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The unmet needs of infants, children and young people with dysphagia

Celia Margaret Harding

Thesis submitted in fulfilment of the requirements for the degree of Doctor of Philosophy

City University, London
Department of Language and
Communication Science

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p 192:

Harding, C. (2008), Issues around non-nutritive sucking. In *Developmental Medicine and Child Neurology*, 50 (1), pp 76-80.

pp 194-197:

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DECLARARTION

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ABSTRACT

This thesis collates a research programme of published papers completed by the candidate during the registration period of study, that are relevant to various aspects of feeding, eating and drinking difficulties (referred to as dysphagia) within a paediatric population from a speech and language therapy (SLT) perspective.

Very few studies examine current SLT practice with this population. In the absence of research specific to the needs of children with congenital disorders, there are approaches being used by SLTs without a full rationale for their use and there is persistence in using therapy approaches that might not be beneficial for a child (Harding & Cockerill, 2014). Key themes present throughout this work include understanding the neurological and physiological underpinnings to an approach; being clear about a therapy rationale; creating therapy methods that consider the capacity of children who are neurologically and learning disabled and their caregivers and integrating communication more clearly into the management of dysphagia.

The studies presented include: i) small case studies describing observations and analysis of communication during typical mealtimes; collaborative therapy programmes specifying strategies and sessions for use of Alternative and Augmentative communication (AAC); evaluation of a therapy programme to reduce aversion to tube feeding; ii) data on use of a straw to evaluate and record changes over age and gender; iii) evaluation of an SLT intervention to train staff within a special school ; iv) a pilot study and RCT investigating the use of non-nutritive sucking (NNS) to wean premature infants off tube feeding onto full oral feeding, and iv) case reports on use of NNS with infants with congenital disorders and the relationship between feeding difficulties and speech development. The studies presented contribute to the evidence base for SLT in a number of ways including describing and evaluating current practice and techniques through case studies and measuring the effectiveness of a SLT protocol through an RCT. The case studies highlight: the importance of checking the knowledge, skills and training of significant others in delivering therapy interventions, the importance of working collaboratively, specifying components of therapy programmes and time needed to implement them, and the importance of

communication in its broadest sense within a meal time context. The non – nutritive sucking (NNS) RCT found that children in the intervention groups were able to leave hospital significantly sooner than in the control groups. However, unlike many other studies there was no difference in the time taken to be able to feed orally.

There are a number of methodological issues to consider in evaluating the studies. The issues arising from conducting research within a complex clinical environment are discussed in Chapter 5. These complexities include using significant others to deliver therapy programmes, accurate understanding and descriptions of the premature population, the inclusion and exclusion criteria for studies, and consideration of infants with congenital and neurodevelopmental needs. The needs of and difference between parents are also considered. Evaluation of results also needs to take into account the paucity of tools to measure infants' skills both by SLTs and parents and other professionals. Recommendations are made for future research. These include more studies to investigate accurate interpretation of infant states, improved descriptions and subsequent stratifications of infant participants; repetition of the RCT with larger sample and in range of settings, inclusion of follow up to 24 months with added measurements of feeding and language skills. The thesis papers also suggest more focus in future studies on the role of communication as a tool to manage risk within mealtimes.

CHAPTER 1

INTRODUCTION: THE UNMET NEEDS OF INFANTS, CHILDREN AND YOUNG PEOPLE WITH DYSPHAGIA

CHAPTER 1: Introduction: The unmet needs of infants, children and young people with dysphagia

1.1 Introduction

This thesis collates a research programme of published papers completed by the candidate during the registration period of study, that are relevant to various aspects of feeding, eating and drinking difficulties (referred to as dysphagia) within a paediatric population from a speech and language therapy (SLT) perspective. Speech and language therapists work collaboratively with a wide range of infants, children and young people who have dysphagia (Bateman et al, 2007; Miller & Willing, 2003; Martino et al, 2004; Pettigrew & O’Toole, 2007). Many children with dysphagia tend to have congenital disorders and therefore are likely to have some level of learning and communication disability (Cook & Kahrilas, 1999; Field et al, 2003; Harding & Wright, 2010b; Hawden et al, 2000; Kerr et al, 2003; Lefton – Grief & Arvedson, 2007). The papers contained in this work have explored areas in the assessment and management of children with dysphagia and consider where further research could develop. The thesis focuses primarily on non-nutritive sucking (NNS) techniques as presented in detail in chapter 4. However the themes of treatment rationale and communication run throughout. The discussion begins with an overview of typical development before moving through assessment, the range of interventions, and the particular case of non-nutritive sucking.

