was evidence of *self-neutral engagement* in all three dyads. Only *self-neutral* engagement was observed in one dyad whilst *object* and *person engagements* were observed in both of the other two dyads. In addition, there was one example of coding disagreement between *object engagement* and *self-active engagement*. The differentiation between these two depended on whether the observed behaviour was felt to be purposeful. No agreement about this could be reached as it was a difficult judgement to make from the video. In all three cases the patient was demonstrating *self-neutral engagement* when the feeding commenced. These findings support those of question 3, as it would be difficult to argue that patients actively participated when they were shown to demonstrate very little *person engagement*.

All three members of staff made some attempt to engage with the patients, as shown in table 4-22. Members of staff 05 and 06 displayed these behaviours more frequently than member of staff 03. Many attempts at eliciting engagement were unsuccessful. Member of staff 03 used predominantly verbal attempts to engage whilst members of staff 05 and 06 were more physical in their attempts (e.g. shaking, stroking). It was apparent that P did not respond to the verbal behaviours of the members of staff but she did respond to physical manipulation. Similarly she only looked at the meal when it was placed in front of her rather than when she was told to look at it. Member of staff 03 did not appear to achieve engagement with the patient, and as discussed above, looked uncomfortable at the start of the interaction.

4.5 Meal profiles and feeding.

Question 7.
What differences can be identified in the way the meals are fed and in feeding success?

Introduction:

The definition of a feeding partnership relies not just on interaction but also on whether feeding is successful. The researcher acknowledges that "feeding success" can be a subjective measurement and depends on how success is defined. A number of different measurements were explored in this section in an attempt to identify measurements of success and provide some clarity to a definition. A conversation analysis or ethnomethodological type approach was used with categories and classifications arising from the observed behaviours.

Whilst feeding is acknowledged as being a collaborative process (Athlin and Norberg, 1987; Satter, 1986, 1990; Shishmanian and Tomlinson, 1989) the members of staff are assumed to have the more active and influential role. Quantitative and statistical methods were used to identify differences between the dyads and the influencing factors contributing to these differences.

Method:

A glossary of terms used in this section is provided in table 4-23.

A visual representation of what the meal process looked like was required. Profiles of each of the meals were compiled by identifying and marking each spoonful of food or mouthful of drink consumed during the meal. These were then plotted against time on a graph to show when each spoonful/mouthful

Term	Definition
Meal profile.	Visual representation of the meal process. Each spoonful of food the patient was fed was marked against a time reference. Each phase of the meal was colour coded for ease of reference.
Length of meal.	The length of time from the first accepted offer to the last accepted offer. i.e. time during which food/drink was consumed.
Meal phases.	The meals each consisted of three meal phases, the main-meal, dessert and drink.
Offer.	A spoon of food or the cup presented to the patient.
Accepted offer.	An offer which was at least partially ingested by the patient. When food was scraped from around the mouth and offered again, this was ignored as the food had already been counted in previous offers.
Refused offer.	An offer which was not accepted. May be accompanied by refusal behaviours such as turning the head away, pushing food away, clamping mouth shut etc.
Completed meal phase.	No food or drink was left at the end of the phase.
Unfinished meal phase.	Part of the meal or drink was left, either because it was not offered or because it was refused.
Consecutive meal phases.	Main-meal, followed by dessert, followed by drink.
Overlapped meal phases.	Main-meal plus drinks, followed by dessert plus drinks.
Offer rate.	The rate at which members of staff attempt to feed the patients, i.e. the rate at which they make offers.
Feeding rate.	The actual rate at which the members of staff feed the patients, i.e. the rate at which the offers are accepted.
Consumption rate.	The rate at which patients accept offers from the members of staff. When discussing individuals the rate is the same as the feeding rate. The difference between the two is only important when data are pooled across the subjects.

Table 4-23. Glossary of terms for section 4.5.

was taken and which phase of the meal it was. Each of the meal profiles is represented in Appendix 8. Working from the meal profiles, information collected on the environmental forms, and using event sampling, a number of observations were made about the type of food, food consistency, amount of food consumed, length of meals, rate of feeding, completion of meals, food preference and need for drinks.

These measurements taken separately do not indicate feeding success. There needs to be a balance between these different measurements, to reflect the dichotomy between quantity and quality. For example, is a member of staff who feeds 100% of a meal to a patient but takes 60 minutes to do so more or less successful than a member of staff who feeds 50% but does so in just 10 minutes?

The limitations of being able to use one measurement for all patients is also acknowledged. What is successful for one patient may not be successful for another as success for one patient may be maximum nutritional intake whilst for another it may be enjoyment of the meal, or to eat more than they did yesterday, or to eat without choking.

Results and findings:

Type of food consistency.

All four patients received their meals in purée form. All meals consisted of a protein (such as puréed meat), a carbohydrate (such as mashed potato) and at least one vegetable (such as puréed carrots). The patients were not observed being fed the same meal as the videos were recorded on different days. The meals were however comparable and a record was kept of what the meal consisted of and the quality of the purée texture. In some cases gravy was added if the purée was dry. The desserts were either very soft puddings such as blancmange, rice pudding or semolina; or were fortified supplements specifically used in the management of dysphagia. Patients B and E received normal fluids whilst patients C and D had their drinks thickened. Patient D's drink was thickened to a pudding consistency which was given on a spoon.

The meals were all delivered to the ward from the on-site kitchen and were served at ward level. A number of members of staff would then work together to plate the meals up, whether they be the regular meals or the modified ones. No one member of staff was responsible for plating up the meals and the combination of staff depended on who was on duty. Sometimes the members of staff who were participating in the project helped with plating up the meals, but more frequently they were busy providing aprons and rearranging furniture ready to commence feeding.

Meals for patients who did not require feeding were made up to order and served at the table. The meals for the patients who required feeding were plated up in one go and then re-heated at ward level as requested by each member of staff. From these records it was judged that the success or lack of success of feeding could not be dependent upon the type of food being offered or who had plated up the meal. It was not possible for one member of staff to consistently feed a particular patient a different texture or a larger or smaller meal. The limitation of these observations and conclusions is however noted.

Visual presentation of food:

In all cases the different parts of the main-meal (meat, potato and vegetables) were served separately, and thus should have been presented to the patients in the same manner. Member of staff 03 however was observed to mix the different food types together on the plate during the meal in all four videos. He therefore altered the presentation of the food. Neither member of staff 05 or 06 were observed to do this.

Hypothesis 7.1.
It will be possible to identify differences in the amount of food fed to each patient, influenced by the members of staff.
(Null hypothesis that differences are due to chance alone).

Amount of food consumed:

This hypothesis addresses a quantitative issue and purely examines how much or what proportion of a meal was consumed. The amount of food consumed was not calculated in weight but was calculated by recording the number of mouthfuls that were consumed. Such a method was selected as it allowed consumption to be measured from the videos. The limitations of this method are acknowledged and are discussed later in this section. The number of offers that were made by each member of staff and the number that were accepted are shown in table 4-24.

Member of staff	Number of offers made	Number of accepted offers	Number of refused offers	% of offers accepted
03	245	223	22	91%
05	295	215	80	73%
06	200	150	50	75%

Table 4-24. Total number of offers made by each staff member over four meals.

This showed that whilst members of staff 05 and 06 had a comparable percentage of their offers accepted, member of staff 03 had considerably more of his accepted. This suggested that member of staff 03 was doing something differently to his two colleagues.

With regard to consumption, the number of offers made to and accepted by each patient was also calculated, as shown in table 4-25. This showed a considerable difference between patient C and the other patients, regardless of which member of staff was feeding. This suggested that patient C was accepting fewer offers and therefore eating less, but also that members of staff needed to persevere and make more offers when feeding her.

Patient	Number of offers made	Number of accepted offers	Number of refused offers	% of offers accepted
B	185	159	26	86%
C	204	125	79	61%
D	175	159	16	91%
E	176	147	29	84%

Table 4-25. Total number of offers made to each patient over three meals.

Only the total number of *accepted* offers for each staff/patient dyad was then considered, as shown in table 4-26.

Patient	B	C	D	E
Member of staff				
03	60	51	49	63
05	66	49	52	48
06	33	26	58	36

Table 4-26. The total number of accepted offers for each staff/patient dyad.

The data were examined using a one-way related ANOVA (table 4-27) which showed no significant differences across the dyads (Appendix 6.3).

Whilst the ANOVA showed no significant difference between the number of mouthfuls consumed across the group, differences were identified within the group and these were extrapolated by using a related t-Test.

Source of variance	Sum of squares (SS)	Degrees of freedom (df)	Mean squares (MS)	F	Significance
Condition variable	734	2	367	$F_{2,10}$ 1.626	>0.05
Subject variable	242.25	3	80.75	$F_{5,10}$ 0.358	>0.05
Error	1354	6	225.667		
Total	2330.25	11			

Table 4-27. Analysis of variance (ANOVA) for number of accepted offers (members of staff as conditions).

The t-Test showed differences between member of staff 03 and member of staff 06 ($p<0.20$) (table 4-28) and between member of staff 05 and member of staff 06 ($p<0.20$) (table 4-29) (Appendix 6.4 and 6.5). Both members of staff 03 and 05 therefore performed differently to member of staff 06.

Σd	Σd^2	t	significance
70	2164	1.978	0.20

Table 4-28. t-Test analysis for number of accepted offers - members of staff 03 and 06.

Σd	Σd^2	t	significance
62	1798	1.856	0.20

Table 4-29. t-Test analysis for number of accepted offers - members of staff 05 and 06.

In addition, the t-Test also showed a significant difference between patient B and patient C ($p<0.10$) (table 4-30) (Appendix 6.6).

The significance of each of these tests was however fairly small.

$\sum d$	$\sum d^2$	t	significance
33	419	3.600	0.10

Table 4-30. t-Test analysis for number of accepted offers - patients B and C.

The mean number of accepted offers per meal was calculated as 49.25 (range 26 - 66; n=12). 75% of meals fed by member of staff 03 contained an above average number of accepted offers, as did 50% of those fed by member of staff 05 and 25% of those fed by member of staff 06. 67% of the meals fed to patients B and D contained an above average number of accepted offers, as did 33% of those fed to patients C and E.

Member of staff 03 could be seen to be feeding significantly more mouthfuls than either member of staff 05 or 06. A comparison of the number of spoonfuls and the weight of food consumed would have been an enlightening measurement, but one that was unfortunately not made.

It was therefore possible to identify differences in the amount of food received by each patient when consumption was measured in accepted offers. The differences appeared to have more to do with which member of staff was doing the feeding rather than which of the patients was being fed. The null hypothesis that differences were due to chance was therefore rejected.

Hypothesis 7.2
It will be possible to identify feeding success from measurements of meal length and the amount of food consumed.
(Null hypothesis that differences are due to chance alone).

This analysis examines more qualitative issues. Food can quickly lose its heat and become less appetising. Feeding as much food as possible whilst it is still as appetising as possible is therefore important. Combining amount of food consumed with time taken to consume it therefore provides a better measure of success than amount alone.

Length of meals:

The amount of food consumed appeared to be dependent on the member of staff feeding. How successful each member of staff was at feeding was measured in the number of spoonfuls consumed (as above) and length of meal. The length of meal was calculated from the first accepted offer to the final accepted offer. This measure was selected as it identified the actual time taken to consume the meal. Including refused offers at the start and end of the meal would have increased the meal length but would have represented the time spent trying to feed the patient rather than the time taken to consume the food.

The patients have limited means by which they can influence the meal length such as refusal, chewing time and the time taken to initiate a swallow. In many cases these behaviours may be used by the members of staff to time their next offer of food. The researcher felt that refusals at the beginning and end of the meals were different to the refusals observed during the meals and that they were responded to differently by the members of staff. Refusals at the start of the meal appeared to interpreted by the staff as the patients not being ready to start eating. See for example the long sequence at the start of 03/B where member of staff 03 commented on patient B's initial refusal as her not being awake yet. Similarly the refusals observed at the end of meals were treated as termination of the meal process rather than refusal of that particular spoonful or offer. The researcher acknowledges that these observations are subjective and that further analysis is required.

The length of each meal is shown in table 4-31.

Staff/patient dyad	Length of meal	Staff/patient dyad	Length of meal
03/B	12:33	05/D	16:09
03/C	16:49	05/E	16:51
03/D	12:34	06/B	15:31
03/E	17:26	06/C	18:49
05/B	18:47	06/D	19:26
05/C	27:03	06/E	10:54

Table 4-31. Overall length of meal for each of the staff/patient dyads (mm:ss).

The one-way related ANOVA (table 4-32) showed a significant difference between the meal lengths when the patients were the conditions ($p<0.05$), but not when the members of staff were. In other words the differences between the meal lengths for each patient was significantly different ($p<0.05$), but there was no significant difference between the length of meals fed by each member of staff (Appendix 6.7). This suggested that it was actually the patient's who were somehow affecting the outcome of the meal length. Due to the limited influence that the patients could exert on the meal it is proposed that it was their refusal behaviours that contributed to an increase in meal length. The null hypothesis that differences were due to chance was therefore rejected.

Source of variance	Sum of squares (SS)	Degrees of freedom (df)	Mean squares (MS)	F	Significance
Condition variable	64.183	3	21.394	$F_{2,10}$5.067	0.05
Subject variable	50.982	2	25.491	$F_{5,10}$2.012	>0.05
Error	76.005	6	12.668		
Total	191.17	11			

Table 4-32. Analysis of variance (ANOVA) for meal length (patients as conditions).

Taking into account the amount of food fed it also suggested that staff were concerned more with feeding a satisfactory amount of food rather than how long the meal took. This is an important factor for nutritional intake but may result in patients receiving food that has gone cold.

The two measurements taken above suggested that the amount of food consumed was directly influenced by the members of staff, whilst the length of meals was influenced by the patients. Neither measure was considered sufficient to indicate feeding success and so further measurements of feeding rate and whether meal phases were completed or not were also taken.

Offer, feeding and consumption rates:

The rate of offers being made (in offers per minute) and the rate of feeding (in accepted offers per minute) was calculated for each staff/patient dyad, as shown in table 4-33.

Member of staff/ patient dyad	Offer rate	Feeding rate	Member of staff/ patient dyad	Offer rate	Feeding rate
03/B	5.42	4.78	05/D	3.53	3.03
03/C	3.69	3.03	05/E	4.04	2.85
03/D	4.06	3.89	06/B	2.64	2.13
03/E	3.67	3.61	06/C	2.66	1.38
05/B	4.05	3.51	06/D	3.45	2.99
05/C	3.40	1.81	06/E	4.04	3.30

Table 4-33. Offer rate (in offers per minute) and feeding rate (in accepted offers per minute) for each staff/patient dyad.

The mean offer rate (in offers per minute) and feeding rate (in accepted offers per minute) were calculated for each member of staff, as shown in table 4-34. Member of staff 03 was shown to be feeding at a faster rate than either of his

Member of staff	Mean offer rate	Mean feeding rate
03	4.21	3.83
05	3.76	2.80
06	3.20	2.45

Table 4-34. Mean offer rate (in offers per minute) mean and feeding rate (in accepted offers per minute) for each member of staff.

two colleagues. This is an important consideration if food is to be consumed whilst still hot.

The mean consumption rate (in accepted offers per minute) for each of the patients was also calculated. This is shown in table 4-35.

Patient	Mean consumption rate
B	3.37
C	2.07
D	3.30
E	3.25

Table 4-35. Consumption rate (in accepted offers per minute) for each patient.

Whilst three of the patients received a similar number of spoonfuls per minute, patient C was fed at a slower rate. It was therefore more likely that patient C's food was no longer warm toward the end of the meal. The consumption rate, like meal length discussed above, was influenced by the number of refused offers.

It is worth mentioning briefly here that patient C had a primary diagnosis of chronic schizo-affective disorder prior to the secondary diagnosis of dementia. It should be considered whether some of the social deficits observed in such disorders contributed to the apparent difficulties observed when members of staff tried to feed her. This is discussed further in Chapter Five with reference to relevant literature.

Completion of meals:

The three phases of each meal (main-meal, dessert, and drink) were identified as having been completed or unfinished, as shown in table 4-36.

The dessert phase (8/12) was completed more frequently than the drink phase (7/12), which in turn was completed more frequently than the main-meal (6/12). This could be a result of patients preferring sweet foods (as discussed below) or staff may have greater rationale for feeding all of the dessert. For example, because the dessert is smaller it may represent a more accomplishable task for staff and may also emphasise the completion of the food stage of the meal.

Staff/patient dyad	Main-meal	Dessert	Drink
03/B	Completed	Completed	Unfinished
03/C	Completed	Completed	Completed
03/D	Completed	Completed	Unfinished
03/E	Completed	Completed	Completed
05/B	Unfinished	Completed	Completed
05/C	Unfinished	Completed	Completed
05/D	Unfinished	Completed	Unfinished
05/E	Completed	Unfinished	Completed
06/B	Unfinished	Unfinished	Completed
06/C	Unfinished	Unfinished	Unfinished
06/D	Unfinished	Completed	Unfinished
06/E	Completed	Unfinished	Completed

Table 4-36. Each meal phase shown as having been completed or left unfinished.

Patients B and C were fed 5 complete meal phases, patient D was fed 4 and patient E was fed 7. Although patient E was fed more completed meal phases, two thirds of her meals contained a below average number of spoonfuls and she accepted only 84% of offers. This could suggest either that she was fed larger spoonfuls and that the meal was therefore consumed in a lower number of spoonfuls, or that her meals were consistently smaller. Not measuring the weight of food at the start of the meal or how much was consumed is an identified limitation of this study.

The differences across and between members of staff were shown to be significant on the one-way related ANOVA (table 4-37) ($p<0.05$). Neither the differences across or between the patients were significant (Appendix 6.8). It was observed that member of staff 03 fed more complete meal phases than his two colleagues and this was supported statistically by the difference found across the group of staff members.

Source of variance	Sum of squares (SS)	Degrees of freedom (df)	Mean squares (MS)	F	Significance
Condition variable	4.5	2	2.25	$F_{2,10}$6.231	0.05
Subject groups	1.583	3	0.528	$F_{5,10}$1.462	>0.05
Error	2.167	6	0.361		
Total	8.25	11			

Table 4-37. Analysis of variance (ANOVA) for number of meal phases completed (members of staff as conditions).

A related t-Test (table 4-38) was used to examine member of staff 03 specifically.

Σd	Σd^2	t	significance
6	12	3.00	0.10

Table 4-38. t-Test analysis for number of meal phases completed - members of staff 03 and 06.

This showed a significant difference between member of staff 03 and member of staff 06 ($p<0.10$) (Appendix 6.9). A correlation between these two members of staff had already been found for the number of offers that had been accepted.

Member of staff 03 could therefore be seen to have fed significantly more completed meal phases and at a faster rate than his colleagues across the four patients. Feeding rate and whether meal phases were completed or not seemed more indicative of feeding success than either the number of spoonfuls consumed or the length of the meal.

In comparisons of feeding success these measurements would therefore be useful. They still represent only part of the picture however as these measurements fail to take into account any interactional components such as those discussed above. This is addressed in section 4.6 and in Chapter Five.

Question 8.
How do patients display a preference for sweet foods?

Food preference:

A liking for sweet foods and a dislike of bitterness are innate food preferences, whilst other food preferences are learned (VOICES, 1998). Damage to the hypothalamus in dementias such as Alzheimer's disease may help explain the common preference of sweet foods demonstrated by patients with dementia. The patients in this study were expected to show a preference for the dessert phase of the meal over the main-meal phase. This could be seen by examining consumption. The number of accepted offers was identified for each meal phase and the percentage of overall accepted offers calculated, as shown in table 4-39.

Dyad	Main meal	Dessert	Drink	Total
03/B	29 (48.33%)	13 (21.67%)	16 (30%)	60 (100%)
03/C	28 (54.90%)	13 (25.49%)	10 (19.61%)	51 (100%)
03/D	22 (44.90%)	11 (22.45%)	16 (32.65%)	49 (100%)
03/E	23 (36.51%)	19 (30.16%)	21 (33.33%)	63 (100%)
05/B	28 (42.42%)	18 (27.27%)	20 (30.30%)	66 (100%)
05/C	22 (44.90%)	13 (26.53%)	14 (28.57%)	49 (100%)
05/D	16 (30.77%)	18 (34.62%)	18 (34.62%)	52 (100%)
05/E	18 (37.50%)	18 (37.50%)	12 (25%)	48 (100%)
06/B	13 (39.39%)	11 (33.33%)	9 (27.27%)	33 (100%)
06/C	5 (19.23%)	7 (26.92 %)	14 (53.85%)	26 (100%)
06/D	20 (34.48%)	6 (10.34 %)	32 (55.17%)	58 (100%)
06/E	18 (50%)	13 (36.11 %)	5 (13.89%)	36 (100%)

Table 4-39. The number and percentage of accepted offers consumed in each meal phase.

There was no difference shown between the number of offers accepted in each meal phase on the one-way related ANOVA (Table 4-40.) (Appendix 6.10).

Source of variance	Sum of squares (SS)	Degrees of freedom (df)	Mean squares (MS)	F	Significance
Condition variable	218.722	2	109.361	$F_{2,10}$3.317	>.05
Subject groups	670.306	11	60.937	$F_{5,10}$1.848	>.05
Error	725.278	22	32.967		
Total	1614.306	35			

Table 4-40. Analysis of variance (ANOVA) for the amount of food consumed in each meal phase (meal phases as conditions).

However, the data for this analysis included the number of offers of drinks. The Wilcoxon signed rank test was used to compare just the number of accepted offers in the main-meal and dessert phases (N=11, W=3). This revealed a significant difference for both two-tailed (0.01) and one-tail (0.005) tests, with more main-meal offers being accepted than dessert (Appendix 6.11).

The main-meals were however larger than the desserts and therefore had a greater number of potential mouthfuls. The mean number of potential mouthfuls was calculated from those meal phases that were completed. Completed main-meals were shown to contain 23 mouthfuls on average (range 18-29; n=6), whilst the completed desserts only contained approximately 14 (range 6-19; n=8). This difference in potential mouthfuls was significant when examined by the Mann-Whitney Test (U=4; p<0.005) (Appendix 6.12).

More spoonfuls of main-meal were consumed than dessert, but there were more potential spoonfuls of main-meal in the first place. More revealing was the fact that more dessert phases (67%) were completed than main-meal phases (50%) as shown in table 4-36, and the fact that fewer drinks were given during the dessert phase(11, mean 0.92, range 0-7, n=12) than the main-meal phase (48, mean 4, range 0-17, n=12).

The rate of feeding across the phases was also examined (in number of accepted offers per minute). This is shown in table 4-41.