Therapy approaches to manage dysphagia vary and have been developed from a variety of different approaches (Brackett et al, 2006; Clark, 2003; Harding & Cockerill, 2014). Some approaches such as those that focus on oral motor work, e.g. pursing and spreading the lips to improve muscle tone, are used with children but have been developed from work on general limb – muscle therapy from the adult acquired

population (De Lateur, 1996; Deschenes & Kramer, 2002; Hellebrandt & Houtz, 1958; Kisner & Colby, 1996; Turvey & Fonesca, 1980; Wakim, 1980). This is surprising, as adult acquired populations are different from children both in terms of neurologic presentation and experiences of swallowing (Harding & Cockerill, 2014). This has led to common mis-perceptions about the links between speech and swallowing skills within a rehabilitative context, with some SLTs believing that work on oral motor skills will improve both speech and eating (Lof & Watson, 2008). Neurological activation for nutritive, non-nutritive and speech skills is distinct, but some practitioners still persist in suggesting that work on oral-motor skills will simultaneously improve both speech and swallowing (Blank et al, 2002; Buckner et al, 1996; Ertekin, 2011; Harding & Cockerill, 2014; Kent, 2004; Martin et al, 1998; 2001; Martin & Sessle, 1993; Moiser & Bereznyaya, 2001; Sciote et al, 2003).

In the absence of research specific to the needs of children with congenital disorders, there is persistence in using therapy approaches that might not be beneficial for a child (Harding & Cockerill, 2014). The papers included by the candidate evaluate therapy strategies that are in current use and discuss critical issues such as the importance of developing techniques that parents and caregivers can use as well as developing realistic goals suited to the needs of children.

The final part of the thesis presents the findings from a randomised controlled study on the use of non-nutritive sucking (NNS) to wean premature infants off tube feeding onto full oral feeding (Harding et al, 2014). Those with congenital disorders who are typically not included in studies were evaluated in a separate investigation with some suggestions as to how to manage more complex dysphagia problems (Harding et al, 2015). Both the paper that examines premature infant feeding development (Harding et al, 2014) and the paper which examines a small congenital population (Harding et al, 2015) evaluate the uses of NNS as part of the management of infants developing early skills including oral feeding. Using NNS as an oral motor approach to support better feeding and later language development is quoted in much of the literature in this

area (Bache et al, 2014; Barlow et al, 2008 ; 2014; Boiron et al, 2007; Boyle et al, 2006;Bragelien et al, 2007; Coker-Bolt et al, 2012; Field et al,1982; Fucile et al, 2002; 2005; 2011; 2012; Gaebler & Hanzlik, 1995; Hill, 2005; Hwang et al, 2010; Lau & Smith, 2012; Lessen, 2011; Liu et al, 2013; Mattes et al, 1996; Measel & Anderson, 1979; Neiva & Leone, 2007; Pimenta et al, 2008; Poore et al, 2008; Rocha et al, 2007; Rochat et al, 1997; Sehgal et al, 1990; Standley et al, 2010; Widstrom et al,1988; Yildiz & Arikan, 2012). Developing a more realistic and accurate rationale for NNS as a method of supporting early oral feeding, oral hygiene and communication development is discussed in the Harding et al (2014; 2015) papers and contrasts with many of the theories in the current literature. Key themes present throughout this work include understanding the neurological and physiological underpinnings to an approach; being clear about a therapy rationale; creating therapy methods that consider the capacity of children who are neurologically and learning disabled and their caregivers and integrating communication more clearly into the management of dysphagia.

1.2 The Mealtime Context

Mealtimes are an everyday, functional activity, and are important for the development of independent feeding skills, culturally specific ways of talking, social interaction and language learning for children (Aukhurst & Snow, 1998; Beals & Snow, 1994; Bochner & Jones, 2003; Bowerman & Levinson, 2001; Ferm et al, 2005; McLaughlin, 2006; Pan Alexander et al, 2000; Tomasello, 2001; Tomasello et al, 2007; Tulviste, 2000). Mealtimes can also help children to learn to improve and develop their oral motor skills when being introduced to new textures and tastes (Evans-Morris, 1981; 1989; Mathisen, 2001; Pan Alexander et al, 2000; Spegman & Houck, 2005). These issues of communication during feeding run through the papers presented whether it be with typically developing children (Harding et al, 2012b),those with neurodevelopmental disorders (Harding et al, 2010a; 2015) or preterm infants (Harding, 2009; Harding et al, 2006; 2014).

The quality of communication and interaction during mealtimes is reduced and impoverished for people with congenital and acquired swallowing difficulties (Curle & Keller, 2010; Ferm et al, 2005; Hemsley & Baladin, 2003; Kayser-Jones & Schell, 1997; Keller et al, 2013; Mathisen 2001; Martin & Corlew, 1990; Paquet et al, 2008; Parker et al, 1996; Tulviste, 2000; Veness & Reilly, 2007; Wilson & Hustad, 2009). One reason for this may be that as a result of having complex eating and swallowing problems, mealtimes may have an increased focus on managing the dysphagia rather than on any social exchange (Hemsley & Baladin, 2003). This means that most children with dysphagia are likely to have complex communication and cognitive needs leading to a mealtime experience that is less social and more about managing the eating and drinking skills from the perspective of the carer (Emerson & Hatton, 2004; Martin & Corlew, 1990; Parker et al, 1996). Some of the difficulties with communication during mealtimes could be due to the augmentative and alternative communication (AAC) needs of the child which may prevent natural communication exchange as well as the parent / carer priorities in managing the eating and drinking needs of the child (Light et al, 1985a; 1985b; Pennington & McConachie, 1999; Sanders et al, 1993; 1997). Yet effective communication in a mealtime setting for people with communication and swallowing difficulties can potentially reduce some of the risks associated with eating and drinking (Harding & Halai, 2009). This could be because focusing on the communication alters the pace of the mealtime to a more manageable speed. It could also represent a carer's increased awareness of a child's non-verbal communication and therefore a heightened awareness of when there is a problem such as aspiration during eating and drinking (Harding & Halai, 2009; Evans-Morris, 1981). Having limited interaction opportunities in everyday contexts has been linked to reduced outcomes in the development of cognitive, language and social skills (Butcher et al, 2004; Girolametto et al, 2002).

There are distinct differences in social communication between typically developing children compared with those who have disabilities

(Sloper et al, 1991; Sloper & Turner, 1993). Mothers of infants born prematurely, particularly those with complex medical needs are likely to interact less and be more disengaged when interacting with their infant (Cho et al, 2008; Cross et al, 1998; Feldman et al, 1999; 2002; Hoddinott & Roisin, 2000; Holditch-Davis et al, 2000; 2003; Jonsson et al, 2013; Miles et al, 1999; 2007; Pridham et al, 1999; 2001a; 2001b; 2007; Reyna et al, 2006; Wilken, 2012). Risk of poorer infant – carer interaction is greater within the very low birth weight premature infant population (Burklow et al, 2002). Some parents feel that communication with their premature infant is not an important strategy to implement (Thoyre, 2000). Serious medical complications experienced by an infant have high correlations with the risk of maternal depression as well as inconsistent interaction (Beck, 2004; Callahan & Hynan, 2002; De Mier et al, 2000; Reyna et al, 2006) and parents of infants who require equipment and technology (including tube feeding) to keep them alive become distanced from their babies (O'Brien, 2001; Thyen et al, 1999; Wilken, 2012). The implications for limited enjoyment and poor quality of life during meals are serious if feeding problems are not managed effectively with premature infants (Cerro et al, 2002; Hawden et al, 2000; Hoddinott & Roisin, 2000).