Member of staff/ patient dyad	Main-meal Rate of feeding	Dessert Rate of feeding	Member of staff/ patient dyad	Main-meal Rate of feeding	Dessert Rate of feeding
03/B	6.02	6.05	05/D	3.63	4.00
03/C	2.98	3.31	05/E	2.30	3.92
03/D	3.41	4.52	06/B	2.09	4.32
03/E	3.69	3.33	06/C	1.16	2.33
05/B	3.15	4.39	06/D	2.91	3.41
05/C	1.60	2.87	06/E	3.08	3.37

Table 4-41. Rate of feeding for main-meal and dessert phases of the meals (in offers per minute).

The mean rate for the main-meal phase was calculated as 3.00 accepted offers per minute (range 1.16 - 6.02; n=12), and the dessert phase as 3.82 accepted offers per minute (range 2.33 - 4.52; n=12). The frequency and rate of feeding was significantly different across the two meal phases when examined using the Wilcoxon signed-ranks test (W=1; p<0.01) (Appendix 6.13).

It could be argued that more dessert phases were completed as a result of the members of staff being more inclined to finish the smaller phase, rather than the patients expressing preference for them. It has already been discussed in earlier sections of this chapter that the amount of food fed appeared to be dependent upon the member of staff and how many offers they made. Members of staff appeared to be more concerned with how much food was consumed rather than how long they were feeding a patient for.

The length of time that was spent feeding however appeared to be influenced by the patients, the length of time they chewed for, the time it took to swallow and how many refusal behaviours they exhibited. The fact that the desserts were consumed at a quicker rate (not overall time as the desserts were smaller and so would be finished quicker than the main-meal phases), with fewer refusal behaviours and fewer drinks being given does suggest that patients were expressing some degree of preference for the desserts.

Question 9.
What are the antecedents to staff members giving the patients a drink?

Offer of drinks:

From the profiles two patterns of meal presentation were evident. The meal phases were either fed consecutively or were overlapped. The pattern for each can be clearly seen on each of the profiles in Appendix 8, and is summarised in table 4-42.

Staff members Patients	03	05	06
B	consecutive	overlapped	consecutive
C	consecutive	overlapped	overlapped
D	consecutive	overlapped	overlapped
E	consecutive	overlapped	overlapped

Table 4-42. Pattern of meal presentation - consecutive or overlapped phases.

This indicates whether drinks were given during the meal or not. It is clear that member of staff 03 fed the meal phases consecutively in all cases and therefore did not interrupt the main-meal or dessert phases to offer drinks. There was just one similar example from member of staff 06 but otherwise drinks were given throughout the other meal phases. There were not enough subjects to reliably use a chi-square analysis (Greene and D'Oliveira, 1982), but this difference is clear and can only be a result of each member of staff's feeding style.

An ABC type approach identified an antecedent in just over half (55.5%) of cases when a drink was offered. Three antecedents were identified, as shown in figure 4-32.

The behaviours identified as antecedent behaviours were counted in each dyad and were found to result in a drink being given in every case when staff members 05 and 06 were feeding and to never result in a drink being given

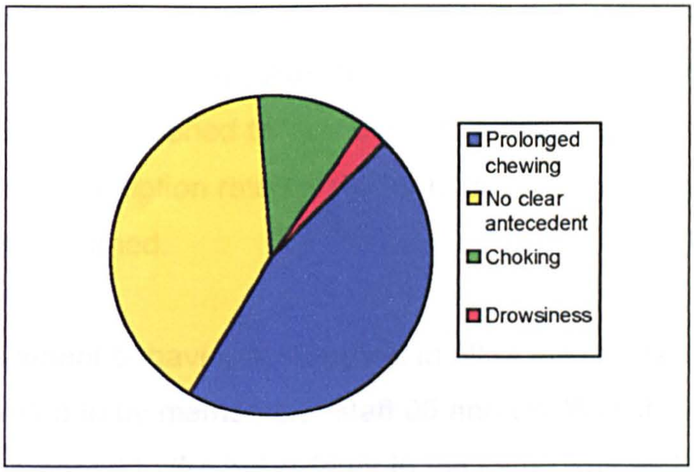


Figure 4-32. Antecedents to a drink being given during one of the other meal phases.

when member of staff 03 was feeding. This factor could account for the increased feeding rate of member of staff 03 observed above.

Member of staff 03 did not respond to the behaviours in the same way as his colleagues. However, it is worth mentioning briefly here that three of the four patients were receiving speech and language therapy intervention at the time of the data collection, for dysphagia. Mixed consistencies, such as would result from adding drink to a mouthful of food are the most difficult for patients with such disorders to manage. Member of staff 03 avoided mixed consistencies and could therefore have minimised the patients' feeding difficulties.

It was not clear why drinks were offered in the remaining 44.5% of cases. There was no clear antecedent and it is proposed that the members of staff were attempting to emulate the normal feeding pattern of consuming drinks throughout a meal. Further investigation into this area would be interesting.

It was not possible to examine the rate of consumption for drinks, due to drinks being interspersed with the rest of the meal in half of the cases. This would however be an interesting measure. The drinks are usually sweet, and when thickened could be likened to the desserts. It might therefore be expected that the consumption rate be similar to that of the dessert phase, particularly when thickened.

There were antecedent behaviours identified in all of the dyads, but these were only responded to by members of staff 05 and 06. Whilst member of staff 03 failed to respond to the behaviours in the same way as his colleagues, it could be argued that his response was actually more appropriate as it reduced the risks associated with dysphagia.

Critique:

The researcher acknowledges that it would have been useful to include nutritional information in the data collection phase for section 4.5. In the absence of accurate food-weight measurements the number of spoonfuls fed was used to give an indication of consumption. It is acknowledged that this measurement was not ideal. It did however provide some information in the absence of necessary data. Replication of this area of the study would need to include the weight of the food to indicate how much had actually been consumed. To add validity to the measurements used there needs to be a comparison of number of spoonfuls consumed and actual food consumption. This was not carried out and therefore the conclusions drawn need to be treated with caution.

Summary of findings:

Due to the number of analyses used in this section, the findings are summarised in two tables; one referring to the members of staff (table 4-43) and one to the patients (table 4-44).

Members of staff.

To discuss the members of staff first, member of staff 03 had more of his offers accepted, had a shorter average meal length and was feeding at a faster average rate than his two colleagues. He fed ten of the twelve meal phases completely and fed all four meals as consecutive meal phases. However, he was also the only member of staff observed to mix the food together on the plate and thereby reduce its visual presentation. Could this enhance the food texture by mixing the stodgier potato with the runnier vegetables for example? Member of staff 05 made the most offers but had the lowest percentage accepted. Member of staff 06 had the slowest feeding rate and completed the least number of meal phases but was shown to interact with the patients more than his colleagues.

Measurements	Members of staff 03	 05	 06
Total offers made	245	295	200
Total offers accepted	223	215	150
Percentage of offers accepted	91%	73%	75%
Average meal length (minutes)	14.84	19.73	16.15
Average feeding rate (accepted offers a minute)	3.83	2.80	2.45
Number of meal phases completed	10/12	7/12	4/12
Average feeding rate for main-meal	4.03	2.67	2.31
Average feeding rate for dessert	4.30	3.80	3.36
Meals fed consecutively	4	0	1

Table 4-43. Summary of measurements for each member of staff.

Members of staff were seen to be responding to the cues from patients (e.g. reduced refusal behaviours, more accepted offers, less coughing), resulting in an increased feeding rate during the dessert phase. Likewise, it is suggested that members of staff may have recognised behaviours that appeared to signal the need for a drink. This was not conclusive as antecedents could only be recognised in half of the cases and one of the members of staff did not respond to the behaviours in the same way as his colleagues.

Patients.

From table 4-44 it is apparent that patient C had the longest average meal length and that she accepted the least number of offers. She accepted at least one offer per minute less than the other patients resulting in the slowest feeding rate. Patient E completed the most meal phases. All patients had at least one meal fed in consecutive phases, patient B had two fed consecutively.

Preference for the dessert phase was shown across the dyads by an increase in feeding rate.

The most effective measurements of feeding success were found to be of feeding rate and whether or not the meal phases were completed. There was a correlation seen between these two measurements, with more meal phases being completed when the feeding rate was fastest. The rate of feeding appeared to be influenced directly by the patients, by the number of offers that were refused. The rate of feeding was slower when there were a greater number of refused offers.

Feeding success could also be discussed in terms of enjoyment. The fact that desserts were consumed more quickly than the main meals suggests that they were preferred and therefore enjoyed more. Enjoyment itself is difficult to recognise or measure in these patients. It would also have been beneficial to discuss feeding success in terms of nutrition received but this was not possible as no measurements were taken of the actual amount of food consumed.

Measurements	Patients			
	B	C	D	E
Total offers made	185	204	175	176
Total offers accepted	159	125	159	147
Percentage of offers accepted	86%	61%	91%	84%
Average meal length (minutes)	15.62	20.87	16.07	15.07
Feeding rate (number of offers accepted a minute)	3.47	2.07	3.30	3.25
Number of meal phases completed	5	5	4	7
Average feeding rate for main-meal	3.75	1.19	3.32	3.02
Average feeding rate for dessert	4.92	2.84	3.98	3.54
Meals fed consecutively	2	1	1	1

Table 4-44. Summary of measurements for each patient.

4.6 Exploration of the "feeding partnership".

Introduction:

At the beginning of the project the researcher considered interaction and feeding to be two separate components and as such the research questions only address either one or the other. During the above small scale studies it became apparent that there were a number of similarities between interaction and feeding and that the two could not be separated. Like conversation, feeding consists of a number of turns. These turns are pre-determined and involve the offering of food and the acceptance of food. The linguistic model introduced by Clark and Schaeffer (1989), which had already been used to examine conversational turns, was therefore utilised to explore feeding exchanges.

Method:

A glossary of terms is provided in table 4-45.

Being fed may be thought of as a passive activity but, as discussed above, like discourse it is achieved only by collaboration between the feeder and the eater. Clark and Schaeffers' model was applied to interactions of feeding observed during the main-meal phases.

In a parallel with linguistic behaviour, the first participant *presents* an action for the second participant to consider, and the second participant *accepts* the action as having been understood. This can be seen throughout the feeding process. The feeder presents or offers the food to the eater who indicates their understanding of it being an offer by accepting or declining it. The first stage of the feeding sequence will be referred to as an *offer* and the second as an *acceptance.* It is a context specific sequence but one in which both partners need to understand the actions of the other.

Term	Definition
Offer.	A spoon of food or the cup being presented to the patient.
Acceptance.	An offer is at least partially removed by the patient. Accompanied by acceptance behaviours such as leaning toward spoon/cup, opening mouth etc.
Refusal.	An offer is not accepted. Accompanied by refusal behaviours such as turning the head away, pushing the food away, clamping mouth shut etc.
No immediate response.	An offer is neither accepted nor refused and there are no acceptance or refusal behaviours.
Comment.	A verbal utterance made by the member of staff in response to the patient's accepting or refusing behaviours.
Follow-up behaviour.	The next natural turn, such as wiping excess food from around the mouth.
Evidence of understanding.	Evidence provided by the second participant to show that they have understood what the first participant intended. See Clark and Schaeffer (1989).
Contribution tree.	A means of representing the turns of conversation. See Clark and Schaeffer (1989).

Table 4-45. Glossary of terms and coding scheme for section 4.6.

Even at a basic response level the patients need to understand that the thing in front of them is food and that it is for them. In terms of collaboration, it is only when the patients accept the food that the staff member is offering them that feeding has been achieved.

Contribution trees were used by Clark and Schaeffer (1989) to represent linguistic sequences, and the same structure can be used to demonstrate the phases and turns of feeding. Rather than *presentation phase,* the first part of the sequence may be referred to as the *offer phase*, to distinguish the sequences from linguistic data.

A coding scheme was devised, based upon Clark and Schaeffers' model, and applied to three of the dyads (3/B, 5/B and 6/B). This scheme (as shown in table 4-45) was subject to an inter-rater reliability study. A speech and language therapy colleague was presented with the above definitions and asked to code the utterances in the same three dyads.

The results of the inter-rater and intra-rater reliability studies are shown in tables 4-46 (page 203) and 4-47 (page 204). The Cohen's Kappa analyses, shown in table 4-48, demonstrated good inter-rater reliability and excellent intra-rater reliability (Fliess, 1981).

	P_0	P_c	K
Inter-rater	0.72	0.0128	0.72
Intra-rater	0.83	0.0091	0.83

Table 4-48. Cohen's Kappa results for types of feeding sequences.

In the inter-rater reliability study there were eight disagreements. Four of these were genuine disagreements but the other four need to be discussed further. Two of the disagreements were a result of the researcher modifying the coding system but not providing this information for the second observer, i.e. training errors. For example the researcher coded responses to verbal information, such as in figure 4-33, as acceptances or refusals.

Thus the researcher coded this particular sequence as *offer/refusal* + *offer/acceptance* + *offer/acceptance* + *follow up*. The second observer coded it as *offer/refuse* + *offer/accept* + *follow up*, as if it were just one offer sequence.

The other two examples of disagreement occurred when the second observer judged two exchanges to be part of the same exchange, as figure 4-34 shows.

Observer one	Observer Two																			
	A	B	C	D	E	F	G	H	I	J	K	L	M	N	O	P	Q	R	S	Totals
A	**7**														1					8
B				1																1
C			**5**							1				1						7
D				**2**											1					3
E																				0
F																				0
G																				0
H								**2**												2
I																				0
J										**2**										2
K										1										1
L												**1**								1
M																				0
N														**1**						1
O															**1**					1
P			1																	1
Q																				0
R																				0
S				1																1
Totals	7	0	6	4	0	0	0	2	0	4	0	1	0	2	3	0	0	0	0	**21**/29 72%

Table 4-46. Inter-rater reliability confusion matrix for types of feeding sequences (03/B).

KEY:

A = offer/acceptance
B = offer/acceptance+comment
C = offer/acceptance+follow up
D = offer/accept+comment+follow up
E = offer/refusal
F = offer/refusal+comment
G = offer/refusal+offer/refusal
H = offer/refuse+offer/acceptance
I = offer/refuse+offer/accept+comment
J = offer/refuse+offer/accept+follow up
K = offer/(refuse/offer)/accept+comment+ follow up
L = offer/Ø+offer/accept
M = offer/Ø+offer/accept+comment
N = offer/Ø+offer/accept+follow up
O = offer/Ø+offer/accept+comment+follow up
P = offer/accept+offer/accept+comment+ follow up
Q = offer/refuse+offer/accept+ offer/accept+ follow up
R = offer/accept+offer/accept+comment+ follow up
S = offer/refuse+offer/accept+comment+ follow up

Observer	Observer Two																			
one	A	B	C	D	E	F	G	H	I	J	K	L	M	N	O	P	Q	R	S	Totals
A	**7**														1					8
B				1																1
C			**5**							1				1						7
D				**2**											1					3
E																				0
F																				0
G																				0
H								**2**												2
I																				0
J										**2**										2
K											**2**									2
L																				0
M																				0
N														**1**						1
O															**1**					1
P																**1**				1
Q																				0
R																				0
S																			**1**	1
Totals	7	0	5	3	0	0	0	2	0	3	2	0	0	2	3	1	0	0	1	**24**/29 83%

Table 4-47. Intra-rater reliability confusion matrix for types of feeding sequences (03/B).

KEY:

A = offer/acceptance
B = offer/acceptance+comment
C = offer/acceptance+follow up
D = offer/accept+comment+follow up
E = offer/refusal
F = offer/refusal+comment
G = offer/refusal+offer/refusal
H = offer/refuse+offer/acceptance
I = offer/refuse+offer/accept+comment
J = offer/refuse+offer/accept+follow up
K = offer/(refuse/offer)/accept+comment+ follow up
L = offer/Ø+offer/accept
M = offer/Ø+offer/accept+comment
N = offer/Ø+offer/accept+follow up
O = offer/Ø+offer/accept+comment+follow up
P = offer/accept+offer/accept+comment+ follow up
Q = offer/refuse+offer/accept+ offer/accept+ follow up
R = offer/accept+offer/accept+comment+ follow up
S = offer/refuse+offer/accept+comment+ follow up

Line no.	Narrative.	Observer 1	Observer 2
110	S: [offers spoon]	offer	offer
111	P: [starts chewing]	refusal	refusal
112	S: open mouth	verbal instruction (offer)	offer
113	P: [opens mouth]	response (acceptance)	
114	S: very good	offer	
115	P: [takes mouthful]	acceptance	acceptance
116	S: [wipes food from around P's mouth]	follow up	follow up

Figure 4-33. Example of coding disagreement due to training error.

Line no.	Narrative.	Observer 1	Observer 2
074	S: [offers spoon]	offer	offer
075	P: [takes mouthful]	acceptance	no response
|			
079	S: Mary [offers spoon]	offer	offer
080	P: [takes mouthful	acceptance	acceptance
081	S: very good [wipes food from around M's mouth]	comment + follow up	comment + follow up

Figure 4-34. Example of coding disagreement due to two exchanges being judged to be one exchange by the second observer.

This disagreement can be seen to be the result of different interpretations of the behaviour in line 075. The researcher judged that food had been accepted whilst the second observer felt that food had not been taken. The segment of tape was examined a number of times and both observers agreed that the second interpretation was more accurate and that it appeared that the first offer of food had not been responded to.

The Cohen's Kappa value of 0.83 for intra-rater reliability indicates excellent reliability.

Results and findings:

The most simple sequence observed was that involving an offer phase and an acceptance phase as represented in figure 4-35.

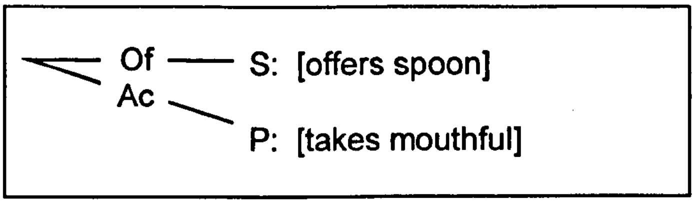


Figure 4-35. Example of an offer and acceptance sequence.

Here the presentation phase was made by member of staff (S) offering the spoon to the patient (P) and the acceptance phase was made by the patient taking the food from the spoon. Three dyads were examined in detail and to enable comparisons to be made each member of staff was observed feeding the same patient (03/B, 05/B and 06/B). Out of the 68 sequences identified across the three dyads only 17 (24.3%) of them consisted of this simple sequence. There was one example of a simple offer and refusal sequence but the remaining 52 sequences all contained a recognisable follow up behaviour or comment from the member of staff.

As discussed earlier, for the acceptance phase to be acknowledged by S as a presentation phase, P's behaviour must be accepted. Across the three dyads (03/B, 05/B and 06/B) four different types of acceptance response were observed. Most common was S moving on to the next relevant contribution. Alternatively S gave a verbal comment, as in figure 4-36; demonstrated a follow up behaviour such as wiping the patient's mouth, as in figure 4-37; or combined these two responses as in figure 4-38.

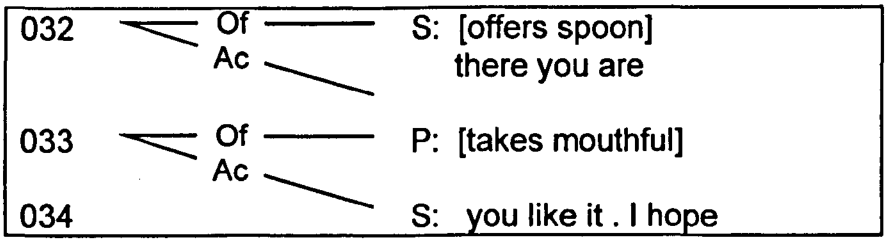


Figure 4-36. Example of an offer/acceptance and verbal comment sequence (03/B).

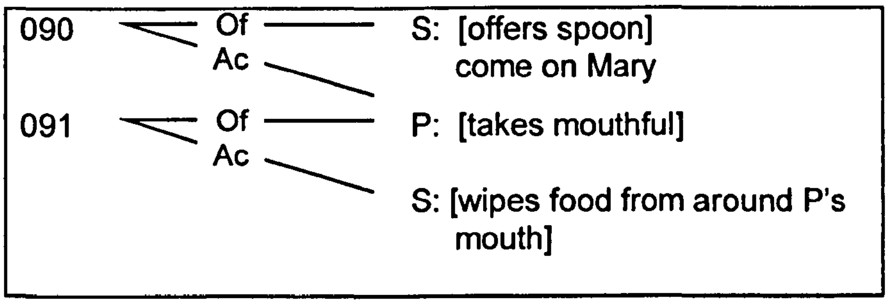


Figure 4-37. Example of an offer/acceptance and follow-up behaviour sequence (05/B).

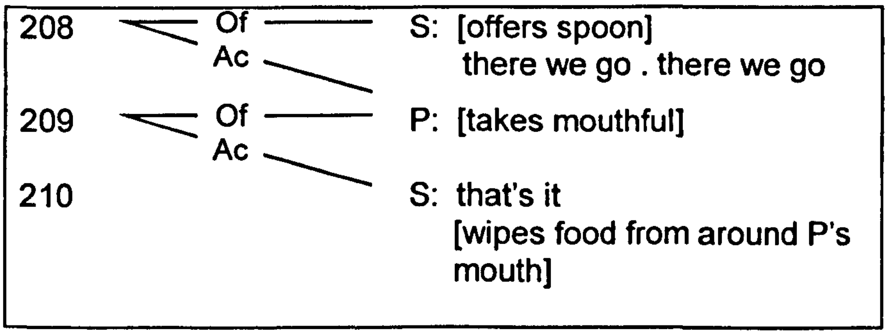
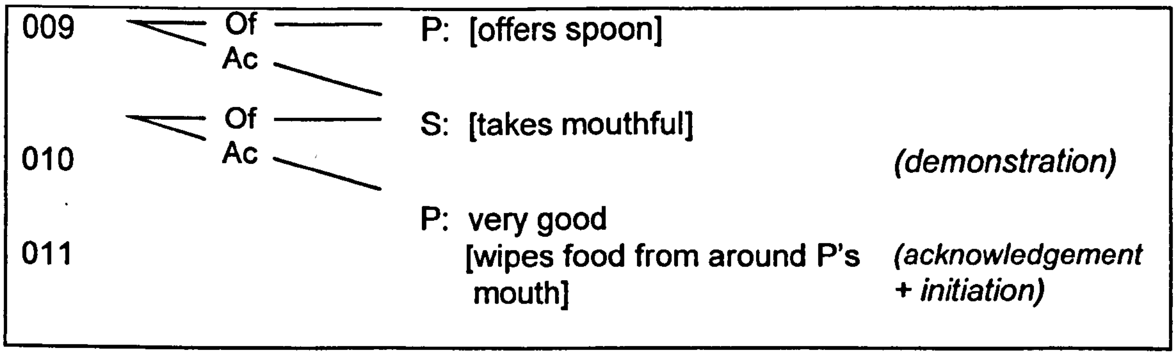


Figure 4-38. Example of an offer/acceptance, verbal comment and follow-up behaviour sequence (06/B).

When Clark and Schaeffer (1989) applied the model to linguistic data they were able to demonstrate *evidence of understanding* which weakened as the sequence continued (refer back to section 2.3.2). A similar pattern was observed during feeding in figure 4-39.



009 P: [offers spoon]

010 S: [takes mouthful] (demonstration)

011 P: very good [wipes food from around P's mouth] (acknowledgement + initiation)

Figure 4-39. Example of evidence of understanding (03/B).

The first piece of evidence required was from P to show that she understood and accepted S's offer of food. This she did by taking the food from the spoon. This was a *demonstration* of understanding which is rated as the fourth level of evidence by Clark and Schaeffer.

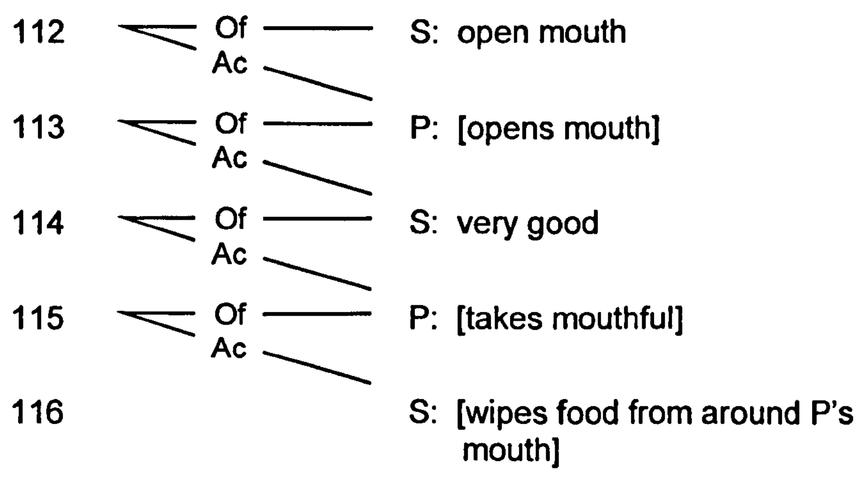
S then needed to show that he had understood P's acceptance of his offer. This he did by a combination of third and second levels. He *acknowledged* her response by saying "very good" and *initiated* the next relevant contribution by wiping her mouth. This particular type of follow up behaviour is discussed in more detail later on in this section.

It could be argued that there are limited contributions that the patient can make in response to an offer of food.

- Acceptance of the food
- Refusal of the food
- Failure to respond

Both acceptance and refusal of food may be considered to be next relevant contributions (in the same way that both agreeing and disagreeing are appropriate next relevant contributions in conversation) or the patient can fail to respond. This has some parallels with Clarke and Schaeffers' evidence of acceptance model which is discussed in Chapter Two (2.3.2) and below (page 213).

There were however instances where P accepted S's offer but did not appear offer a high enough level of evidence. For example, in figure 4-40, P opened her mouth following S's instructions to do so (lines112 - 113). Whether P had understood the request or not, S accepted her response as if she had by acknowledging "very good" (line 114). At the same time S kept the spoon by P's mouth to indicate that her response had not been sufficient, that he had actually meant for her to take the food. P then took the food from the spoon (line 115) and the whole sequence appeared to be collaborative.[5]



112 S: open mouth

113 P: [opens mouth]

114 S: very good

115 P: [takes mouthful]

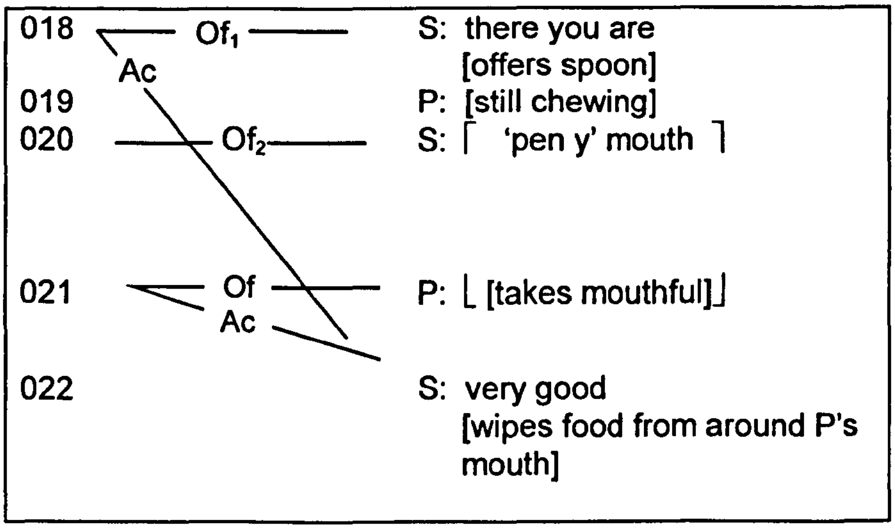
116 S: [wipes food from around P's mouth]

Figure 4-40. Example of an offer/acceptance/offer/acceptance sequence (03/B).

---

[5] The researcher acknowledges that there is a difficulty here which arises from using the term 'acceptance' to mean both the taking of food from the spoon and showing understanding of the offer. This contributed to the disagreement noted in figure 4-33 and will need further consideration.

The example in figure 4-41, is also an interesting one as it shows a misunderstanding on the part of the staff member. In this extract S offered P the spoon (Offer$_1$). P was actually still chewing a previous mouthful and this appeared to be interpreted by S as a refusal (although observers may argue that it was an indication of understanding of an offer being made and an attempt to clear the mouth so that the offer could be accepted).



018 S: there you are
[offers spoon]
019 P: [still chewing]
020 S: ⌈ 'pen y' mouth ⌉
021 P: ⌊ [takes mouthful]⌋
022 S: very good
[wipes food from around P's mouth]

Figure 4-41. Example of a misinterpretation of the patient's response (03/B).

S then made a renewed offer (Offer$_2$) by asking P to open her mouth. Simultaneous with S saying this P took the food being offered, suggesting that she had understood the offer but was not quite ready when it was first made. In this instance it appeared that S misinterpreted P's chewing as a refusal behaviour.

The example in figure 4-42 appeared on first sight to be similar to the above example from 03/B. In fact S either did not accept or misinterpreted the acceptance behaviour of P. Line numbers 185b and 186b have been added for ease of reference. P accepted the first offer made in line 185 by opening her mouth, line 185b. She was unable to take the food however as the spoon was not close enough. S misinterpreted P's behaviour and asked her to do what she was already doing when he made the second offer in line 186. What enabled P to take the food was that simultaneous with the second offer S moved the spoon closer to P's mouth. The actual acceptance of the offer made in line 185 did not therefore take place until line 187.

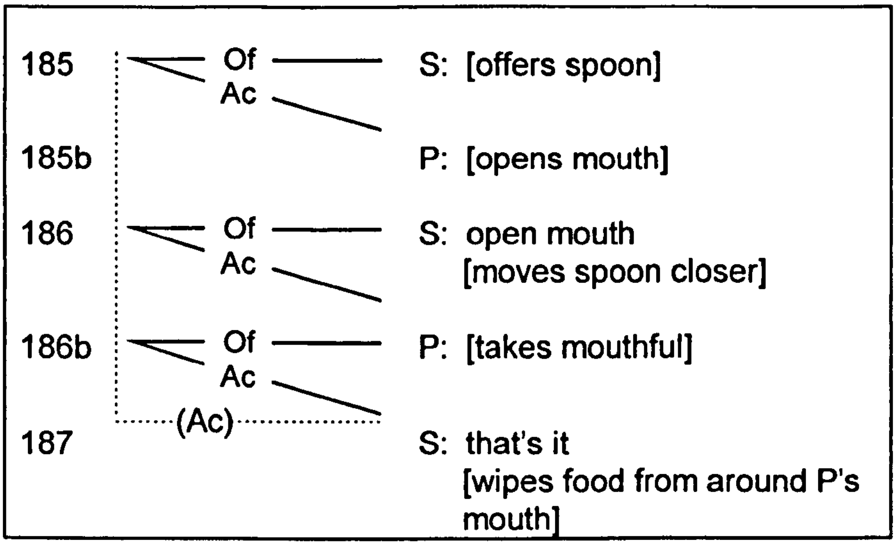


Figure 4-42. Example of a misinterpretation of the acceptance phase (06/B).

Whilst contribution trees are a useful means of representing and discussing the data, it is probably easier to discuss feeding in terms of adjacency pairs. Feeding has a specific, predetermined first and second part pair in that it has to involve an offer of food and an acceptance or refusal of the food. Each of the last three examples contained such an adjacency pair which was then followed by a related utterance or behaviour. From now on these adjacency pairs will be discussed, rather than presentation and acceptance phases.

The four most common sequences have already been represented above, those of offer/acceptance (figure 4-35), offer/acceptance plus comment (figure 4-36), offer/acceptance plus follow-up (figure 4-37) and offer/acceptance plus comment plus follow-up (figure 4-38). Across the three dyads (03/B, 05/B and

06/B) a large variety of different sequence structures could be identified. Each consisted of at least one adjacency pair. Examples of each of these are summarised in table 4-49.

Type of sequence	Number of Examples			Total
Dyad	03/B	05/B	06/B	
offer/accept (A)	8	9	0	**17**
offer/accept+comment (B)	1	0	5	**6**
offer/accept+follow up (C)	7	10	1	**18**
offer/accept+comment+follow up (D)	3	0	1	**4**
offer/refuse (E)	0	0	1	**1**
offer/refuse+comment (F)	0	0	1	**1**
offer/refuse+offer/refuse (G)	0	0	1	**1**
offer/refuse+offer/accept (H)	2	0	0	**2**
offer/refuse+offer/accept+comment (I)	0	0	1	**1**
offer/refuse+offer/accept+follow up (J)	2	3	0	**5**
offer/(refuse/offer)/accept+comment + follow up (K)	1	0	0	**1**
offer/Ø+offer/accept (L)	1	0	0	**1**
offer/Ø+offer/accept+comment (M)	0	1	1	**2**
offer/Ø+offer/accept+follow up (N)	1	0	0	**1**
offer/Ø+offer/accept+comment+follow up (O)	1	0	2	**3**
offer/accept+offer/accept+follow up (P)	1	0	0	**1**
offer/refuse+offer/accept+offer/accept + follow up (Q)	1	0	0	**1**
offer/accept+offer/accept+comment + follow up (R)	0	0	1	**1**
offer/refuse+offer/accept+comment+ (follow up?) (S)	0	0	1	**1**
Total	**29**	**23**	**16**	**68**

Table 4-49. Different types and numbers of feeding sequences identified.

It is clear that the vast majority of the 68 sequences involved immediate acceptance of the food (45) with a further 20 resulting in acceptance even if there was initial refusal or failure to respond. Only 3 of the 68 feeding offers resulted in refusal.

Follow up behaviours such as scraping food from around the patient's mouth are frequently observed during feeding. Even when there was no food to remove members of staff were observed to scrape the spoon round the patient's mouth. This did not appear to serve any function until Clark and Schaeffers' (1989) *strength of evidence principal* was examined. The behaviour appeared to be a means by which the members of staff could acknowledge the patient's acceptance. In this way the behaviour could be seen as affirmation of the patient's contribution to the feeding sequence.

There were a number of sequences where neither acceptance nor refusal behaviours were evident. Within the transcripts these instances are marked as "no immediate response" and represented by a Ø symbol in table 4-49 above (In section 4.5 these instances were grouped with refused offers). The patients appeared to be neither refusing nor accepting an offer and it was considered whether they may have missed the presentation phase i.e. not noticed that the spoon was being offered to them.[6]

---

[6] The sequences identified in table 4-49 each refer to a single offer of a spoonful of food or mouthful of drink. Therefore in figure 4-40 the first part of the sequence was the member of staff requesting the patient to open her mouth and the patient responding. The second part of the sequence entailed the member of staff acknowledging the behaviour and patient actually taking the food from the spoon. The member of staff did not move the spoon or make a second separate offer. The exchange was therefore classified as one offer sequence containing two offer components.

This is different to the example given in figure 4-42 where the patient was unable to take the food from the spoon as the food was too far away. This sequence was analysed as offer/acceptance (A) for the patient opening her mouth in response to the offer, and then a separate offer/acceptance+comment+follow up (D) when the member of staff moved the spoon closer to the patient. This behaviour was seen as a separate offer in recognition that the patient had been unable to take the food from the first offer.

Clark and Schaeffer (1989) discussed four states of understanding in their model, rated from weakest to strongest:

- *State 0* in which the second participant does not notice the presentation phase of the first participant;
- *State 1* in which the second participant notices that the first participant has made a presentation phase but is not in state 2;
- *State 2* in which the second participant correctly hears the first participant's presentation phase but is not in state 3; and
- *State 3* in which the second participant understands the first participant's presentation phase.

It could be argued that states 1 and 2 are not relevant to feeding as there is not an equivalent behavioural response. States 0 and 3 are however relevant. In state 3 the patient may either accept or refuse the offer whilst state 0 may explain why the patients sometimes did not respond, such as the example in figure 4-43.

048	S:	[offers spoon]
	P:	[no immediate response]
	S:	[keeps spoon by P's mouth]
	P:	[takes mouthful]

Figure 4-43. Example of an offer/failure to respond/offer/acceptance sequence (03/B).

046	S:	[offers spoon]
	P:	[pulls head away]
	S:	[keeps spoon by P's mouth]
047	P:	[takes mouthful]

Figure 4-44. Example of an offer/refusal followed by continuation of the offer sequence (03/B).

S continued to offer the spoon to P even though she had not responded to the offer immediately. Each time this type of sequence occurred the member of staff continued to offer the food and on each occasion the patient accepted it.

In the majority of cases where refusal behaviours were seen the member of staff likewise either continued with the offer or made a new offer, as in the examples in figures 4-44 and 4-45.

071	S:	[offers spoon] just taste it
	P:	[turns head away]
072	S:	just taste
	P:	[takes mouthful]
	S:	that's it

Figure 4-45. Example of an offer/refusal followed by new offer sequence (06/B).

Neither member of staff in these two examples accepted P's refusal behaviour. In the first extract, S kept the spoon by P's mouth in a repeat of the offer whilst in the second extract S made a new offer. In both instances P accepted the offers and the feeding process was achieved.

A alternative analysis of the above observations is that neither member of staff interpreted the behaviours of the patients to be refusal behaviours. A reliability study examining the interpretation of behaviours by the members of staff themselves would have been useful at this stage.

The researcher had not provided clear guidance as to what constituted a failure to respond and what was a delayed acceptance, yet both observers had reached agreement as to when the patient had refused the food and when there had been no immediate response. To explore this a measurement was taken of the time between the spoon reaching the patients' mouth and the food either being accepted or being withdrawn again. The results are shown in table 4-50. The values from the three dyads were then combined, as represented in Figure 4-46.

Staff/patient dyad	Acceptance	No immediate response (Ø)	Refusal
03/B	Range 0.6 -2.13 seconds (n=21)	Range 1.57-1.98 seconds (n=3)	Range 2.20-4.76 seconds (n=5)
05/B	Range 1.28-2.78 seconds (n=19)	2.92 seconds (n=1)	Range 3.24-3.69 seconds (n=3)
06/B	Range 0.88-2.71 seconds (n=9)	Range 2.49-2.69 seconds (n=3)	Range 1.99-3.66 seconds (n=4)

Table 4-50. Length of time between food being offered and accepted/ withdrawn for each coding description.

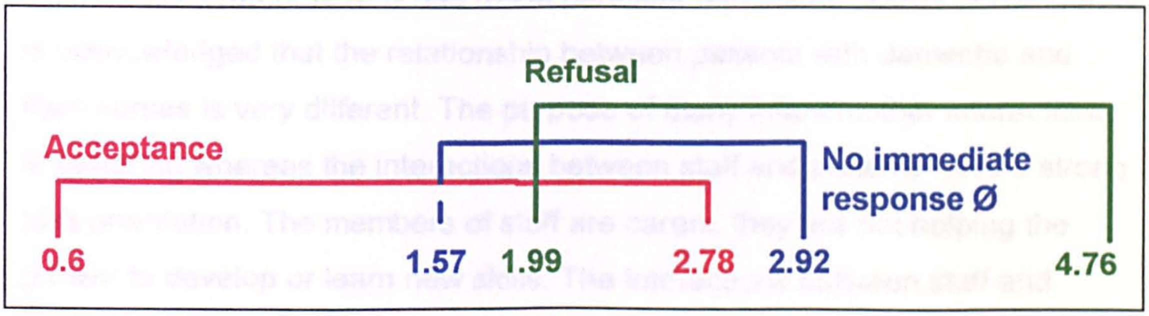


Figure 4-46. Range of pause lengths (in seconds) within each coding description.

There was a relatively clear distinction between the length of pause in each of refusal and acceptance codes. Refusal behaviours did not occur before 1.99 seconds into the offer and acceptance behaviours were not observed after 2.78 seconds into the offer. The two codes do overlap with each other and also with the offers coded as receiving no response.

All of those coded as acceptance contained an acceptance behaviour and all of those coded as refusal contained a refusal behaviour. It is unclear whether the members of staff prolonged the offer when the patient exhibited refusal behaviour or whether a prolonged offer resulted in refusal behaviour. Those offers to which there was no observed response fall in the middle of the other two categories where all three codes overlap. Were such offers held long enough to ascertain that an acceptance would not be made, but withdrawn before a refusal behaviour was elicited? This would be an interesting area for further study.

The feeding partnership is the result of collaboration between the members of staff and the patients. Feeding is a synchronised activity which relies on the co-operation of both parties.

Whilst the literature review has made parallels with infant-mother behaviour, it is acknowledged that the relationship between patients with dementia and their nurses is very different. The purpose of many infant mother interactions is nurturing whereas the interactions between staff and patients have a strong task orientation. The members of staff are carers, they are not helping the patient to develop or learn new skills. The interactions between staff and patients may take place on a very simple level but unlike infants, patients with dementia may be more difficult to relate to.

Clark and Schaeffers' contribution to discourse model (1989) which had been used to examine linguistic exchanges was also used to examine the sequences of feeding. What had been thought of as a very simple feeding adjacency pair of *offer* and *acceptance* was shown to be far more complex. Follow up behaviours and comments were observed, as were breakdown and repairs to the offer sequence.

Critique:

It must be remembered that the theory being applied to feeding here was actually designed for the discussion of conversational data. The framework does however provide a useful structure to examine feeding exchanges. The turns of feeding are pre-determined unlike conversation and so there is less scope for different exchange types. Further exploration of feeding exchanges is proposed.

Summary of findings:

The same model as Clark and Schaeffer (1989) used to examine linguistic behaviour was used to examine feeding sequences. The model enabled the feeding sequences to be isolated and identified. A sequence could be seen to be more than just an offer and acceptance of food, more of a collaborative process with the patient deciding whether feeding would take place or not. Sequences ranged from simple offer and acceptance, to complex follow up comments and behaviours.

4.7. Summary of research questions.

Each of the research questions have been examined and discussed. A summary of the findings is given in table 4-51 (pages 219-221). Conclusions are drawn in Chapter Five.

<table>
<tr><th colspan="2">Question 1:
What are the identified differences in staff-patient interaction over the twelve dyads?</th></tr>
<tr><td>Hypothesis 1.1: There will be a difference in the amount of speech used by each member of staff which is not dependent on which patient they are talking to.</td><td>One member of staff interacted with patients far more than the other two. He was noted to use many more utterances over the course of a meal, and to have a much faster speech rate.</td></tr>
<tr><td>Hypothesis 1.2: There will be a difference observed in the type of utterances used by each member of staff.</td><td>One member of staff used more utterances that were not directed to the patients and a great number of non-related incidental ones. He also used fewer preparatory phrases and therefore did not mark where feeding was about to take place.</td></tr>
<tr><th colspan="2">Question 2:
What patterns of normal conversation can be identified in the interactions between members of staff and patients?</th></tr>
<tr><td colspan="2">Patients were observed to have what appeared to be turns. Evidence was found of both vocalisations and non-verbal behaviours being used to complete adjacency pairs.</td></tr>
<tr><th colspan="2">Question 3:
How are patients able to indicate an understanding of it being their turn?</th></tr>
<tr><td colspan="2">The patients' apparent turn taking was actually preserved by the member of staff attributing meaning to the minimal vocalisations and behaviours. They provided scaffolding in which the patients' behaviours could be interpreted as meaningful contributions. In doing so the members of staff preserved the shape of the interaction.</td></tr>
</table>

<table>
<tr><td colspan="2">Question 4:
What components of normal greeting and closing sequences can be identified in the interaction of staff members and patients?</td></tr>
<tr><td colspan="2">Elements of both greetings and closings could be identified. Greetings were more of a re-engagement than an initial engagement. Closings were used to end the activity rather than the contact.</td></tr>
<tr><td colspan="2">Question 5:
How does the patients' engagement status change when the members of staff begin to interact with them?</td></tr>
<tr><td colspan="2">Limited change in engagement was observed but two patients demonstrated shifts from self-neutral to both object and person engagement. Patients were displaying self-neutral engagement when feeding commenced.</td></tr>
<tr><td colspan="2">Question 6:
How do members of staff attempt to elicit engagement from the patients?</td></tr>
<tr><td colspan="2">A range of behaviours were observed such as orientation toward the patient, attempts to make eye contact and touch.</td></tr>
<tr><td colspan="2">Question 7:
What differences can be measured in the way the meals are fed and in feeding success?</td></tr>
<tr><td><u>Hypothesis 7.1</u>: It will be possible to identify differences in the amount of food fed to each patient, influenced by the members of staff.</td><td>Significant differences were found in the amount of food fed to each patient. One member of staff was found to have fed significantly fewer spoonfuls and have a much slower feeding rate.</td></tr>
<tr><td><u>Hypothesis 7.2</u>: It will be possible to identify feeding success from measurements of meal length and the amount of food consumed.</td><td>Neither quantity of food consumed or length of meal were sufficient to indicate feeding success. Feeding rate and whether meal phases were completed or not were more useful measurements.</td></tr>
</table>

Question 8: How do patients display a preference for sweet food?
Preference for sweet food was demonstrated by fewer refusal behaviours and an increase in feeding rate during the dessert phase.
Question 9: What are the antecedent behaviours to staff members giving the patients a drink?
Antecedents were identified in just over half of the cases. Behaviours were found to be common in all dyads but were responded to differently by one member of staff as compared to his colleagues.