Parents of children with learning disabilities often find it hard to adjust to their child's communication behaviours and interaction style and this can lead to use of more directive language compared to typically developing children of a similar developmental age (Ferm, 2006; Ferm et al, 2005). The language style that a parent opts to use is also governed by an infant's or child's responsiveness as responsiveness generates interaction (Maurer and Sherrod; 1987; Reyna et al, 2006). In addition, the child's feeding history also has an effect with parents of infants who have had persistent feeding difficulties showing less adaptive and more intrusive interaction during mealtimes (Silberstein et al, 2009). Parents of infants born prematurely continue to perceive that their child has persistent difficulties with eating regardless of whether there are problems or not which in turn affects interaction (Jonsson et al, 2013). Thus, social interaction for children with

disabilities in everyday settings is likely to be more didactic and require dependence on additional communication methods such as AAC (Ferm et al, 2005; Light et al, 1986a; 1986b; Pan Alexander et al, 2000; Tulviste, 2000; Veness & Reilly, 2007). Despite these differences, parents still value the social aspects of everyday situations and feel that they have lost an important part of their relationship with their child if oral feeding ceases (Craig et al, 2003a; Craig & Scambler, 2006; Craig et al, 2003b; Mahant et al, 2009; Thorne et al, 1997; Sullivan et al, 2005). This suggests that mealtimes are considered to be an important communication opportunity for carers and children with dysphagia. This is an area which needs further research to examine the benefits both for language and social development as well as management of a swallowing difficulty.

To fully understand feeding difficulties in infants and young children, and the (sometimes erroneous) rationale behind some intervention techniques, it is first necessary to address the nature of typical development. Two papers in this thesis use typically developing premature infants and children to give such a context (Harding et al, 2012b; Harding et al, 2014). The next section also gives a comprehensive overview of normal development in feeding, eating and drinking.

1.3 Development of feeding, eating and drinking

1.3.1. Infant feeding

Early infant feeding skills develop simultaneously alongside communication (Alexander et al, 1993; Bosma, 1986; Bowlby, 1969). The mother-infant dyad, especially during breast feeding provides a close interactive environment (Callen & Pinelli, 2005; Davis, 1992; Whitelaw et al, 1988). Within this environment an infant can learn to obtain milk by sucking as well as develop awareness of others (Bosma, 1986; Bowlby, 1969). The tactile sensation from feeding as well as the smell of milk can help bonding and this stimulates milk flow (Bingham et al, 2003; Raimbault et al, 2007; Whitelaw et al, 1988; WHO, 1989). Breast milk has many health benefits for the infant, in particular, the development of the immune system, but breast

feeding is also important in the development of early interaction (Bell et al, 1995; Bowlby, 1969; Hylander et al, 2004; Hambraeus, 1977; Innis et al, 1990; Lucas & Cole, 1990; Schanler et al, 1999). Even with bottle feeding, it is still possible to create a close and interactive setting.

Infants use two different sorts of sucking: nutritive sucking (NS) and non-nutritive sucking (Bingham et al, 2009; 2010; Daniels et al, 1996; Dubignon & Campbell, 1969; Kelly et al, 2007; Lau et al, 1997). The differences between NS and NNS are described in Table 1. 1. Nutritive sucking is the process of drinking milk at a rate of one suck per second, and it maintains the same pattern during feeding (Bingham et al, 2009; 2010; Dubignon & Campbell, 1969; Kelly et al, 2007; Lau et al, 1997). During NS there is an alternation between expression and suction when sucking and an increase in transcutaneous oxygen levels during NNS (Paludetto et al, 1984). The process involves the co-ordination of sucking, swallowing and breathing involving the lips, cheeks, jaw, tongue, palate, pharynx and larynx working together (Bingham et al, 2009; Kelly et al, 2007). The suck – swallow ratio of 1:1 changes in the first month of life, with patterns of 2:1 and 3:1 emerging as the infant matures (Qureshi et al, 2002). Premature infants also develop mature NS skills though this may take longer (Howe et al, 2010; Pickler et al, 2012; Pridham et al, 2001b). In contrast, NNS is different and involves two sucks per second. No nutrient flow occurs, so the movement is quicker with less jaw excursion; it may be used to satisfy an infant's basic sucking urge or as a state regulatory mechanism (Lau et al, 1997). It comprises of bursts of tongue movements followed by brief pauses. Tongue and laryngeal movements are distinctly different between nutritive and non-nutritive sucking (Kelly et al, 2007; Mizuno & Ueda, 2006). Nutritive sucking involves significantly greater displacement and excursion in both the anterior and posterior areas of the tongue compared to non-nutritive sucking. Hyoid movement during NNS is smaller than the angle of movement recorded in NS (Miller & Kang, 2007).

Table 1.1: Comparison of Nutritive and Non-nutritive sucking

<u>Non-nutritive sucking</u>	<u>Nutritive sucking</u>
Two sucks per second with no nutrient flow	One suck per second with nutrient flow
Small tongue and laryngeal movements in comparison with NS	Greater displacement of the tongue and larynx during NS
Breast feeding NNS pressure range = (-93.1 ± 28.3mmHg)	Breast feeding NS pressure range = (-77.3 ± 27.0mmHg)
Bottle feeding NNS pressure range = (- 27.5 ± 11.2 mmHg)	Bottle feeding NS pressure range = (-87.5 ± 28.5 mmHg)

(Created by Harding, 2014 from the work of Bingham et al, 2009; 2010; Kelly et al, 2007; Mizuno & Ueda, 2006)

Apart from the differences already noted in tongue and laryngeal movements, sucking pressures differ between NNS and NS, as well as between breast fed and bottle fed infants (Lang et al, 2011; Medoff – Cooper, 1991; Medoff – Cooper & Ray, 1995; Mizuno & Ueda, 2006). Breast fed infants demonstrate a higher NNS than NS pressure, compared to bottle fed infants who display the opposite pattern. The main mechanism of removal of milk from the breast is by the creation of a vacuum stimulated by the infant’s sucking to stimulate the milk ejection reflex (Geddes et al, 2012). Breast fed infant NNS and NS suck pressures are different to the sucking pressures of bottle fed infants (see Table 1.1). Mizuno & Ueda (2006) hypothesise that the reason why breast fed infants have a higher NNS is that the suck needs to be at a greater pressure to stimulate the milk ejection reflex from a mother’s breast. This also helps to stimulate further expression of milk. Breast feeding involves elevation of the tongue beyond the infant’s alveolar ridge. The tongue maintains a cupped shape during this process. This configuration allows the milk bolus to move into the pharynx (Logan & Bosma, 1967). It is important to consider breast feeding in comparison with

bottle feeding as there are some key physiological differences (Moral et al, 2010). Infants who only breast feed or who only bottle feed show differences in their sucking abilities (Moral et al, 2010). Those infants who have access to both breast and bottle feeding tend to alternate between both types of sucking patterns. The duration of pauses during sucking bursts with bottle feeders tends to be greater than breast feeders; the number of sucks per minute is greater with breast feeders than with bottle feeders (Moral et al, 2010). Both breast and bottle feeders have higher NNS sucks per minute than NS, but breast fed infants produce more NNS bursts at a higher pressure than bottle feeders, and breast fed babies display greater NS bursts during feeding compared to bottle feeders (Mizuno & Ueda, 2006). As an infant matures sucking amplitude, rate, pressure, timing of sucking cycles, sucking efficiency and proficiency begin to change developing from 55 sucks per minute to 70 sucks per minute (Qureshi et al, 2002).