Table 4-51. Research questions, hypotheses and summary of the findings.

In addition to the above research questions the researcher carried out a further qualitative study to examine feeding sequences. Clarke and Schaeffers' (1989) model of conversation was applied to the video data which enabled a more detailed analysis of the turns of feeding.

The following chapter returns to the summary model for the dysphagia service outlined in Chapter One and applies these findings to it. The feeding partnership that exists between members of staff and their patients is discussed at length as the model is reconfigured.

Chapter Five

Chapter Five

Discussion

This discussion chapter is presented in seven sections:

1. The first section re-caps the problem situation and outlines the summary model presented in Chapter One. The interface between the components of the model are also discussed.
2. The second section examines the staff-patient partnership in detail and introduces the first stage of a reconfigured model, where this relationship is central.
3. The findings of the study are applied to the first stage of the reconfigured model in the next section.
4. The fourth section introduces the second stage of the model reconfiguration and examines implications of the findings for speech and language therapists.
5. A third stage of the reconfiguration of the model is then added in the next section, resulting in a comprehensive model for the dysphagia service.
6. Areas for further exploration and scope for future research are then identified.
7. Current practices are challenged in the final section.

5.1. Re-cap of problem situation:

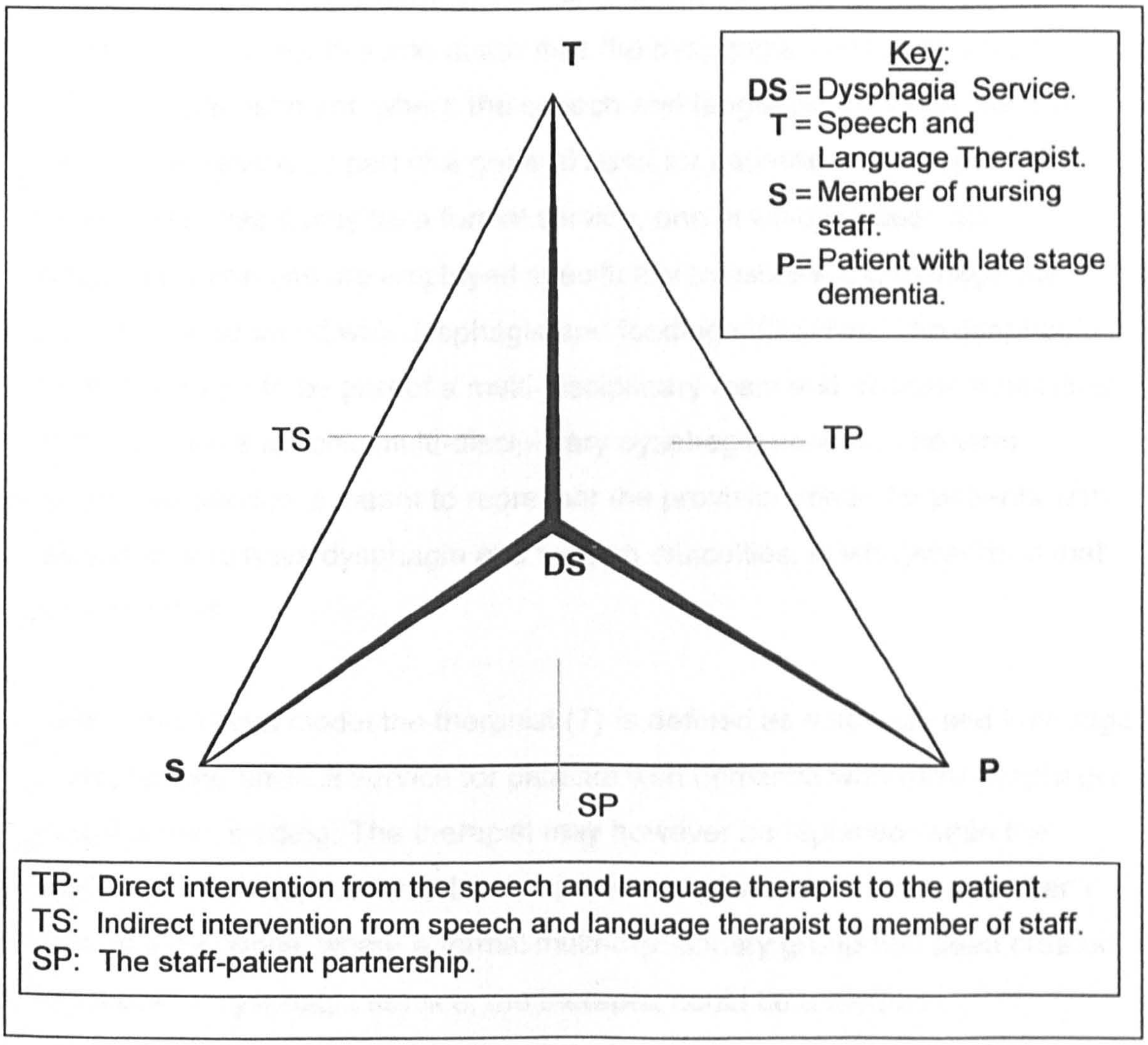
A number of methods have been utilised in this study, to explore the relationship between the member of staff and the patient during feeding. In Chapter One the researcher presented a summary model for the dysphagia service offered to patients with late stage dementia. For ease of reference this model is reiterated in figure 5-1. The glossary of terms is also reiterated in table 5-1.

Term	Definition
Pyramid.	The 3 dimensional shape of the model.
Apex.	The top point of the pyramid.
Components.	The corner points of the pyramid.
Faces.	The three solid sides rising to meet at the apex of the pyramid.
Base.	The solid bottom of the model comprising of the three components and their contribution to the apex.

Table 5-1 Glossary of terms for model structure.

The base of the model has been added to the glossary. This was not discussed in Chapter One but will be introduced in the course of this chapter.

The model is pyramidal in shape with three faces. It is three dimensional with the apex coming out of the page toward the reader. The three corner components contribute to the element represented at the apex of the model. Letters are used to represent the main element of the model and the components.



Key:
DS = Dysphagia Service.
T = Speech and Language Therapist.
S = Member of nursing staff.
P= Patient with late stage dementia.

TP: Direct intervention from the speech and language therapist to the patient.
TS: Indirect intervention from speech and language therapist to member of staff.
SP: The staff-patient partnership.

Figure 5-1. Model of dysphagia service for patients with late stage dementia.

The faces of the model are formed from two adjacent components rising up to the apex point. Letters are used to label these and a more detailed description provided in the captions underneath the model. The base is formed from the three components and their contribution to the apex element.

The theoretical structure of the model is discussed in more detail below.

5.1.1 The dysphagia service:

The dysphagia service (DS) is a global term encompassing the speech and language therapist (T), members of nursing staff (S) and the patients with late stage dementia (P). In some authorities the dysphagia service may be an informal establishment, where the speech and language therapist offers a dysphagia service as part of a general remit for patients with dementia. In other authorities it may be a formal service, one in which speech and language therapists are employed specifically to assess and manage the problems associated with dysphagia and feeding difficulties. The dysphagia service is likely to be part of a multi-disciplinary team and in some authorities there may be a specific multi-disciplinary dysphagia service. The term dysphagia service is meant to represent the provision made for patients with dementia who have dysphagia and feeding difficulties, in whatever form that service takes.

Within the above model the therapist (T) is defined as a speech and language therapist who offers a service for patients with dementia who have dysphagia or difficulties feeding. The therapist may however be replaced within the model by any other therapist involved in feeding issues. In the researcher's clinical experience, where a formal multi-disciplinary group has been created to provide a dysphagia service, the therapist could be a dietitian, physiotherapist, occupational therapist, dentist, nurse specialist or tissue viability advisor. The model could be applied to any professional involved directly and indirectly with patients with dementia and the nursing team caring for them. The definitions of each of the faces of the model would however differ to reflect the specialist knowledge and experience each profession brings to the dysphagia service. The above model must therefore be viewed as specific to the role of the speech and language therapist in providing a dysphagia service.

The member of nursing staff (S) is often the primary feeder for patients with late stage dementia who are cared for in hospital. Nurses with a wide range of training, experience and qualifications are involved in feeding, from student nurses, through auxiliary nurses, to the senior ward managers. In authorities where volunteers are recruited to feed patients or where family members are encouraged to feed patients, the same model can be used with the volunteers or family members replacing the members of nursing staff. The therapist will still be involved in training and advising the volunteers or family members, for the best interests of the patient. The feeder is responsible for ensuring that the patient receives adequate nutrition and that the food ingested by the patient is appropriate for their needs.

The efforts of the therapist and the feeder are for the benefit of the patient with late stage dementia (P). A care planning model would place the patient at the centre of the model with others on the outside feeding in, contributing to the care of the patient. A social model would similarly place the patient at the centre, but with an active rather than passive role within the model. The patient would still be able to function without the other components of the model. Patients who have dementia become so dependent upon other people that placing them at the centre of a social model would not reflect what happens within the environment being examined. Likewise, placing the patient within the centre of a care planning model does not reflect the role of the patient within activities such as feeding.

This model represents three way input to the dysphagia service and it is therefore appropriate to place the patient at a point equal with the therapist and member of staff. However, the patient is unable to contribute in an independent way. The intervention of the speech and language therapist has little influence on what the patient does and by the later stages of the dementia process such patients are unable to modify or monitor their own behaviour. Many may be unaware even that they are being fed, may have 'forgotten' how to eat, or may not recognise food put before them. Such patients are totally dependent, and by virtue of this dependency would be unable to survive without the support provided by the members of nursing staff and therapy services. The model therefore illustrates how the members of nursing staff and therapists involved 'prop up' the patient. Without these other two components of the model the patient would be unable to receive life sustaining intervention.

In a service provision model, the patient may be viewed as the consumer, the member of staff as the provider and the speech and language therapist as the mediator of quality assurance. Any changes made to the individuals in the model will change the roles and relationships between the individuals.

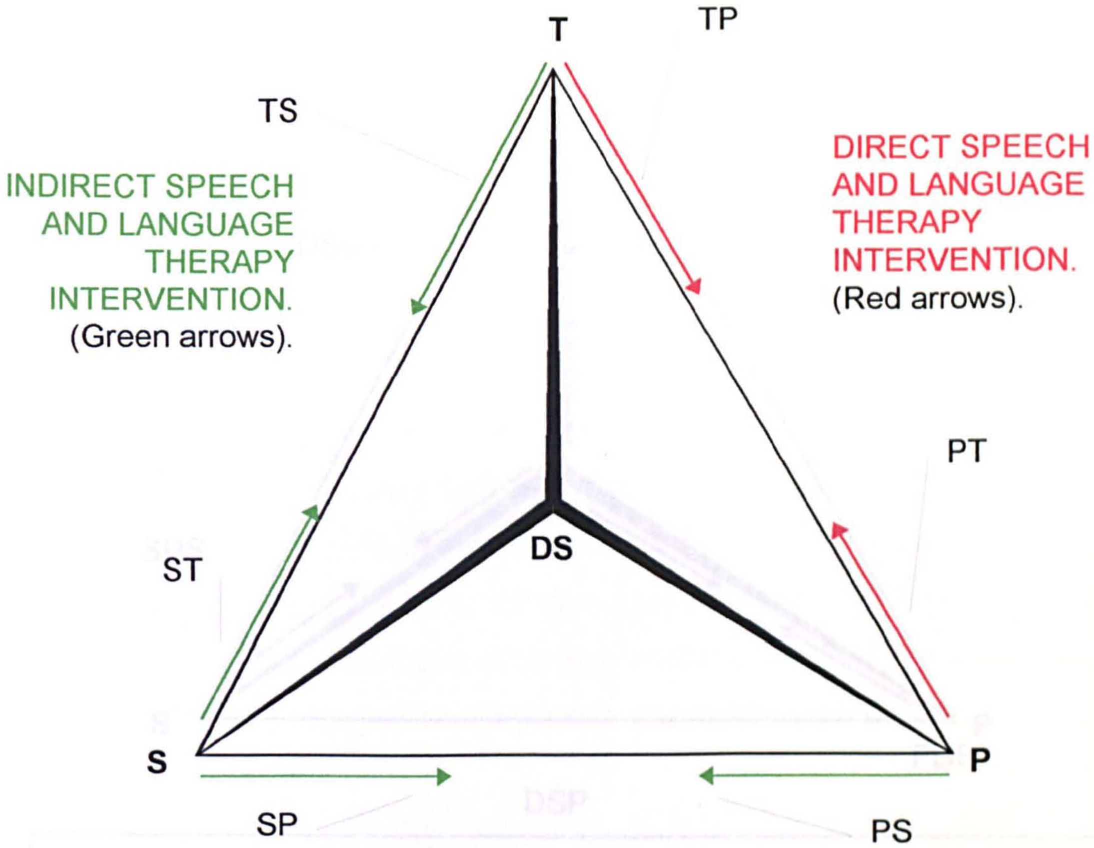
5.1.2 The faces of the model:

The faces of the model are formed from two components, rising to the apex point. Having examined the three components of the pyramidal model, the faces are now explored. The face representing therapist and the patient (T-P) has been discussed in Chapter One. This face of the model represents the direct intervention provided by the speech and language therapist. Such intervention includes assessment, data collection, data analysis, therapy and clinical decision making. This face might represent dynamic assessment such as videofluoroscopy, swallowing rehabilitation, or swallow adaptation. But in a service for people with late stage dementia it mostly represents clinical assessment and judgements based on bedside examinations. There is very little that a therapist may do to directly influence the behaviour of the patient. It is for this reason that the face representing the therapist and the member of staff (T-S) is so crucial. The therapist may be able to influence what happens to the patient even though it is not possible to influence what the patient does.

The model therefore shows two distinct routes by which the speech and language therapist may access and intervene with the patient. The direct route is shown between the therapist and the patient, whilst the indirect route is shown between the therapist and the member of staff and between the member of staff and the patient. This indirect route may be described as a *transplant model*, where the professional hands over skills and is in charge of what information the member of nursing staff receives (Law, 2001). Much of the intervention provided for the patient is not related to influencing what the patient does but is concerned with adapting the meal time environment around them, whether that be the member of staff feeding them, the food, or the environment etc.

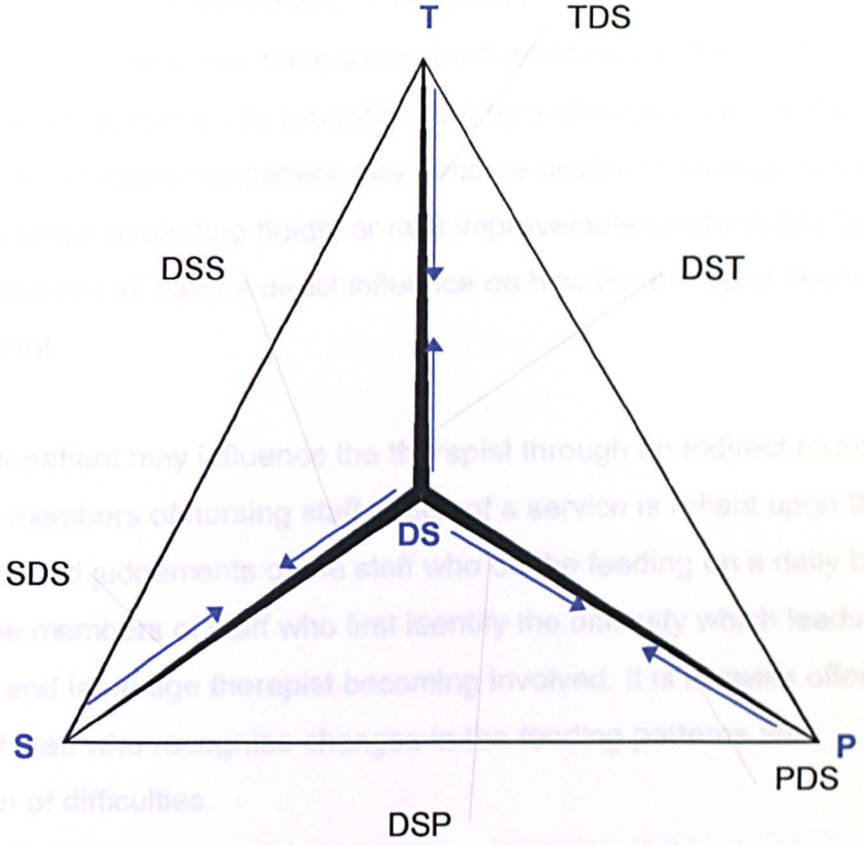
The routes shown in the model are not however uni-directional as transactional intervention requires negotiation between each contributor. For ease of access the model is represented from two perspectives, the activities at the base level and the activities at the apex level. Directional arrows have been added to represent this transaction, as in figure 5-2 and 5-3 below.

The arrows represent the bi-directional influence between the therapist and patient (TP; PT), therapist and member of staff (TS; ST) and member of staff and patient (SP; PS).



TP: Direct intervention - assessment, data collection, data analysis.
PT: Changes in presentation, response to intervention.
TS: Indirect intervention - training, advice, guidelines, programmes.
ST: Changes in staff member's skills.
SP: Observation of patient, clinical judgements, interpretation of behaviours, meeting patient's needs, enhancing patient's well-being.
PS: Communicative attempts, needs, nutritional requirements, well-being.

Figure 5-2. Stage 1, base level: contributions of activities to the dysphagia service.



TDS: Contribution to central knowledge base, experiences, feedback into MDT.
DST: Agreed and adapted policies, procedures. MDT shared responsibility, joint decision making, support and advice.
DSS: Agreed and adapted policies, procedures. MDT shared responsibility, joint decision making, support and advice.
SDS: Contribution to central knowledge base, experiences, feedback into MDT.
PDS: Indirect influence via the nursing staff and therapies, and direct influence of advocates.
DSP: Ensures patient safety, satisfaction, nutrition, comfort and well-being.

Figure 5-3. Stage 1, apex level: contributions of activities to the dysphagia service.

Both the member of nursing staff and the therapist are influenced by the behaviours and needs of the patient. The model is therefore reciprocal, and is multi-routed. The patient may have a direct influence on the therapist and such an influence is commonly brought about by a change in presentation in the patient. For example the patient may become unable to manage a specific texture, may begin aspirating fluids, or may improve/deteriorate in any facet of feeding. These will all have a direct influence on how the therapist intervenes with the patient.

Likewise the patient may influence the therapist through an indirect route, through the members of nursing staff. Much of a service is reliant upon the observations and judgements of the staff who do the feeding on a daily basis. It is often the members of staff who first identify the difficulty which leads to the speech and language therapist becoming involved. It is likewise often the members of staff who recognise changes in the feeding patterns and presentation of difficulties.

This information is fed back to the therapist and will often trigger further direct assessment of the patient. It is this interactive system that defines the dysphagia service, where the service is derived from the activities that take place within it.

The routes of intervention take place at two different levels, that of individuals (base level, as shown above), and that of the dysphagia service (apex level, as shown in figure 5-3).

The dysphagia service could be viewed as a philosophy of care and as such may include formal policies and procedures. These will be in place for the benefit of the patient but also to provide guidance to the therapist and members of nursing staff. The experience and knowledge of the therapist and member of staff is fed into the dysphagia service. The dysphagia service could be viewed as a connection with the multi disciplinary team, or a multi disciplinary team in its own right. As such it may be considered to be a central knowledge base, a joint decision making process and a shared responsibility. It is therefore a conjuncture of different disciplines, whether that be just the therapist and the member of nursing staff, or whether it involves the whole multi disciplinary team. In essence, the dysphagia service will expand through the input of the therapist and nursing staff, and will likewise offer support for the therapist and the member of nursing staff.

The patient may be unable to have direct influence into the dysphagia service, but will have indirect influence via the responses evoked in both the nursing staff and the therapist who then act as advocates. Other advocates, such as family members or volunteers, may also contribute to the knowledge base of the dysphagia service on the patient's behalf.

So far this chapter has discussed the components and activities that take place within the dysphagia service, specifically:

- the therapist, the member of nursing staff and the patient as insular components of the dysphagia service;
- the activities between the therapist and the patient (direct intervention) and between the therapist and member of staff (indirect intervention), and the benefits of this multi-directional route for the patient; and
- the contributions of the therapist, staff member and the patient to the dysphagia service.

As yet the relationship between the nursing staff and the patient, the staff-patient partnership, has not been discussed in detail. The model as currently proposed is inadequate to represent the complex relationship that exists between nursing staff and their patients. With this in mind the researcher has extended the model into three stages. The first of these examines the staff-patient partnership in more detail, the second examines the role of the therapist and the final stage combines the two in a new model for the dysphagia service. This is presented and discussed in the following sections.

Summary of section:

The summary model proposed in Chapter One to define the dysphagia service has been reiterated. The interface between the speech and language therapist, the member of nursing staff and the patient has been discussed. The model is now extended, resulting in a new model for the dysphagia service.

5.2 Stage one of the model reconfiguration: the staff-patient partnership.

The problem arises in trying to describe the relationship between the member of staff and the patient. As identified above, there is a direct relationship between the member of staff and patient in terms of a service provision model. The member of staff provides a service of which the patient is the consumer. It seems too simplistic however to assume that the one face depicting this partnership in the above model is sufficient. Rather there are a number of layers associated with this relationship. The nursing staff need to consider a number of variables both separately and simultaneously. For example, they need to find a balance between promoting nutritional intake whilst preserving patient autonomy and choices, and they need to make time to interact with the patient in a way that is meaningful to the patient and yet carry out a number of caring activities under time restraints.

The staff-patient partnership may be defined as the combination of two very different aspects. On the one hand the member of nursing staff is a paid employee, recruited for the specific task of caring for patients with dementia. On the other hand there is the relationship that develops between the member of staff and the patient over time. The crucial components of this latter relationship are familiarity, experience, expectations and knowledge base. The patient needs to be able to trust the member of staff to interact with them in an appropriate way. Familiarity is often the key to a member of staff understanding some of the vague communicative cues that a patient may try to make. The member of staff also needs to have trust in his own instincts as this will result in continuity of responses. Continuity is important if a patient is to realise that a particular behaviour will be responded to in a particular way.

The importance of a meaningful nurse-patient partnership is demonstrated in the videos of Patient C. Patient C was observed to have had the most offers of food made to her and to have made the highest number of refusals. Also, she was calculated to have the longest mean meal length and the lowest mean feeding rate. Such measurements indicate low feeding success. However, patient C was frequently fed by a family member who visited on a very regular basis, and so it was often not necessary for nursing staff to feed her. This may have contributed to a lack of success in the nursing staff establishing a strong relationship with the patient. The absence of such a partnership could contribute to staff feeling unsure of the patient's communicative cues and less confident of attributing meaning to them (Athlin and Norberg, 1987).

In addition, Patient C had a primary diagnosis of a chronic Schizo-affective disorder prior to the secondary diagnosis of dementia. It is known that such disorders can affect social functioning, even at very basic communicative levels (Henton *et al.*, 2001). It is therefore reasonable to suppose that patient C's interaction could be affected even at the very minimal level being examined. Evidence for this supposition comes from studies examining infants diagnosed with disorders such as autism, Down's syndrome or childhood schizophrenia. Such children have been shown to have limited basic interaction, even at the pre-linguistic level of communication being paralleled in this project (Berger and Cunningham, 1981; Bierberich and Morgan, 1998; Clegg *et al.*, 1999; Willemsen-Swinkels *et al.*, 1998).

The member of staff has a duty of care which includes feeding the patient, whilst the patient has needs such as hunger and thirst which need attending to. This contributes to the physical health of the patient by ensuring adequate nutritional intake and reduction in risks associated with swallowing difficulties. The member of staff needs to be able to understand patients' communication in order to understand their needs, whilst the patient has only a limited communication repertoire which relies on interpretation by the members of staff. The nursing staff's understanding of the patient's personality and background and their familiarity with the patient both aid in interpretation of behaviours, vital to interaction. It must be remembered that the patient has complex processing needs as a result of the cognitive impairment associated with dementia. This means that patients will have difficulty coping with conflicting demands, such as the task in hand and the distractions in their immediate environment, talking and eating, eating and listening etc. The member of staff is required to enhance the patient's well-being whilst the patient has a right to expect that well-being will be considered as an integral part of their care. This is summed up in the equation proposed by Kitwood (1990, 1993b);

$$\mathbf{D=P+B+H+NI+SP}$$

where discussing a person with dementia (D) involves consideration of the person's personality (P), biography (B), health (H), neurological impairment (NI) and social psychology (SP).

Using this model as a base the researcher extrapolated the primary areas of focus for feeding. The key components of the nurse patient relationship with regard to feeding (F) were identified as *nutrition* (N), *interaction* (I) and the patient's *well-being* (W).

$$\mathbf{F=N+I+W}$$

Each of these may be seen to belong to larger models pertaining to total nursing intervention. Therefore interaction may be viewed as part of a model of *communication*, nutrition as a model for *health*, and well-being as a model for *quality of life*.

These three components represent three key areas of consideration during intervention - social inclusion, physical health, and psychological health. Nutrition refers to adequate intake of food and fluids in order for the body to function adequately and to prevent health complications such as malnutrition, dehydration, pressure sores, chest infections etc. Well-being is the qualitative component which considers the patient's distress or satisfaction, discomfort or comfort. The term well-being is used to reflect the role of intervention in promoting feelings of comfort or wellness. Interaction relates to the exchanges that take place between the member of staff and the patient. Such exchanges may include speech, verbalisations, vocalisations or non-verbal behaviours, and interpretation and attribution of meaning.

In the first stage of the reconfiguration of the model (figure 5-4) the staff-patient partnership (SP) is placed at the apex of the pyramid with interaction (I), nutrition (N) and well-being (W) as the corner components. This is a reasonable position for the staff-patient partnership to be placed as it has already been discussed how both direct (therapist to patient) and indirect (therapist to member of staff to patient) intervention is required for effective therapy (Purcell *et al.*, 2000). The therapist is therefore not concerned with accessing the patient or the member of staff in isolation.

It is important to stress here that successful feeding should be considered as being a result of maintaining a balance between these three key components. Attempting to address only one or two of these issues within the dysphagia service will not be sufficient.

A synthesis of the different components, feeding, interaction and well-being is required. Whilst the members of staff need to consider each of these components simultaneously, for the purpose of this discussion they are best examined separately.

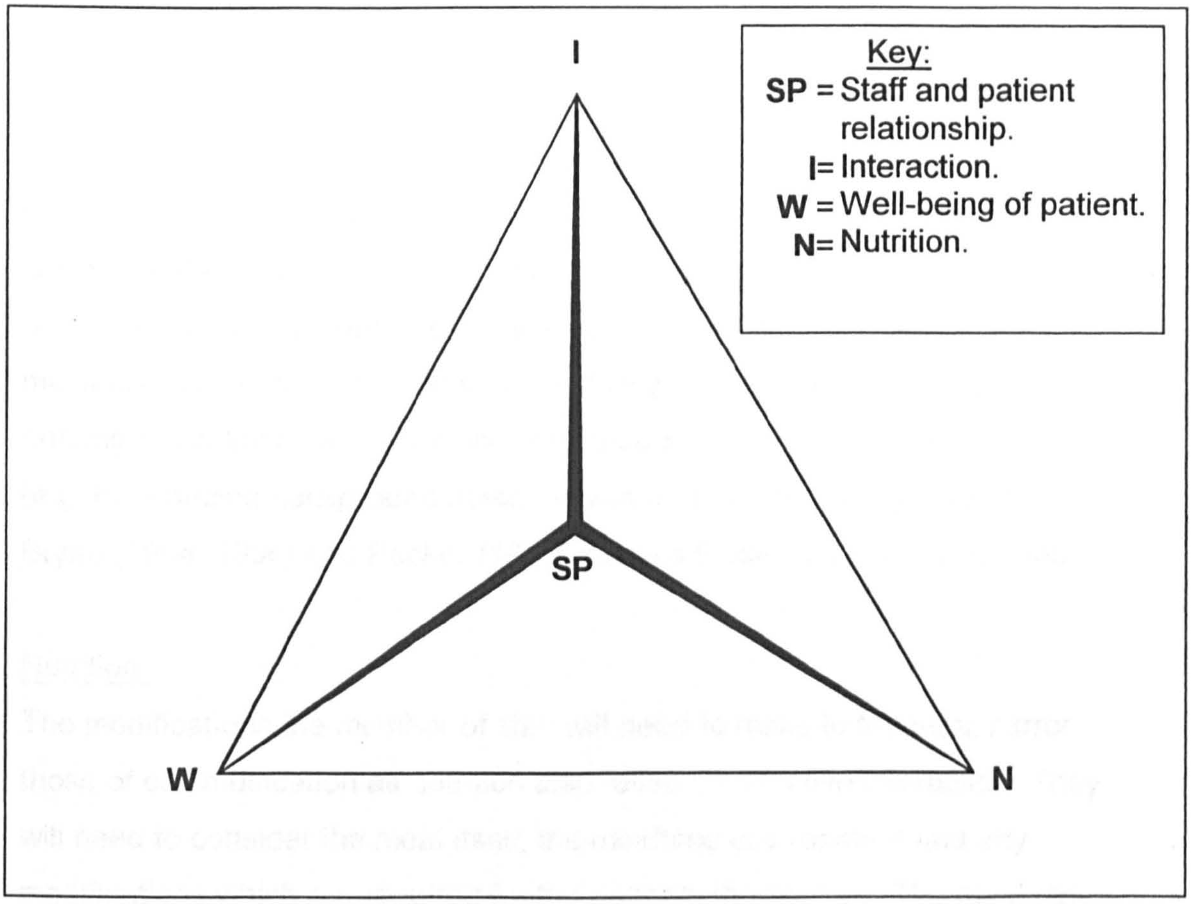


Figure 5-4. Stage one of model reconfiguration - key components of the staff-patient partnership.

The first stage of the model reconfiguration therefore examines the micro level of components within the staff-patient partnership.

Both interaction and nutrition have been discussed at length in earlier chapters. Just the key components of both are therefore discussed below. Well-being has been discussed only with reference to end of life decisions in dementia, in Chapter One. A review of literature pertaining to well-being is therefore offered separately in section 5.2.2.

5.2.1 Interaction and nutrition:

Interaction.

The members of staff have a major role in the interaction of patients with dementia. This is displayed not only in modifications to their own communication, but also the way in which they enable the patients to communicate to the best of their ability. Members of staff need to accommodate the patient's sensory, emotional and linguistic needs, such as manipulating the immediate environment (e.g. by ensuring that the patient's hearing aid is fitted and is working) or manipulating the general environment (e.g. by reducing background noise). Bryan and Maxim (1998), Maxim and Bryan (1994, 1996) and Packer (1999) discuss these issues in more depth.

Nutrition.

The modifications the member of staff will need to make to the meal mirror those of communication as nutrition also relies on effective interaction. They will need to consider the meal itself, the mealtime environment and any modifications which are required for the patients themselves. The meal may be inappropriate for a number of reasons: it may be cold, be something that the patient does not like, not be what the patient ordered, or may be an inappropriate consistency etc. Modification of consistency is probably the most common modification required for patients with dementia. It may be necessary to purée food or to add thickener if there is excess fluid and it may be necessary to thicken drinks. In some cases alternative feeding may be used and then the member of staff will be responsible for operating the feeding system and ensuring that it works well. The patient's position may also need modifying, such as being sat upright for optimum swallowing safety. Such issues are discussed by Hogstel and Robinson (1989), Kolasa *et al.* (1989), Layne (1990), Malone (1996) and Steele *et al.* (1997).

5.2.2 Well-being:

Well-being is the third component of the proposed model, but it has not yet been addressed and nor was it measured in this study. Although attempts have been made to measure well-being there are many problems, not least of which is difficulty agreeing upon its definition. Different people have different views as to what well-being is (Flacker *et al.*, 2001; Haas, 1999), yet practitioners refer to a patient's 'well-being' as if every one had the same concept of what the term means. The Collins dictionary defines well-being as *"the state of being well, happy, or prosperous".* Haas (1999) suggests that well-being is one part of the definition of quality of life, the other concepts being satisfaction with life and functional status. (In terms of the model structure being used in this thesis, quality of life could be seen as an apex with well-being, satisfaction with life and functional status as corner components).

Well-being tends to be discussed most with reference to people who are ill or disabled. Disabled people constitute the largest minority in many countries, yet legislation to prevent discrimination is way behind that for other minority groups. The UK Disability Discrimination Act (HMSO) was only introduced in 1996. The number of disabled people is increasing, primarily due to medical advances which prevent infants dying from premature birth or people dying from injury or disease etc.

An early framework introduced by the WHO (1980) is that of *impairment, disability, handicap and distress* (*ICIDH*), which has been used and utilised by clinicians (Enderby, 1992; Enderby and John, 1997; Enderby and John, 1999; John and Enderby, 2000). *Impairment* describes the loss or abnormality of psychosocial, physiological or anatomical structures or functions. *Disability* describes the consequences of the impairment in relation to performance by the individual. *Handicap* describes the disadvantages experienced by the individual as a result of the impairment and disability, whilst *distress* relates to the individual's personal experience. Recently the WHO (2001) altered the classification to include health domains and health-related domains (*ICIDH-2* or International Classification of Functioning, Disability and Health (ICF)). These domains relate to body functions, structures, activities, participation and the social aspects of disability. Simeonsson *et al.* (2000) provide a detailed comparison of these two systems.

Both systems are complimentary to the ICD-10 (WHO, 1992-1994) and together with the ICD-10 provide information on diagnosis and functioning. Thus two people with the same physical disorder or impairment may experience differing levels of functioning. Enderby relates the distress experienced by an individual to life satisfaction:

> *"Disease is a psychophysiological process which limits a persons coping abilities, and patients who use effective coping strategies report higher subsequent general life satisfaction. Therefore the aim of rehabilitation should be to harness the resources of impaired individuals to attain a satisfactory life by realising achievable goals."*
> (Enderby, 1992, p62).

Studies have shown that measures which do not reflect these anxiety or depressive symptoms inadequately reflect a person's quality of life (Sullivan *et al.*, 2000). For example, people with progressive illness reported impairment in physical and social functioning whilst their pain or emotional adjustment ratings were similar to the general population (Schrag *et al.*, 2000). This suggested a better quality of life than they had been attributed with based on their physical disabilities. Likewise, physical activity and fitness failed to correlate with quality of life scores for people with spinal cord injuries (Manns and Chad, 1999). The Bradford Dementia group (pioneers in the advance of person centred care and Dementia Care Mapping) have developed a well/ill-being profile (WIB) (Bruce, 2000; Kitwood and Bredin,

1992) which demonstrates that relative well-being is independent of the severity of the dementia process (Wey, 2001).

Bio-psycho-social models therefore examine the connections between adaptability, severity of the disability, and experienced helplessness. Such models imply that adapting to the impairment, disability and handicap is the key to enhanced well-being (LaPointe, 1999; Voll, 2001). Mihaylova and Liotchkova (1999) advocate the use of coping strategies to aid "*revitalisation*" of elderly people in geriatric homes. They argue that failing to incorporate such strategies into planning and organisation of everyday activities results in a "*disabled existence*". This adaptation to disability may help explain the *disability paradox* where people with serious and persistent disabilities report high life quality, whilst external observers assume them to have low life quality. Albrecht and Devlieger (1999) suggest that quality of life is dependent on the balance between body, mind and spirit, and a harmonious relationship between the social context and external environment.

The social model portrays the medical model as tending to assume that impairment is *tragic*. The medical model is criticised for questioning whether people would wish to live with particular illnesses or *afflictions*. Judgements about whether a person could or would want to live with illness or disability are usually subjective (made by observers) rather than objective (made by the person himself). Although medicine claims to be value free, Marks (1999) argues that it prejudices against incurable or damaged people.

The care being offered to disabled or ill people is considered to make a large contribution to their well-being. This is particularly so for people with terminal illnesses (Woodrow, 1998). Stewart *et al.* (1999) consider there to be five main concepts to quality of life at the end of life, including patient/family context, structure of care, process of care, satisfaction with care, and quality and length of life. Flacker *et al.* (2001) add the information given to patients, comfort, emotional support, the amount of time spent with patients and symptoms at the end of life to this list.

The social model views disability as a result of an excluding and oppressive social environment rather than an impaired body or mind (Barnes, 1994; Oliver, 1990, 1996). The Social model is core to UK disability studies and focuses on citizenship, rights and the social oppression of disabled people. It advocates that disability is a social product with different societies recognising different norms and therefore different dissimilarities.

> *"... rather than seeing disability as being a consequence of individual differences, it can be understood as a result of perceptions rooted in social practices, which mark out some differences as being abnormal and pathological."* (Marks, 1999, p79).

Playing a role in society, 'citizenship', or a sense of belonging to something larger than self or family is seen by some to be the centre of what constitutes well-being. People who do not contribute to society, such as disabled or older people, are therefore viewed as experiencing a "social death" before their actual death. People who are seen as making a useful contribution and have a high level of personal happiness are seen as valued members of society. People who are dependent or experience high levels of suffering may be viewed as having lives that are *'not worth living'* (Glover, 1990.) Within society there tends to be more focus on what the person is able to achieve rather than their experiences or emotions about what they are doing (Cotter, 2001).

The right to life can often be seen to depend on "personhood" (Teichman, 1996). Such personhood involves the capability of autonomous and independent action (Marks, 1999). A person who is seen to lack the qualities defining personhood will therefore be seen to lack the qualities required for an ideal fit citizen. People are therefore judged as having low quality of life or well-being when they have characteristics which are different from those which are culturally valued.

In much the same way as disability is a social concept, so too are *needs* (Oliver, 1990, 1996). All people have needs. The differentiation lies in the dependency upon those whose needs are met automatically (and therefore have no “needs”) by those who must ask for support (Marks, 1999). There is an assumption that needs can be ascertained objectively and that other people can judge what a person needs. A person may subjectively express their wants or demands but needs are an objective judgement. The very term “needs” implies, helplessness and passivity (Woodhead, 1990).

Within the staff-patient partnership being examined, the well-being of the member of staff is also an important consideration. Many care workers and nursing staff feel undervalued and criticised, to the extent that it is easier to identify faults or things they are not good at than identifying strengths. Packer (2001) stresses the importance of identifying what staff gain from the caring role in order to reduce the risk of co-dependency. Co-dependency attempts to describe how people take on a caring role as a subconscious way of dealing with their own psychological needs (Herrick, 1992; Skynner, 1991). The danger is that well-meaning staff may disempower their patients by becoming unintentional ‘prosecutors’, in order to fulfil their own needs rather than those of the patient. Staff are thought to depersonalise the person they are working with to protect themselves from the anxiety of facing traumatic and upsetting situations. Nursing staff are viewed, and view themselves, as being independent and capable, whilst their patients are dependent and weak (Cotter, 2001).

One major issue within services for people with dementia (and other vulnerable groups at risk of being marginalised) is recruitment and retention. The value accorded to the people with dementia tends to also be accorded to the professionals who work with them.

> *"Even within the prestigious profession of medicine, those doctors working in the area of mental health, learning disability and gerontology (all of which are concerned to a great extent with disabling impairments) tended to be accorded lower status than doctors working within more "glamorous" specialist areas such as surgery, which are not associated with a particular devalued social group."*
> (Marks, 1999, p108).

Well-being can therefore be seen as an important consideration for both the patient and the member of staff. There is a mutually dependent relationship whereby the well-being of one directly influences the well-being of the other.

There is a tendency to polarise social and medical models. For example the disability movement or social model look at barriers to social inclusion whilst the medical model examines the impairment itself. Both perspectives are needed along side each other.

A framework which makes a clearer distinction is that of Priestly (1998) who devised four research paradigms, as shown in table 5-2. Jordan and Bryan (2001) discuss this framework in relation to the clinical work of speech and language therapists. The advantage of this classification over more traditional ones is that it presents models as compatible alternatives. In relation to people with dementia it is important to be clear about where intervention is targeted. The main focus of this project has been to examine the interactions between patients with dementia and nursing staff. Whilst the cause of communication difficulties lies with the patient's impairment (individual materialistic), the solution is aimed at the communicative skills of the nursing staff (social creationist).

	Materialist models	Idealist models
Individual	Individual materialist models: concerned with the functioning of 'impaired bodies'.	Individual idealist models: concerned with the beliefs of disabled and non-disabled people about disability and with disabled people's identities and roles.
Social	Social creationist models: concerned with disabling barriers and material relations of power.	Social contructionist models: concerned with cultural values and representations in relation to disabled people.

Table 5-2. Priestly's disability research paradigms (1998) taken from Jordan and Bryan (2001).

Summary of section:

The summary model proposed in Chapter One has been reconfigured throughout the discussion. In this section the first stage of reconfiguration was introduced, incorporating the key components of the nurse-patient partnership: interaction, nutrition and well-being. The three components of the model have been discussed in detail, either above or in earlier chapters. The findings from the study will now be applied to this first stage of the modified model.

5.3 Applying the findings to the first stage reconfiguration of the model.

The faces of the pyramid can be discussed in terms of the findings from Chapter Four, as labelled in figure 5-5.

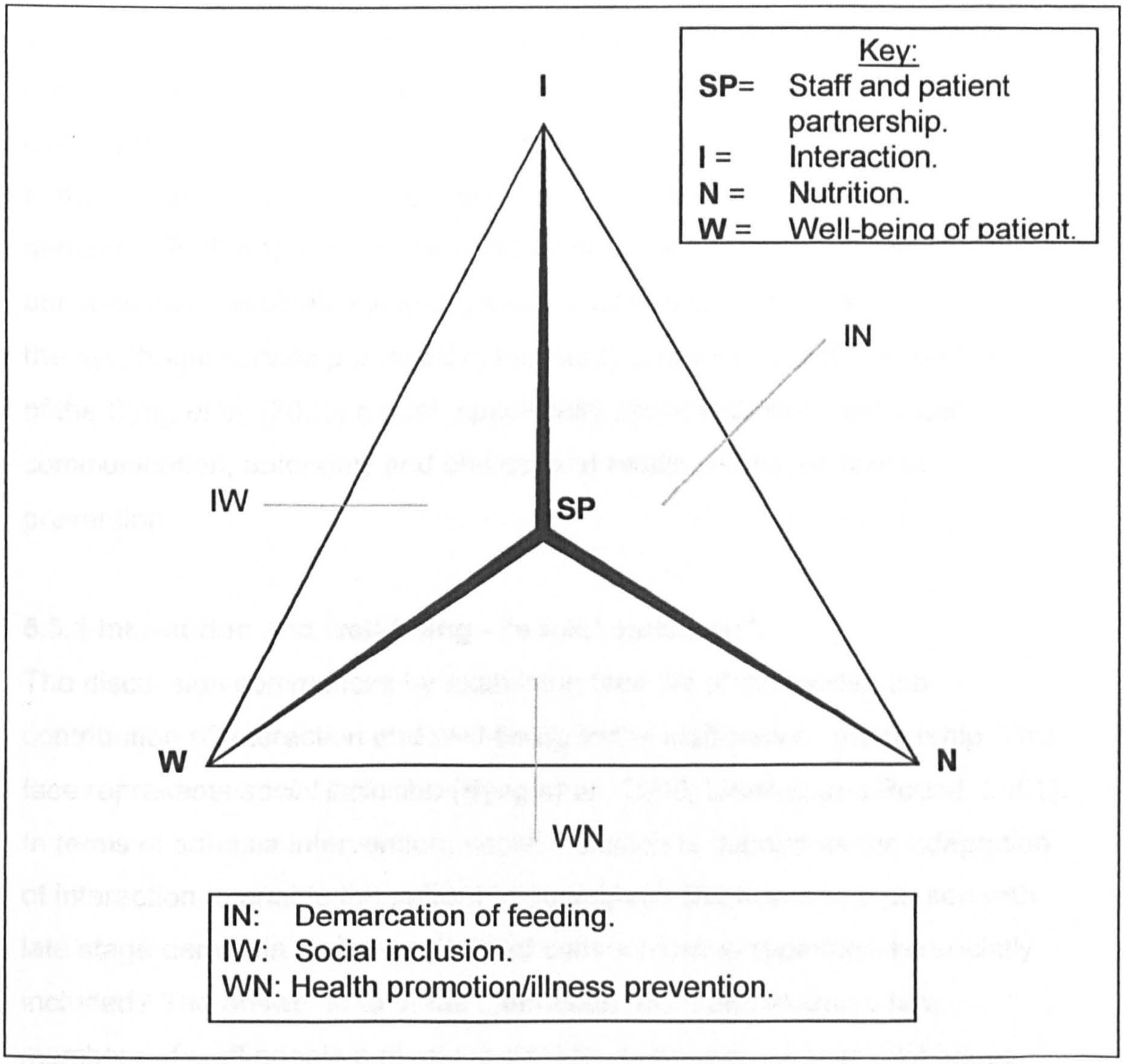


Figure 5-5. Stage one of reconfiguration - faces of the pyramid.