With bottle feeding, the tongue retains a cupped configuration but the tip remains compressed against the bottle teat against the alveolar ridge (Oommen & Bhatia, 1989). The mean number of sucking episodes between breast and bottle feeding infants varies, with the mean number of breast sucks per minute being higher than in bottle fed infants. With bottle feeders, there are fewer pauses per minute compared to breast fed infants (Moral et al, 2010). Infants who take both breast and bottle feeds show no significant differences with pauses between those who just take milk from one or other of the mediums (Moral et al, 2010). For infants who are breast and bottle fed concerns have been raised by some practitioners about using mixed methods to feed (Collins et al, 2004). However, there is no clear evidence that the inter-changeable use of teats and nipple presentations cause confusion or that pacifier use diminishes the ability to breast feed (Benis et al, 2002; Collins et al, 2004; Neifert et al, 1995), but infants who both breast and bottle feed tend to stop breast feeding sooner than those who are just breastfeed (Scott et al, 2001).

1.3.2 The development of weaning

As the infant grows and develops, posture becomes more stable and subtle changes with tongue and jaw movement occur as weaning is typically introduced around six months (Bernard-Bonin, 2006; Northstone et al, 2001). Anatomical changes also occur with the larynx descending at this time and moving away from its close proximity to the epiglottis and soft palate (Bosma, 1963a; 1963b; 1967). With the introduction of semi-solids, the infant learns to suck food from a spoon and habituates to the expected tongue patterns that enable managing food from different utensils and of different textures rather than a persistent sequential suck pattern (Bosma, 1967; 1985; Carruth & Skinner, 2002). As a wider variety of textures are gradually introduced at around 9 months, a more vertical tongue-tip pattern accompanied by less jaw movement develops. This allows the infant to develop competencies to cope with mashed foods and bite and dissolve textures. Time taken to acquire competent spoon feeding skills can average around 5.7 weeks (SD 2.1) with a range of between 2 to 10 weeks (Van den Engel – Hoek et al, 2014). Interestingly, the study cited here found no significant correlation between age at the start of spoon feeding and weeks required to achieve competence (Van den Engel – Hoek et al, 2014). Oral skills continue to increase in range and refinement of movement alongside independent skills and as the infant reaches around a year of age, there is a further tolerance of chopped foods (Alexander et al, 1993; Carruth & Skinner, 2002; Green et al, 1997; Stevenson & Allaire, 1991). Although independent feeding skills increase, it may still be necessary to have some adult modelling with both physical and verbal guidance to support skill development (Alexander et al, 1993; Pinder & Faherty, 1999). Oral motor competence with the management of fluids and a variety of textures continue until the child is three years of age (Gisel, 1988; Schwaab et al, 1986; Stevenson & Allaire, 1991; Wohler & Smith, 2002). Knowledge about how typically developing children develop eating and drinking skills is used to guide clinical management, although for children with disabilities,

this may not always be appropriate as they have not had a typical early experience of eating and drinking (Harding et al, 2012a; 2012b).

1.3.3. Describing eating skills

Eating, drinking and swallowing are often described in the clinical context and in the literature as “the phases of the swallow” (Logemann, 1983). The phases are; the oral preparatory phase (Table 1: 2), the oral phase (Table 1: 3), the pharyngeal phase (table 1: 4) and the oesophageal phase (Table 1: 5) (Cichero & Murdoch, 2006; Logemann, 1983). Although the terminology used is based on artificial anatomical landmarks, these descriptors do provide a useful framework for the identification of where specific problems with eating and drinking may occur, particularly when interpreting instrumental assessment results such as videofluoroscopy (VFSS) (Arvedson et al 1994; Rogers et al, 1994). The process of swallowing involves the phases being linked sequentially (Logemann, 1983). The whole process involves a complex interaction between cortical and lower brain activation with active recruitment of cranial nerves (V trigeminal nerve; VII facial nerve, XI glossopharyngeal nerve; X vagus nerve, XI spinal accessory nerve and XII hypoglossal nerve)(Ertekin & Aydogu, 2003; Martin & Sessle, 1993; Martin et al, 2001). The cranial nerves play an important role in swallowing as they relay sensory information from the oral tract to the nucleus tractus solitarius via the brainstem which in turn sends information to the nucleus ambiguus and from there to the relevant muscles, mainly the oro-facial muscles (Ertekin et al, 2001). Upper and lower motor neurons are active in sending this information. Interacting with this muscle and nerve activation are sensory and cognitive processes that occur simultaneously (Ertekin & Aydogu, 2003; Martin & Sessle, 1993; Martin et al, 1991; 2001). Although much is understood about the complex nature of swallowing and its neurological activation for nutritive and non-nutritive movements, it seems that only specific aspects of the process are considered clinically with little distinction made between nutritive and non-nutritive skills (Harding & Cockerill, 2014).