The proposed model may be viewed within a larger framework, such as that of Byng *et al.* (2000), which has been used to plan therapeutic interventions for people with aphasia. Byng *et al.* offer a framework for goals of intervention and mapping of goals onto participation levels. Underpinning this is the therapist's ability to create optimum conditions for interaction and participation, and the importance of working with people in the environment surrounding the patient as well as the patient himself. The person with aphasia is placed at the core of the model which is then built outwards in a series of layers. The layer surrounding the patient represents the immediate social context, the next layer the community and the outer layer society and citizenship in general. The model identifies areas for intervention within each of these layers. Many of the same issues are salient for a person with dementia. Both require a better understanding of their impairment, altered attitudes towards disability, and greater accessibility of services. The model of the dysphagia service proposed in this study targets some of the components of the Byng *et al.* (2000) model, specifically social inclusion, enhanced communication, autonomy and choice, and health promotion/illness prevention.

5.3.1 Interaction and well-being - "social inclusion":

The discussion commences by examining face IW of the model, the contribution of interaction and well-being to the staff-patient partnership. This face represents *social inclusion* (Byng *et al.*, 2000; Lindsay and Pound, 2001). In terms of aphasia intervention, social inclusion is defined as the adaptation of interaction to enable the patient to participate. But how can a person with late stage dementia and a very limited communicative repertoire be socially included? The answer is to break interaction down and examine how members of staff enable patients to participate in even minimal exchanges.

It is only by attempting to interpret behaviours that the members of staff can attempt to understand the patient. There is a tendency to assume that most behaviours of severely demented patients are incidental rather than being communicative. The person then becomes depersonalised, a thing to which things are done rather than an active participant. When this happens synchrony can be seen to be non-existent and communication to be unsuccessful. Collaboration between the member of nursing staff and the patient, fundamental to the nurse-patient partnership, is only possible through interpretation of behaviours as communicative attempts. Interaction between the nurse and the patient is about more than socialisation, it is about expression and understanding of basic needs. Such needs can only be met if they can be identified, and they can only be identified by assuming that behaviours are purposeful rather than incidental.

The structure of interaction between the members of staff and patients with late stage dementia was examined, based on transcriptions from an adapted conversation analysis approach. Many authors have argued that turn taking is preserved in dementia, even in the late stages (Causino *et al.*, 1994; Golper and Binder, 1981; Hamilton, 1994; Sabat, 1991). Evidence for turn taking has been offered in the form of minimal vocalisations being produced where second parts of adjacency pairs might be anticipated (Hamilton, 1994). Such findings were replicated in this study, whereby minimal vocalisations and behaviours appeared to fulfil second pair parts of greetings and questions or to make confirmations and corrections.

A different interpretation can however be offered, that the responsibility for these turns lay not with the patient but with the member of staff. Patients' vocalisations could be treated as if they were responses or they could be ignored. The researcher is making the underlying assumption that the vocalisations were not active turns but were incidental and could be seen to be meaningful purely by the way to which they were responded. This has already been discussed in section 4.2.

There are of course many examples of vocalisations occurring when a turn was not expected. The transcripts from patient C in this current study are a good example as patient C produced vocalisations, or moans, throughout the mealtime. Only sometimes were the vocalisations interpreted as responses. What appeared to make vocalisations a turn was the way in which the member of staff responded. By responding to a vocalisation as if it were meaningful that meaning could be ascribed to the vocalisation. It does not mean that the vocalisation was made with that meaning implied.

It was supposed that if the patients were communicating actively, or intentionally, then they would be demonstrating behaviours parallel to shared attention observed in infants. In the social constructivism theory of language acquisition intentional communication is identified by the emergence of shared attention (that is, the alternating eye gaze between an object and a person). In infant development shared attention indicates that the child realises a connection between the object and the person, that the person can act upon the object for the infant's gratification. Shared attention can also be recognised in Bunning's (1996; 1998) coding scheme as person-object engagement. Bunning's codes were utilised in this study to examine changes in engagement during feeding. It was anticipated that patients would initially be engaged in self-occupation but that they would engage with the member of staff and/or the meal when the member of staff arrived and began feeding them. Changes in engagement were noted in two of the three dyads examined, but these were minor and fleeting, such as orientation towards the plate (object engagement) and eye-contact with the member of staff (person engagement). No object-person engagement was observed. This might suggest that patients were communicating in an affective rather than an intentional way.

However, the number of dyads examined was very limited and the period of observation only for the duration of the greeting sequence. It would therefore be inaccurate to suggest that shared attention or person-object engagement was not present, but more accurate to say that it was not observed during this small study. Further research into this area would be informative. Although the cognitive functioning of people with dementia gradually deteriorates there is no clear evidence to suggest that it does so in the exact reverse pattern to development.

The structuring of exchanges between competent communicators and affective communicators is referred to as "scaffolding". Vygotsky (1962, 1978) argues that scaffolding is used to enable infants to participate in discourse whilst still learning language skills. He refers to "apprenticeship" whereby an infant acquires skills in a structured fashion, moulded by the competent adult. Whilst this theory makes good sense for child language acquisition there must be a different purpose for the use of the same structure when conversing with patients who have severe dementia. Such patients do not acquire or learn skills. One answer may be that the members of staff preserve the patient's involvement in discourse. Evidence of this may be found by referring to the work of Clark and Shaeffer (1989).

Clark and Shaeffer (1989) argue that one person may permit or disallow another speaker to contribute to discourse by the way in which they respond. It is only by acknowledging, or *accepting,* the utterance of another person that it is allowed to contribute. It is therefore by ascribing meaning and by providing conversational structure that the members of staff enable the patients to contribute.

At a more fundamental level it may be argued that members of staff ascribe meaning to the vocalisations and behaviours of patients in order for their own utterances to contribute. For their utterances to contribute they must be accepted by the patient. The patient has very limited means by which they are able to accept an utterance and so it is necessary for the member of staff to look for minimal evidence of acceptance. By ascribing the appropriate response to the vocalisations and behaviours of the patient the member of staff enables the patient to accept the utterance and therefore contribute to the discourse.

The interactive style of the members of staff was examined in terms of the amount and type of utterances used throughout the recorded meal-times, across the twelve dyads. The amount of speech was not found to differ depending on which patient was being addressed, but did differ significantly across the three members of staff. This supports the work of Norberg (1996) and Grove *et al.* (1999), who argue that different members of staff respond to patients in different ways, but that their interactive style does not change when communicating with different patients.

There were particular differences observed in the transcripts of member of staff 06. From watching member of staff 06 on video he appeared to be a more competent communicator than his colleagues. Specifically he talked more and was "chatty" with the patients. He used a high proportion of utterances that were not related to the feeding activity whilst the majority of utterances made by his colleagues were related to feeding. The findings from members of staff 03 and 05 therefore support the findings of White (1999), that the communication of staff members is mostly task orientated. Member of staff 06 on the other hand could be described as being non-task orientated.

There were also qualitative differences observed in the staff members' non-verbal interaction. Member of staff 06 was the only member of staff to gain eye contact during the study of engagement and was observed to use many methods to attain this. He was more physical than his colleagues, manipulating the patients' limbs and head in an attempt to gain eye contact with them. He was also noted to adapt his own body posture to maximise engagement. On one occasion he was observed to lower his body to the same level as the patient and then lower his head so that the patient could look down onto his face. This was met with eye contact from the patient.

Whilst member of staff 06 may have been a more effective *communicator*, his interaction was shown to negatively influence the patients' nutritional intake. The discussion therefore moves on to develop the NI face of the model, the interface between nutrition and interaction.

5.3.2 Interaction and feeding - "demarcation of feeding":

Face NI represents *demarcation of feeding* and deals with enabling the patient to play an active role in the feeding process. In the terms of the model proposed by Byng *et al.* (2000) this may be seen to be promoting autonomy and enhancing communication.

It is well known that the members of staff greatly influence how patients perform. Tenseness or an attempt to hurry feeding by the member of nursing staff can be communicated to the patient (Hall, 1991) and the subsequent anxiety this creates for the patient can contribute to swallowing difficulties and coughing (Sanders, 1990). The performance of patients also influences the members of staff and it has been shown that the more refusal behaviours a patient demonstrates the more people tend to be involved in feeding them (Athlin and Norberg, 1987). The consequence of this is that the nursing staff are unlikely to build a meaningful relationship with the patient and will therefore fail to develop collaborative processes. This will result in the persisting view that the patient is difficult to feed. Such a cycle may be broken by an individual or a very small number of staff members being assigned to feed the patient. Familiarity and experience will help the development of a synchronous relationship and the patient will be perceived as increasingly easier to feed.

The amount of food consumed by the patients in this study was calculated in number of spoonfuls successfully fed. Member of staff 06 was found to have fed significantly fewer spoonfuls than his two colleagues, regardless of which patient was being fed. Member of staff 06, as already stated, used fewer task orientated utterances and more non-related ones. More specifically, he used only a small proportion (14%) of preparatory utterances such as "are you ready?", "here you are", "open your mouth" etc. By comparison members of staff 03 and 05 used 50% and 44% respectively. Particular emphasis is placed on these preparatory utterances as it is thought that they play a vital role in marking where feeding is about to take place.

The cognitive impairments of the patient with late stage dementia need reiterating again here. The patient will have significant processing problems as a direct result of the brain atrophy associated with the dementia process. The consequence of this, in particular relation to feeding, is that the patient will have difficulties filtering relevant information from general information and background noise (Grimes, 1995). The patient is fed on a ward where there are other patients and members of staff. This produces a background noise of voices, plates being scraped, cutlery being rattled, furniture being moved and trolleys being wheeled. Added to this there is at least one television and/or radio playing on the ward, other internal noises (such as caged birds singing, the pump on the fish tank, telephones etc.) and external noises (such as traffic, people outside, rain on the window etc.). For people who do not have processing problems it is relatively easy to block out much of the ambient noise and selectively listen to the salient information. For a patient with processing problems however the sounds will be processed equally and the background noises of the ward environment will not be in the background at all. This can create confusion and the member of staff has a crucial role in helping the patient to selectively attend to important information. This is where the preparatory phases play their part, in helping the patient tune into the task in-hand.

It is feasible that what the members of staff say is less important than the fact that feeding is marked. It is of course unlikely that the patient, by the late stage of the dementia process, will be able to understand what is being said to them. One study has shown that even in the mid stages of dementia patients' utterances during meal times tend to be related to the food and are nearly always in the present tense (Sandman *et al.*, 1988). This provides evidence of the decreased cognitive functioning available to such patients. They are only able to deal in the here-and-now, and therefore become task orientated themselves.

Even in the latter stages of dementia patients may be able to recognise that an utterance from the member of staff indicates that feeding is about to take place. By their very virtue preparatory utterances were found immediately prior to feeding and evaluatory ones immediately afterwards. Preparatory utterances have a rising intonation "ready?" [_↗], whilst evaluatory ones tend to have a falling intonation, "well done"[_↘]. It may be that these paralinguistic features are more salient to the patients than the actual words used. This may help explain why members of staff 03 and 05, who used a greater number of preparatory phases than member of staff 06, were more successful in feeding.

It is unlikely to be the whole story however, and all three members of staff were observed to use non-verbal behaviours, such as tapping the patient's arm or touching the spoon to the patient's mouth, to indicate feeding was about to take place. Similarly non-verbal behaviours could be observed at the end of each mouthful. These could contribute to the evaluation, that the feeding of a spoonful has been accomplished. This could provide an explanation for the follow-up behaviours observed in Chapter Four.

Using physical behaviours such as touch may be even more salient for patients with dementia. Whilst verbal communication is processed at the highest neurological level (the cortex), tactile and touch information is processed much lower (in the brain stem) (Ayres, 1973). Touch is therefore of a lower order than speech and has simpler processing demands (Bunning, 1996). There is additional benefit to the patient as verbal or tactile demarcation of feeding helps the member of staff to keep a reduced and steady feeding pace. (Researchers in the field of signing have observed a similar effect on the presentation of speech when linguistic demarcation is used).

A role of demarcation in the feeding process is presented in figure 5-6.

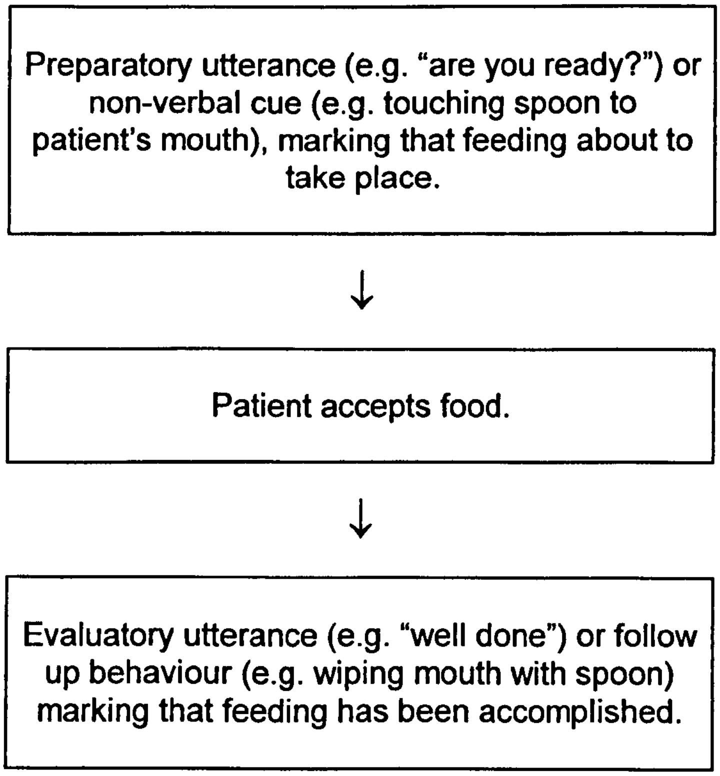


Figure 5-6. The role of demarcation in feeding exchanges.

As already discussed above, one of the factors which made member of staff 06 appear to be a better communicator than his colleagues was the amount of non-verbal behaviours he exhibited in an attempt to engage with the patient. Member of staff 06 used higher amounts of both verbal and non-verbal communication and yet had the least successful feeding rate in terms of accepted offers and completed meal phases. The researcher argues that the behaviours which singled member of staff 06 out as a good communicator were detrimental to the feeding process. Because he used a lot of speech and a lot of non-verbal behaviours, the marking of when feeding was about to take place was less clear than with members of staff 03 and 05 who clearly marked feeding.

This then challenges the conclusions of authors such as White (1999) who have been critical of nursing staff for being task orientated and for not socialising appropriately with patients. It has been shown in this study that being task orientated is of higher value for the patient in enabling them to carry out the task. Members of staff need to be aware and respond appropriately to the processing level of their patient.

It is not disputed that patients need social stimulation and that the members of staff need to converse with them. Indeed the findings of this study have shown that members of staff can interact appropriately, and enable the patients to assume an active role in communication through interpretation, ascription of meaning and providing communicative structure. The key factor appears to be deliberate interaction where the member of staff is disciplined in ensuring that different processing demands are delivered separately and consistently.

Another important consideration is the effect that high levels of speech might have on the physiology of the patient. Even when a patient is unable to respond verbally, the musculature of the laryngeal area may still undergo changes as if a response were about to be given. Speech requires the larynx to be open and air to flow from the lungs, through the vocal folds, and into the oral cavity. Ingestion of food on the other hand requires that the larynx is closed to protect the airway so that food and liquid is channelled into the oesophagus. A lack of integrated neurological behaviours as a result of the dementia process may prevent responses being stopped once they have been started.

A member of staff may ask questions, or present other first parts of adjacency pairs which require a response throughout feeding. It is reasonable to suppose that physiological changes have taken place to permit voice to be produced rather than for a swallow to be performed. This could result in an increase in feeding difficulties and contribute to the choking risk of patients. This could be investigated instrumentally, perhaps using electro-physiological methods or videofluoroscopy. Laryngeal movement may be reduced if the patient is anticipating speaking rather than swallowing. This may be detectable on videofluoroscopy, although in both cases normative data would need to be collected.

The importance of the member of staff's speech has been discussed in terms of feeding demarcation and in terms of increasing choking risk when the patient is asked to perform a function other than swallowing.

5.3.3 Nutrition and well-being - "health promotion / illness prevention":

The NW face of the model refers to the interface between, nutrition and well-being. The face represents *health promotion/illness prevention* and *choice.* This again relates directly to the model of aphasia intervention proposed by Byng *et al.* (2000). Adequate nutrition is vital for healthy well-being and infection prevention. A patient who is undernourished will be at greater risk of developing pressure sores and chest infections and be more susceptible to other infections due to a reduced immune system. Nutrition is therefore a major consideration in the care of these patients and accounts for 25% of the cost of caring for a dependent elderly person (Siebens *et al.*, 1986).

This aspect of the model emphasises the role of the feeder in selecting what the patient is to be fed with. It is where the knowledge the members of staff have of the patient's likes and dislikes is put into practice. It is where the member of nursing staff may choose not to feed one component of the meal whilst persevering with the rest. Likewise it is where the member of staff may need to modify the meal in some way. This is especially the case when patients receive a purée or soft diet and nursing staff are responsible for ensuring that the food is safe for the patient. Quality assurance might include checking the temperature of the meal, checking for lumps, adding seasoning, checking appropriate consistencies and modifying appropriately.

It is the communicative attempts of the eater and the feeder's interpretation of them that allow a patient's preferences to be identified. Some behaviours may be intentional, particularly those of refusal during feeding. Other behaviours may be reflexive such as pulling the head away, but they still communicate a clear message that the patient is not ready or does not want to proceed with being fed.

It is these issues which may account for how a patient responds to a particular meal. The refusal behaviours seen in patient C for example could be explained by her having a particularly sweet tooth. Observation has revealed that patient C's sister, who feeds her on a regular basis, always tastes the dessert prior to feeding and often adds sugar to it. The sister has explained that when they were younger the two sisters both had a very sweet tooth, and she can therefore tell from tasting the dessert herself whether patient C would prefer additional sugar. It is this "insider knowledge" that enables the preferences of patient C to be met. Such information passed on to the nursing staff ensures that other feeders also add extra sugar to desserts. With reference to the model, in this scenario the relative may take the place of the therapist. The relative influences the care offered to her sister directly, by adding sugar herself, and indirectly, via the members of nursing staff.

Some patients are able to indicate their preferences by making choices. It is common to see patients who have become disinhibited as part of the disease process make their feelings very clear, by pushing food away or leaving the table without touching the meal. Relatives have sometimes expressed surprise when it becomes apparent that in the past food has been eaten out of "politeness". Even those patients who are severely demented may show their dislike by spitting food out or refusing further spoonfuls.

Tastes change and patients, like the rest of us, may become tired of a food they have eaten willingly in the past or may show a preference for food they have previously avoided. The sense of taste is thought to diminish with increasing age. It is not really clear how much or how little patients with severe dementia are able to taste, or whether they are only able to distinguish between the tastes of sweetness, sourness, bitterness and saltiness (VOICES, 1998). The researcher is aware that patients with severe dementia often eat foods their contemporaries dislike, such as spicy curries or seasoned pasta dishes. Maybe the strong spices or heavy seasoning are detectable to the severely demented patients when other tastes are diminished. The researcher has also heard anecdotal stories of patients "forgetting" that they do not like some foods and those foods being reintroduced into their diets after having been avoided for many years.

Nurses who are familiar with their patients will know which foods are liked and which are disliked. This familiarity accounts for why some patients are fed different meals to the others, why some patients have sugar added to drinks or desserts and why some patients are given larger portions than others. There are many anecdotal reports from institutions of the patients being served tea from one teapot containing tea, milk and sugar mixed together, about all patients being given exactly the same drink or meal and about one member of staff feeding more than one patient simultaneously. Thankfully many of these practices have ceased in the newer culture of person-centred-care. Nursing staff do collate information on patients' preferences, likes and dislikes. They speak to the relatives of patients or obtain information from the patient directly in the earlier stages of the illness. Most importantly, where possible these preferences are respected.

Members of staff in this study were shown to be sensitive to the patients' preference for sweet foods in that more dessert phases of the meal were completed, and the dessert was always offered even if very little of the main-meal had been accepted. The patients' preference for sweet foods was concluded from increased feeding rate. The rate of feeding was calculated in the number of spoonfuls successfully fed per minute. The rate of feeding was found to increase for the dessert phase of the meal, and across the twelve dyads this difference was found to be significant. The number of refusal behaviours was fewer during the dessert phase than the main-meal phase and this in turn will have contributed to the increase in feeding rate.

The behaviour of the members of staff should be examined in more detail. The researcher suggested in Chapter Four that the members of staff appeared more inclined to complete the dessert phase than the main-meal phase. Reasons for this could be that the dessert indicated that the end of the meal was near, or indicate the end of the food phase before the drink was given. It could reflect the member of staff's own preference for sweet foods, or could have resulted from the desserts looking more normal than the puréed main-meal. In some cases the dessert was a fortified pudding rather than a normal dessert. In these cases the researcher suggests that the pudding took on a more medicinal role i.e. the fortified puddings are prescribed for the patient and therefore become part of the drug regime rather than the meal process. Subjective feedback from members of staff however indicates just that the desserts are easier to feed to patients than the main-meal phases, suggesting that patients do indicate a preference for them.

It was also shown that members of staff were giving drinks in response to antecedents such as coughing or refusal behaviours. Although the questionnaire was not used fully in this study (see Chapter Three), some of its findings are of interest. Member of staff 06 for example rated patient B as never showing signs of anxiety or tension and never choking. In the video of him feeding patient B however, there was evidence of both anxiety and of the patient coughing when being fed. This raises the question as to whether member of staff 06 was less aware of the patient's behaviours. It may be that he was less tuned in to the patients and that this was the reason he failed to modify his communication appropriately as discussed above. Alternatively there could have been a problem with the terminology of the questionnaire. Member of staff 06 may for example have not considered the coughing observed to have constituted choking. Interestingly, member of staff 06 rated the level of difficulty in feeding patient B as higher than his colleagues although he rated the presenting difficulties as occurring less frequently. This may also be indicative of the role member of staff 06 himself had in patient B's feeding difficulties.

The questionnaire was designed in such a way that it could be easily examined statistically. It would however have been of more benefit to collate qualitative information: how members of staff judge feeding difficulty; how they judge anxiety or distress in the patients; how they know whether a patient is enjoying the meal; how they know if the patient is full, doesn't like something, or just wants a rest. Such information would have added qualitatively to this study by providing information on how the members of staff interpret their patients' behaviours.

Summary of section:

The first stage of the model reconfiguration, focusing on the nurse patient partnership, has been examined with reference to the findings of this study. The three faces of the model have been described and labelled, in terms of the key components of feeding for patients with dementia. The next section now examines the implications of these findings for speech and language therapists and introduces the second stage of the model reconfiguration.

5.4 Stage two of model reconfiguration: implications for speech and language therapy.

Having developed the first stage of the model reconfiguration, where the key components of the nurse patient partnership were discussed in terms of the findings, this section examines the implications for speech and language therapy. Here it is necessary to consider the role of the speech and language therapist and introduce the second stage of the model reconfiguration. The structure of the second stage is consistent with the first, in that the speech and language therapist (T) is at the apex. This is shown in figure 5-7.

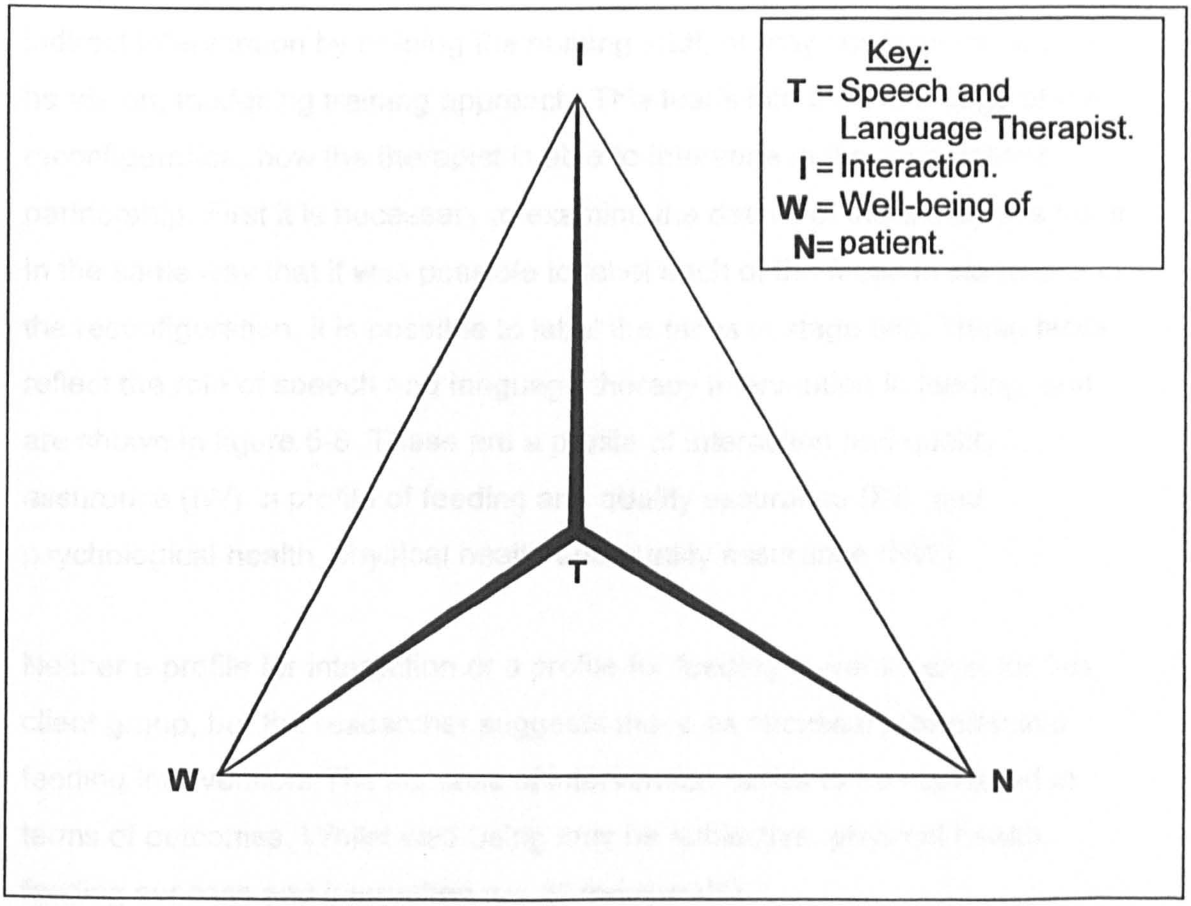


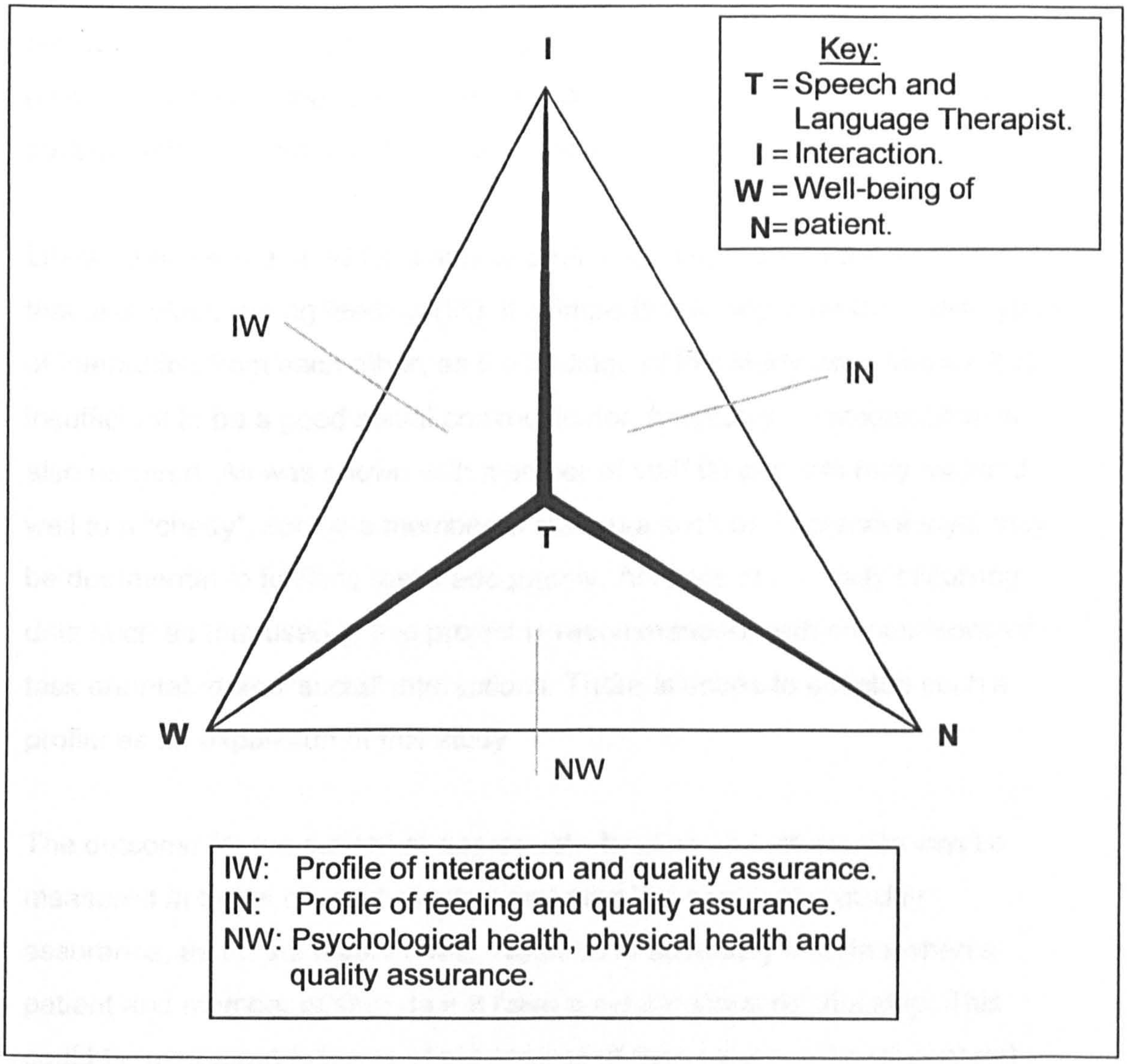
Figure 5-7. Stage two of model reconfiguration - key components for speech and language therapy intervention.

The corner components are the same as for the first stage of the reconfiguration, and relate to a shared aim of intervention regardless of who is providing the intervention. Thus the speech and language therapist is concerned with promoting interaction and enhancing communication partnerships, maximising nutritional intake, enhancing the feeding partnership, reducing the risks associated with dysphagia and promoting the patient's well-being.

As discussed in Chapter One, there are three ways of doing this. The therapist may undertake direct intervention with the patient, may undertake indirect intervention by training the nursing staff, or may combine these in a hands-on, modelling training approach. This leads into the third stage of the reconfiguration, how the therapist is able to intervene in the staff-patient partnership. First it is necessary to examine the details of the therapist's input. In the same way that it was possible to label each of the faces in stage one of the reconfiguration, it is possible to label the faces in stage two. These faces reflect the role of speech and language therapy intervention in feeding, and are shown in figure 5-8. These are a profile of interaction and quality assurance (IW), a profile of feeding and quality assurance (IN), and psychological health, physical health and quality assurance (NW).

Neither a profile for interaction or a profile for feeding currently exist for this client group, but the researcher suggests these as necessary for effective feeding intervention. The success of intervention needs to be measured in terms of outcomes. Whilst well-being may be subjective, physical health, feeding success and interaction are all measurable.

A communication or interaction profile (IW) would need to be different to profiles depicting the communicative behaviours of just the patient, and would need to examine the interaction between an individual patient and an individual member of staff. Such interventions are already available in other clinical areas, such as the Hanen programme for children (Manolson, 1985; Proctor-Williams, 1996), conversation analysis studies of communication partnerships in aphasia (Lock *et al.*, 2001), and Intensive Interaction for people with severe learning difficulties (Nind and Hewett, 1994, 2001).



Key:
T = Speech and Language Therapist.
I = Interaction.
W = Well-being of
N = patient.

IW: Profile of interaction and quality assurance.
IN: Profile of feeding and quality assurance.
NW: Psychological health, physical health and quality assurance.

Figure 5-8. Stage two of model reconfiguration - faces of the pyramid.

These, and other similar interventions (Caldwell, 1996; Caldwell and Stevens 1998) reveal natural communication skills and are directed at the communication partner. They focus on natural communication abilities to guide the process and borrow principles from parent-infant interaction. Intensive Interaction is a practical approach which involves spending time with people who have reduced communicative ability, to help them relate and communicate better with people around them (Nind and Hewett, 2001). Such deliberate intervention is aimed at replacing undesirable or "challenging" behaviours with more acceptable methods of expressing the same meaning (Bunning and Bradshaw, 2001), or providing the stronger communication partner with a means of relating to the weaker one.

Likewise there is a need for a similar profile, concerned with the interactions that take place during feeding (IN). It is important to separate these two types of interaction from each other, as the findings of this study have shown. It is insufficient to be a good social communicator, functional communication is also required. As was shown with member of staff 06 patients may respond well to a "chatty", sociable member of staff, but such an interactive style may be detrimental to fulfilling tasks adequately. Analysis of naturally occurring data such as that used in this project is recommended, with comparisons of task orientated and 'social' interactions. There is scope to develop such a profile as an expansion of this study.

The outcome for the patient of appropriate feeding and interaction can be measured in terms of psychological and physical health and quality assurance, as on the model (NW). Nutrition is adversely affected when a patient and member of staff do not have a synchronous relationship. This could be measured in terms of the amount of food (and nutritional content) consumed, by feeding success (as measured in this study) and by the number of supplements prescribed (where better nutrition would necessitate the prescription of fewer supplements). Weight and body mass index (Garrow and Webster, 1984) could also be used as objective measures of nutritional status. With clinical outcomes being recognised as a vital part of speech and language therapy practice, the promotion of such outcomes is timely.

An additional challenge for speech and language therapists would be to communicate the findings of the two profiles to the members of staff. Law (2001) describes three models of joint working with parents which although very different are applicable to joint working with members of nursing staff. He describes the *expert model*, where the professional holds all the information and makes all the decisions; the *transplant model*, where the professional hands over the skills but still makes the decision about what information is given; and the *consumer model*, in which the parent (or member of nursing staff) selects what is most appropriate from a given package of intervention. The last of these is thought most likely to lead to successful joint working, with the member of staff "buying into" the intervention process.

In many dysphagia services the former of these models is most likely used, although some teams/therapists may offer a transplant type model of service. It is unlikely that a consumer model is used. This is primarily because parents tend to be involved to a greater extent in their child's therapy than a member of nursing staff is with their patient's, although family members or advocates for patients with dementia may be involved. A change in emphasis is therefore required whereby members of staff recognise the importance of the staff patient partnership, and view themselves as having the crucial role in influencing this relationship. If this vision is only held by the speech and language therapist then little headway will be made. See for example the Allan (2001).

It is acknowledged that some parents will need help learning to interact with and feed their own children (Chatoor *et al.*, 1997; Satter, 1986, 1990) but nursing staff rely on their intuitive knowledge for feeding and interacting with patients (Pierson, 1999). The members of nursing staff need to take responsibility for changes made within the staff-patient partnership. This will predominantly involve them making adjustments and adaptations to their own communication. This should result in the member of staff's mode of communication being appropriate to an individual patient and altering depending on which patient is being interacted with.

Feeding programmes for people with dementia (and other dependent patient groups) rarely include a mention of a particular member of staff who has more success feeding the patient. Indeed, feeding is often left to auxiliary staff who may be under qualified in the feeding of such patients (Mairis, 1992). Neither do programmes, such as those previously produced by the researcher, make reference to how to interact with the patient other that to advise "socialisation" during feeding.

Many authors identify the need for consistency when feeding people with dementia (Van Ort and Phillips, 1992; Watson, 1990) and it is suggested that this might best be achieved through the introduction of primary nursing systems (Hall, 1991; Sellick *et al.*, 1983). Such a system would allow for consistent allocation of staff to feed individual patients and the opportunity to build relationships with the patient. Many of today's psychogeriatric wards are however understaffed with many team members comprising of bank or agency staff. Such an allocation system would therefore not work. Discussion by staff on each shift to ascertain who is best suited to feed which patient would be an alternative solution, and identifying named staff members during assessment would aid this process.

The role of the speech and language therapist is therefore three-fold. To work directly with the patient in terms of assessment and clinical decision making, to work indirectly through the member of staff and to improve feeding through modelling of appropriate interactions.

Summary of section:

This section has introduced the second stage of the model reconfiguration and has discussed the role of the speech and language therapist. The therapist's intervention mirrors that of the nursing staff with regard to the key components of feeding intervention. Interaction, nutrition and well-being are central to the quality of care being offered and the three modes of therapeutic intervention (direct, indirect and combined) have been discussed. This stage of the reconfiguration can therefore be seen to compliment the first stage relating to the staff-patient partnership, but neither of the first two stages represent the dysphagia service. This is only achieved in the third stage.

5.5 Stage three of the model reconfiguration: the dysphagia service.

The first and second stages of the model reconfiguration lead to a final third stage which combines them. Only when the two stages are combined, as in figure 5-9, does the model fully reflect the dysphagia service. The model is formed by turning the two pyramids on their sides and joining them at the base.

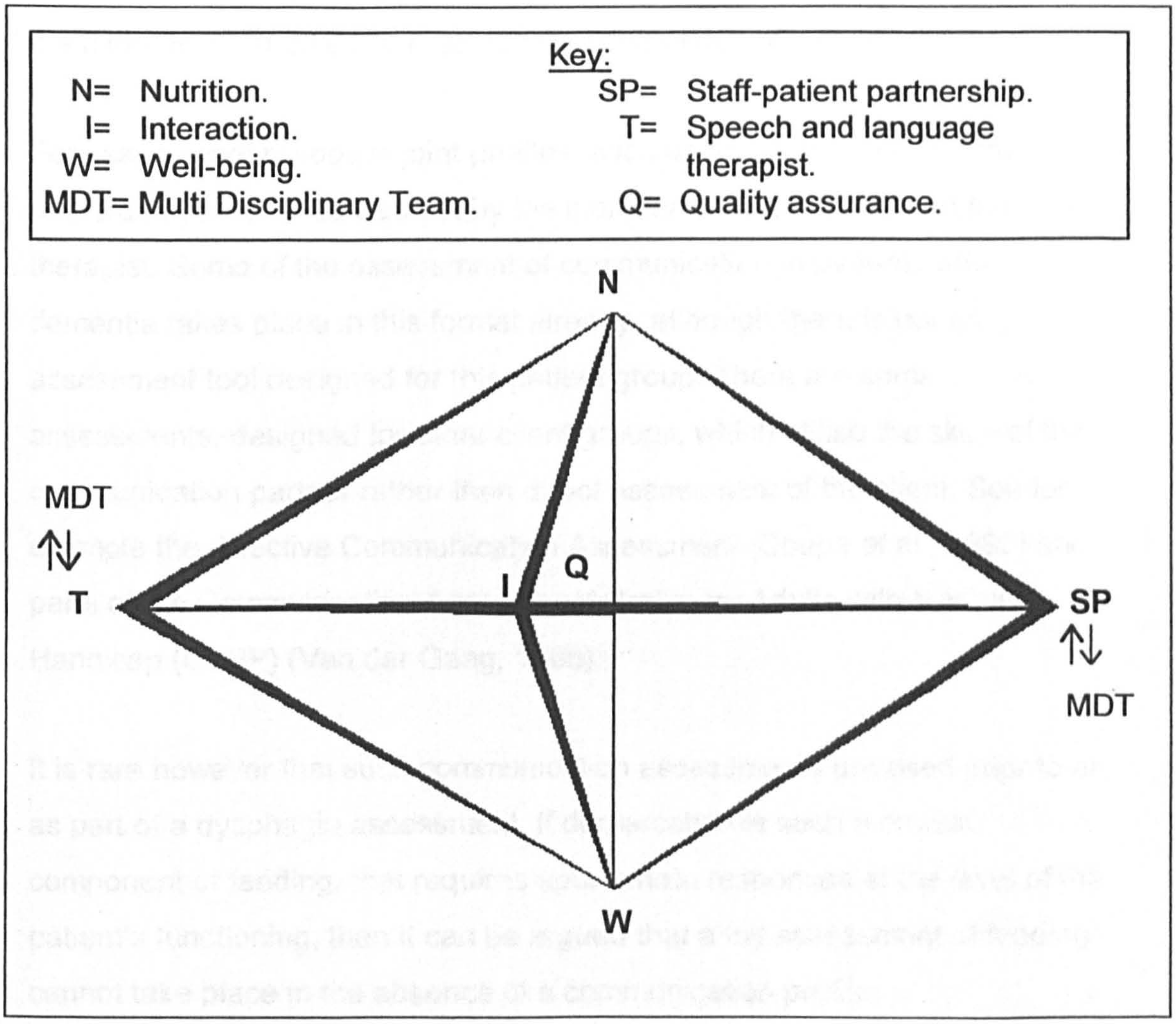


Figure 5-9. Stage three of model reconfiguration - the dysphagia service.

The apex of each pyramid represents the speech and language therapist (T) and the staff-patient partnership (SP) respectively. The components of interaction (I), nutrition (N) and well-being (W) can be seen as belonging mutually to both sides of the model. Each can also be considered as parts of larger models for nursing intervention, such as communication, health, and quality of life, as discussed in section 5.2. In addition these components now form a solid, shaded base to both pyramids representing the core components of feeding intervention. This solid shape may be thought of as representing *quality assurance* (Q) for care being offered during feeding. Each component is necessary to ensure quality of care and there must be a balance between them that is appropriate to meet the differing needs of individual patients.

For assessment purposes joint profiles, such as those proposed by the researcher, may be carried out by the member of nursing staff and the therapist. Some of the assessment of communication in patients with dementia takes place in this format already, although there is not an assessment tool designed for this patient group. There are some assessments, designed for other client groups, which utilise the skills of the communication partner rather than direct assessment of the client. See for example the Affective Communication Assessment (Coupe *et al.*, 1995) and parts of the Communication Assessment Profile for Adults with Mental Handicap (CASP) (Van der Gaag, 1988).

It is rare however that such communication assessments are used prior to or as part of a dysphagia assessment. If demarcation is such a crucial component of feeding, that requires appropriate responses at the level of the patient's functioning, then it can be argued that a full assessment of feeding cannot take place in the absence of a communication profile.

Assessment of the feeding process (in addition to the assessment of dysphagia) is also required. Formal assessments such as that designed to evaluate feeding behaviour between mothers and infants (Chatoor *et al.*,

1997) may be utilised. Alternatively a feeding profile consisting of measures studied in this project could be developed.

One disadvantage of the development of such profiles is the time that each would take to administer. Whilst time should not be an issue in planning appropriate care and intervention for patients, it is very much a reality in over-stretched wards and speech and language therapy departments. Emphasis needs to be placed on this kind of indirect intervention when looking at services and resource allocation. The clinical and service care aims project pioneered by Malcomess (RCSLT, 2000a) is a useful way of planning services and provision around the work being undertaken at a clinical level rather than what is requested at a management level.

The full assessment of feeding would therefore require two profiles, one for communication and one for feeding interaction, both relating to the staff patient partnership rather than to the patient in isolation. The speech and language therapist and member of nursing staff would then need to examine the relationship between these two profiles and identify any particular conflicts and agreements between the two.

For example, the measures carried out in this study showed a tension between the communication and feeding profile of member of staff 06. Whilst member of staff 06 demonstrated good communicative behaviours in general and was able to engage with the patients, he had the lowest feeding success. His communication would require further modification to enable feeding to be successful. *Good* communication does not always mean *more* communication. Verbal demarcation of feeding is more complex in terms of processing than non-verbal demarcation and verbal communication may therefore need to stop altogether to enable non-verbal communication to take place.

Interventions.

Patients in different stages of dementia present differently in terms of their processing capability. In the early stages of the dementia process it is assumed that high level functions (such as language processing) will be gradually lost. The lower level functions (such as processing of touch and sensory information) are likely to be preserved for much longer. Thus it may be possible to establish a hierarchy of feeding demarcation.

The lower end of the hierarchy could involve physical demarcation of feeding, whilst the upper end would involve verbal demarcation and a combination of verbal and non-verbal demarcation. Assessment of feeding partnerships would start at the bottom of the hierarchy, to see how well the patient was able to respond to non-verbal demarcation. The next level would be to assess how the patient responded to verbal demarcation, and finally how the patient responded to a combination of verbal and non-verbal demarcation. By working up the hierarchy in this manner the patient's level of processing would be established and the staff members would know which demarcation technique to use with each individual patient. The emphasis would be on deliberate communication (Bunning, 1996), ascertained by the level at which the patient is functioning rather than the communicative style of the members of staff. As the patient with dementia deteriorated it would be possible to travel back down the hierarchy, the demarcation behaviours of staff adapting to the changing and fluctuating processing needs of the patient.

This is similar to the use of a hierarchy in assessing food consistencies during a dysphagia assessment. Much as the patient will primarily be assessed using purée, followed by soft textures, followed by normal textures, so could the patient be assessed using non-verbal demarcation, followed by verbal demarcation, followed by a combination of the two.

There is therefore huge scope for further work to be carried out building on this present study. A comparison of demarcation processes and the development of a hierarchy are central to this. The development of an appropriate communication profile and a feeding profile is necessary. But most importantly there needs to be a change in emphasis from the patient's functioning to that of the member of staff. The importance of the nurse patient partnership needs to be a view shared by both the therapist and the individual members of staff. Staff members need to view themselves as pivotal to the success in feeding patients with dementia. They need to be empowered to make decisions regarding how they should respond to their patients. A patient's levels of processing may fluctuate on a daily basis in addition to gradually deteriorating as the disease progresses. Members of nursing staff who are able to assess a patient's level of functioning on any given day and adapt their feeding technique based on that level will be more successful feeders.

Speech and language therapy guidelines.

This flexibility and day-to-day decision making is key to successful feeding and is relevant to every aspect of the meal process. In the researcher's clinical experience there is a tendency for staff members to request prescriptive rather than descriptive guidelines. For example, staff may ask how many spoonfuls of thickener should be added to drinks rather than gradually adding thickener until the desired consistency is achieved. Drinks may therefore be served that contain the correct measure of thickener but are too thin. Such drinks may not be further modified despite the patient coughing. The success of thickeners fluctuates and appears to be dependent on room temperature, drink temperature, acidity and milk content of the drinks. This cannot all be accounted for when suggesting how much thickener to use.

Similarly the purée meals may be served and fed to patients regardless of their quality. The meals may be too stodgy and difficult for the patients to swallow, and liquid such as extra sauce or gravy may be needed to produce a more appropriate texture. Food that has separated may cause coughing and pose an aspiration risk. Thickeners may be added to bind the food and produce a more consistent texture. The use of thickener at ward level does pose difficulties as in many health settings thickeners are prescribed by the doctors and are labelled in the same way as medications, for the use of an individual patient. Progress has been made in preventing food thickeners being locked in drug cabinets where they are inaccessible at meal and drink times, but systems are still required whereby thickeners are accessible for all patients.

Emphasis needs to be placed on meeting the individual needs of each patient. Inevitably this will involve some degree of modification at the ward level. Modifications may range from returning the meal to be replaced by a more appropriate alternative, to adding additional fluid of thickener. The researcher is working alongside nursing, catering and dietetic colleagues within the dysphagia service to promote recognition of these problems and enable staff to act on them accordingly. Modification of food at the catering level is only effective if the quality is monitored at ward level.

The negative attitudes associated with caring for elderly people are argued to arise from the misconception that nursing staff do not improve the patient's difficulties and that what they do is intuitive rather than research based (Watson, 1992). In reality, there is very little that any professional can do to reduce the impairments of patients in late stage dementia, although it is possible for nursing staff to directly influence the distress or handicap associated with it (Enderby, 1992). This study has shown how well-being, nutrition and physical health may be influenced by the way a member of staff interacts with a patient during feeding.

Speech and language therapists play a vital role in enabling this empowerment to take place. Therapists may have made a "rod for their own back" by disempowering nursing staff and being rigidly prescriptive in the writing of guidelines. Whilst this is often to protect the patient it diminishes the necessity for the staff who carry out feeding to make their own decisions. Speech and language therapy guidelines should be just that, guidelines rather than prescriptions. Therapists need to move away from the *expert* and *transplant* models of joint working where the therapist is responsible for the decision making and aim more for a *consumer* model where the staff are enabled to select interventions using their own clinical judgements (Law, 2001). Research alone is not enough to change practice. Rather there needs to be a bridge between research and clinical practice, as advocated by the Joseph Rowntree Foundation (RCSLT, 2000b). Hands-on modelling and talking decision making processes through with staff can promote their active role in this process.

Broader client groups.

The issues raised in this study do not only affect patients with dementia. There are many parallels with other client groups where feeding rather than dysphagia is the key issue. Other progressive disorders, such as Motor Neurone Disease (MND), Multiple Sclerosis (MS), Huntingdon's Chorea etc. often involve diminished abilities to feed oneself and impairment of the swallow reflex. The use of a demarcation hierarchy is indicated with these patients, especially when cognitive deterioration is associated with the disorder.

Another readily comparable client group is that of learning disability where clients may have reduced cognitive abilities and poorly developed skills. Extensive work has already been undertaken to promote effective interaction with these clients (Bunning, 1996, 1998; Bunning and Bradshaw, 2001; Nind and Hewett, 1994, 2001). Many such clients are referred to speech and language therapy services for swallowing assessments where feeding is the actual problem. Unlike patients with dementia many clients with learning disabilities will have problems associated with delayed development rather than progressive deterioration.

Another parallel can be seen for patients who have suffered cerebro vascular accidents (CVAs). Many patients do present with dysphagia following a CVA and speech and language therapy intervention is often successful in minimising aspiration risk (Lucas and Rogers, 1998). From discussion with colleagues in the acute setting it is apparent that once the risk of aspiration has been reduced such patients do not continue to receive speech and language therapy input. Colleagues do however recognise that adapting to being fed and carers adapting to feeding are important developments in a patient's rehabilitation. Such work is currently not undertaken and advice given to carers tends to focus on 'safe eating' rather than on feeding.

Feeding receives more attention within paediatrics, where it is acknowledged that the interactions between the feeder and the eater are important for successful nutritional intake (Chatoor *et al.*, 1997). The findings of this study are wider reaching than the field of dementia care alone. There is an impact across the field of speech and language therapy intervention, with an emphasis on interaction similar to that observed within paediatrics.

Summary of section:

This section has examined the implication of the findings for the speech and language therapist. It has advocated the development of interaction and feeding profiles for assessment purposes and the further study of demarcation processes. A hierarchy of demarcation processes has been suggested which can be used for assessment and management of feeding. The emphasis has been on individualised and deliberate approaches to interaction, particularly during feeding. A third and final stage of the model reconfiguration has been proposed, converging the components of the previous two stages, which represents a new model for the dysphagia service. The role of speech and language therapy intervention and guidelines are discussed, as well as the applications of such intervention for other client groups.

The next section examines areas for further and future development.

5.6 Areas for further exploration and future development.

The researcher has identified a number of areas in the study where more information is required. Not least of these is the subjective, qualitative data that could have been obtained from a questionnaire. It would have been useful to know how members of staff recognise when a patient is refusing food, how they know when a patient is willing to accept food or how they tell if a patient likes or dislikes food. Further research into how members of staff make inferences from their patient's behaviours, and distinguish between comfort and distress, would be enlightening.

More research is also required into the role of material objects in the feeding process. For example the researcher is interested in the significance of the bib which is put on the patient prior to meals, and whether later adjustments of it signify the commencement of feeding. It would be interesting to establish the reasons for observed behaviours, such as covering the patient's hands with the bib and discouraging patients from playing a more active role in their feeding. The researcher is also interested in whether holding objects such as spoons and cups could help to orientate the patient to the meal time process.

Physiological changes that may take place during feeding need to be explored further. If it is possible to identify differences in physiology between readiness to speak and readiness to eat in normal subjects then it would be interesting to examine similar differences in patients with dementia. If a patient is asked a question it is feasible to expect physiological responses which suggest speech would be produced if the patient were cognitively able to formulate a reply. Patients with cognitive impairments may experience difficulties over-riding physiological changes once initiated, which could contribute to the swallowing difficulties observed in such patients.

The study has identified the need for a specific communication and feeding profile for patients with dementia. Although communication level and dysphagia can be assessed separately, there is no instrumentation to evaluate feeding. Such a profile would need to examine both social and task specific interaction and examine how a patient responds to verbal and non-verbal behaviour in different environments. It may be possible to identify a member of staff or an individual who interacts better with the patient and if so it would be important to explore what they do differently. Similarly it would be useful to identify any individual who gains better feeding success and explore what they do differently. It may or may not be the same member of staff who interacts well socially and if not the different methods of interaction need to be examined. Such an assessment or exploration should not be carried out by the speech and language therapist alone. Rather the speech and language therapist needs to work along side members of the nursing team to observe, explore and discuss the interactive methods of different staff members. See for example the work of Allan (2001).

The success of such a profile needs to be measured and this requires observable and measurable outcomes. The amount of food consumed by the patient and whether this is dependent on different members of staff is a useful measurement, as identified in this study. This may have a direct bearing on the patient's weight and the need for the prescription of supplements. A member of staff who successfully feeds a patient their meals will reduce that patient's need for a supplemented diet. Some health complications related to inadequate nutrition, such as pressure sores or chest infections, may also provide useful outcome measurements. Quantitative outcome measures should however be viewed cautiously, especially for patients with a progressive illness, as they are likely to show no over-all improvements. Improvement can only be measured on an individual basis in the same way that intervention can only be administered on an individual basis. For many individuals with dementia, a positive outcome will be that the effects of further deterioration in their feeding are reduced.

Central to assessment and management of feeding difficulties is the requirement of a demarcation hierarchy. Development of such a hierarchy is the natural next step to this project and provides the training intervention suggested in Chapter One. Stages of the feeding hierarchy need to be mutually exclusive, easily definable, recognisable and measurable. With simple, easily differentiated steps it should be possible to introduce one method of intervention for any individual patient, based on the functional level of that patient rather than the individual styles of the member of staff.

5.7 Challenges to current practice - moving forward.

The findings of this study challenge some aspects of dysphagia practice including the advice given to nursing staff. Current dementia care practice emphasises treating people with dementia as normal as possible and to preserve social environments. This study has demonstrated that there needs to be a deliberate approach to interaction and that it may need to be adapted beyond recognition to enable the patient to gain maximum benefit.

At the beginning of Chapter One the division that currently exists within the field of speech and language therapy was highlighted, between the assessment and treatment of dysphagia versus intervention for communication. The historical argument was used, that speech and language therapists are the most appropriate profession to implement dysphagia work due to the knowledge they have of the anatomy, physiology and neurology of the laryngeal area.

Dysphagia and communication are however intrinsically linked during feeding. A large number of people who have dysphagia are dependent upon other people for food preparation and feeding. What this study has shown is that such feeding can only take place when there is good interaction between the member of nursing staff and the patient.

This does not mean that the two individuals need to converse with each other during feeding, but that the feeder and eater learn to understand the very small, subtle behavioural cues that help them develop synchrony. It is this collaboration between the feeder and the person being fed that is referred to as the "feeding partnership".

The Royal College of Speech and Language Therapists refers to communication and dysphagia intervention as two separate constituents of speech and language therapy practice. This disconnection of the two does not enable the type of intervention discussed in this study. For feeding to be considered within the realms of speech and language therapy intervention there needs to be a continuum, with communication at one extreme and dysphagia at the other, as shown in figure 5-10.

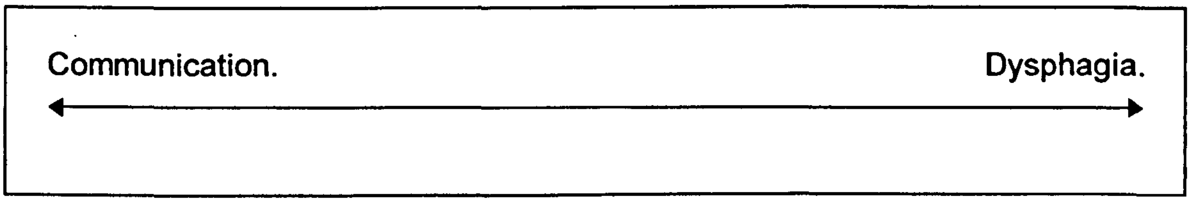


Figure 5-10. Continuum of speech and language therapy intervention.

By considering the speech and language therapy provision to exist on such a continuum complex patients, such as those with late stage dementia, are prevented from being excluded from services. Such patients may not have dysphagia and may not benefit from communication therapy, but many will benefit from intervention within task specific environments such as feeding.

Clinical experience reveals that the referrals to such a dysphagia service include many patients, who may or may not be dysphagic, for whom the primary difficulty is being fed. Such patients exhibit problems interacting with their carers at a functional level. Intervention to this aim should therefore be directed at the relationship between carers and patients rather than the patients alone. The researcher advocates that dysphagia services should be wider reaching with increased awareness and provision for patients who have impairments of feeding rather than swallowing.

The Royal College of Speech and Language Therapists cite the extensive knowledge in anatomy, physiology and neurology as the reason speech and language therapists are involved in dysphagia work. The comprehensive training in interaction and communication, and the role of these within feeding, equip speech and language therapists with the skills to intervene in feeding partnerships. This moves the clinical practice of speech and language therapists forward in meeting the complex needs of patients.

The discussion and model reconfiguration is summarised in the next, final chapter.

Chapter Six

Chapter Six
Summary and concluding remarks

This final chapter summarises the study and offers some concluding thoughts on the application of the findings in the clinical setting.

6.1 Summary of study.

This study commenced with a description of speech and language therapy services available for patients with late stage dementia. The division between dysphagia and communication therapy was highlighted and clinical solutions to the problem of an increasing number of dysphagia referrals discussed. The role of the speech and language therapist in indirect intervention through staff training was highlighted. This had been the focus of an earlier training-based design. A summary model was developed to conceptualise the dysphagia service offered to these patients and the need to measure the partnership between members of staff and patients acknowledged. This relationship has been referred to as the "feeding partnership".

The literature review explored the dementia disease process and dementia care philosophy. Communication deficits associated with dementia were described with particular reference to language, non-verbal communication and sensory impairment. Functional communication and the communication environment were also considered. This lead to a discussion of communication partnerships and the comparison of different communication models. The ability of conversation partners to contribute and enable other speakers to contribute to conversation was highlighted. Asymmetrical communication partnerships develop when one person relies on the other to compensate for their communication difficulties and this was discussed in relation to parent-infant and nurse-patient interactions. Methods of analysing these communication partnerships, such as conversation analysis and engagement states were presented. The literature review contributed to the research questions and hypotheses which were stated at the end of Chapter Two.

Chapter Three described the methodology for the study. The project design and Local Research Ethics Committee approval were discussed. The participants were described and the method for collecting video date examined. The issue of consent, which had delayed the progression of the study process substantially, was discussed in depth and the process of how this was solved explained. The data transcription phase of the project was carried out by undergraduate students using an adapted conversation analysis method. This process was described in detail. The chapter concluded with a critique of the study design.

The fourth chapter described in detail the data analyses carried out. A number of small scale studies were designed to answer the research questions. This involved the development of a coding system for utterance types; the adaptation of Clark and Shaeffers' (1989) contribution to discourse model; the study of greeting and closing sequences; the application of Bunning's (1996, 1998) state of engagement codes; freeze frame video analysis of staff members' communicative behaviours; the development of a meal profile and a number of measures to define feeding success; and the exploration of feeding partnerships. Each of these were presented in terms of research question/hypothesis, methodology, findings and critique.

The theoretical summary model presented in Chapter One was reiterated in Chapter Five. The model allowed for both direct and indirect intervention of speech and language therapists to be represented. The findings however suggested that the model was insufficient to describe the complex and collaborative partnership of members of staff and patients during feeding. Reconfiguration of the model was therefore proposed, the development of which is summarised in figure 6-1.

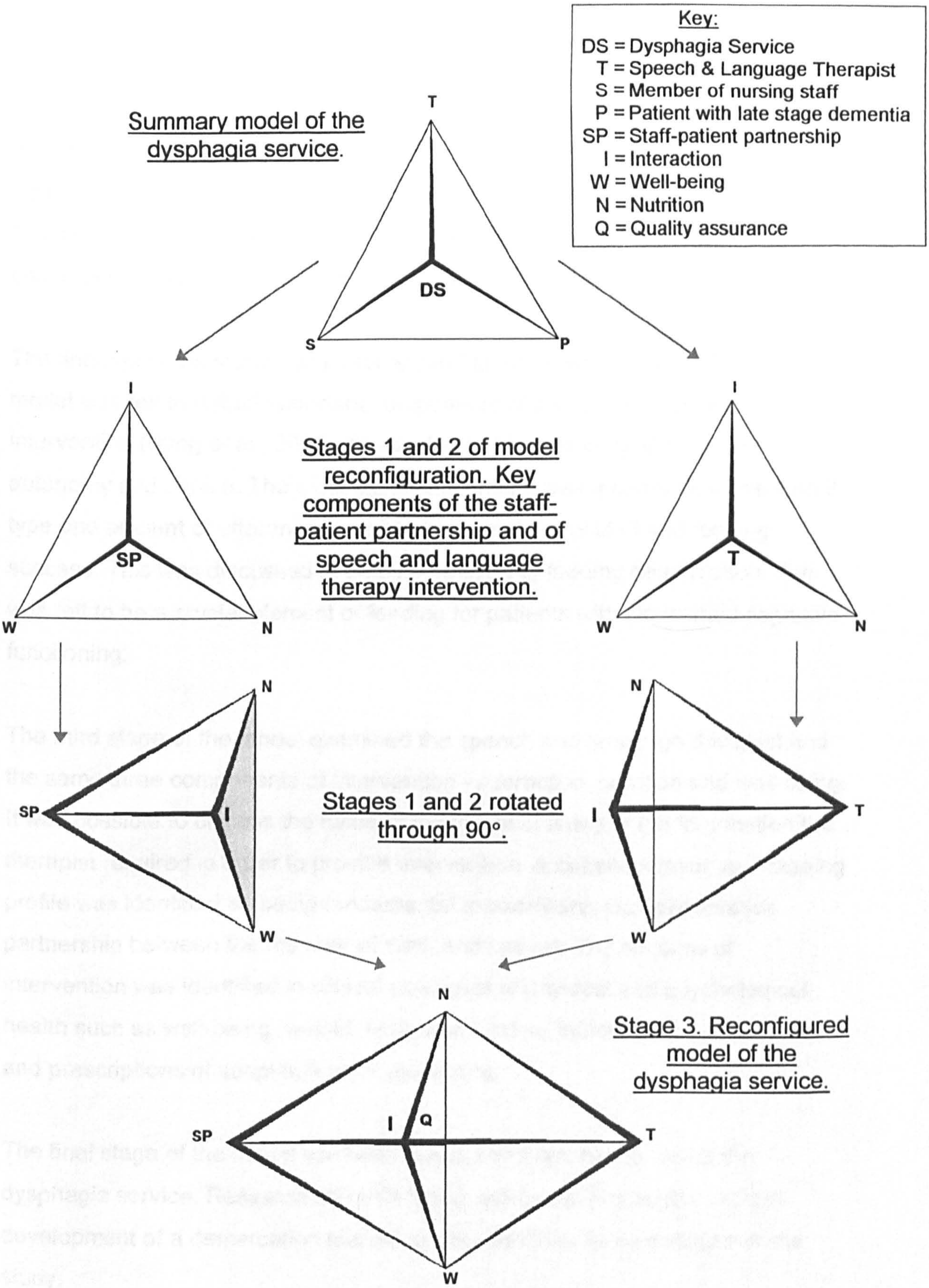


Figure 6-1. Reconfiguration of the model of the dysphagia service - summarised.

Rather than the member of staff, the therapist and the patient being discussed as separate elements of the model, the member of staff and patient were placed together, this partnership forming one element. The first stage of the model focused on this staff-patient partnership and examined key intervention components, namely *interaction*, *nutrition* and *well-being.*

The findings of the study were then applied to this stage of the model. The model was felt to reflect important components of a well known model of intervention (Byng *et al.*, 2000), those of social inclusion, health, patient autonomy and choice. The most significant finding was a correlation between the type and amount of utterances used by the members of staff and feeding success. This was discussed in detail in relation to feeding demarcation. This was felt to be a crucial element of feeding for patients with diminished cognitive functioning.

The third stage of the model examined the speech and language therapist and the same three components of intervention - *interaction*, *nutrition* and *well-being.* It was possible to discuss the faces of the model in terms of the information the therapist required in order to provide intervention. A communication and feeding profile was identified as being fundamental to examining the collaborative partnership between the member of staff and patient. The success of intervention was identified in clinical outcomes of physical and psychological health such as well-being, weight, body mass index, infections, pressure sores and prescriptions of supplements or antibiotics.

The final stage of the model combined stages one and two to reflect the dysphagia service. Research into different demarcation processes and the development of a demarcation hierarchy was identified as an outcome of the study.

The discussion then returned to speech and language therapy services and the researcher challenged the current mind-set of treating dysphagia and communication intervention as two separate entities. Instead a continuum was proposed, with dysphagia at one end and communication at the other. This continuum allowed for intervention into the feeding partnership to be recognised as a role appropriate to the speech and language therapist, and one which speech and language therapists are well equipped to take on. Such a concept of speech and language therapy provision would prevent complex patients (such as those with late stage dementia, other degenerative disorders, learning disabilities or chronic stroke patients) from being denied access to a valuable service on the basis that they neither have dysphagia nor require communication intervention. Rather, clinical emphasis would be placed on functional interaction in a task specific environment, namely that of feeding.

6.2 Conclusions and the way forward.

There are many patients with late stage dementia referred for dysphagia assessments, primarily due to staff experiencing difficulties feeding them. Whilst a large number of these patients may present with the symptoms of dysphagia a significant number do not. Regardless of whether dysphagic or not, these patients pose a significant challenge to nursing staff who are required to feed them on a daily basis. Until now many of these patients may not have received intervention from the speech and language therapy service. They may have been discharged as *inappropriate referrals* and, in the researcher's experience, staff may be advised that the problem is one of *feeding* rather than *swallowing.*

This study has demonstrated that feeding is very much within the domain of the speech and language therapist. The synchrony and collaboration required for staff and patients to be successful during feeding is dependent upon the interaction skills of the member of staff. Speech and language therapists receive extensive training on communication partnerships and basic level interaction. Feeding is one area where maximising this basic level of communication can result in measurable improvements, both for the patient and for the member of staff.

As a result of this study, and of the reconfigured model of the dysphagia service, the researcher is now working with nursing and therapy colleagues in the clinical setting to explore the service available for such patients. In this era of holistic, patient centred care this is seen as a step forward in meeting the needs of patients.

This step is conceptualised by a change in emphasis for the role of services providing dysphagia intervention. A swallowing difficulty only accounts for a proportion of referrals to such a service, particularly for patients with cognitive impairments. This small scale study has begun to define the topics for debate within the clinical field of dementia care, and has recognised the relationship between interaction and nutrition. A deliberate approach to interaction is required for these patients, one that takes into account the different processing needs of each individual patient. Only then can there be significant improvements made to the feeding difficulties widely observed in this patient group.