Table 1. 2: Oral preparatory phase

Process	Neurological activity
Sensory response to fluid & food in the oral cavity.	Olfactory receptors respond to the smell of food and send messages to the olfactory nerve. This is processed by the primary olfactory cortex.
Lip closure.	Sensory responses: Trigeminal nerve (CN V) receptors send messages to the cortex via the ascending sensory pathway. Motor responses: the lips receive a message via the descending motor pathway.
Mastication (if eating solids).	Sensory responses: Chewing sends messages about the type of texture, size, viscosity, etc to the Trigeminal (CN V), Facial (CN VII) and Glossopharyngeal nerves (CN IX). Motor responses: Messages received in the primary motor cortex are conveyed to the upper motor neurones to the pons and the nuclei for the trigeminal nerve, and the lower motor neurones which extend from the trigeminal nerve to the muscles of mastication.
Tongue cupping.	Sensory information from the tongue is relayed to the motor cortex via the Trigeminal (CN V) and Glossopharyngeal (CN IX) nerves. The motor cortex sends messages to direct and control tongue movements.
Taste.	Sensory information is processed by the anterior 2/3 of the tongue via the facial nerve and the posterior 1/3 of the tongue to the cortical area for taste. Salivation follows.

(Ertekin & Aydogu, 2003; Martin & Sessle, 1993 ; Martin et al, 2001)

Table 1.3: Oral phase

Process	Neurological activity
Lip seal.	Sensory info from facial nerve with motor control exerted from motor cortex (as in Table 2).
Buccal musculature is activated and prevents loss of bolus in lateral sulci.	Sensory information is sent via the Trigeminal nerve (CN V) to the cortex. The motor cortex sends efferent messages to buccinator muscles via pons and the Facial nerve (CN VII).
Food and fluid from the anterior to the posterior part of the tongue by an undulating movement.	Sensory information from the tongue and hard palate is relayed to the cortex via the Trigeminal (CN V) and Hypoglossal (CN XII) cranial nerves (for the tongue) and the Facial nerve (CN VII) (for the hard palate), and this stimulates motor movement of the tongue (the Glossopharyngeal nerve, CN IX).

(Ertekin & Aydogu, 2003; Martin & Sessle, 1993 ; Martin et al, 2001)

Table 1.4: Pharyngeal phase

Process	Neurological activity
Swallow triggered.	Sensory information from CN IX, X, XI is projected to Nucleus Tractus Solitarius (NTS) in medulla. NTS communicates with Nucleus Ambiguus (NA), the motor nuclei, to trigger swallow by stimulating CN IX X and XI. Innervates muscles of velum, pharynx, larynx and upper oesophageal sphincter (UES).
Velum elevates and retracts	Innervated by pharyngeal plexus (CN IX and X)
Hyoid and larynx elevate and move anteriorly	Complex interconnected sequence of movements involving the Trigeminal, Facial and Hypoglossal nerves (CNs V, VII and XII) are involved in elevation/anterior movement of hyoid and larynx.
Larynx closes	The Vagus nerve (CN X) – innervates the intrinsic muscles of larynx to adduct vocal folds.
Cricopharyngeal sphincter opens	Innervated by pharyngeal plexus –this causes the UES to relax.
Bolus is pushed through pharynx	Progressive contraction of the posterior pharyngeal wall (pharyngeal constrictor muscles) innervated by Pharyngeal Plexus.

(Ertekin & Aydogu, 2003; Martin & Sessle, 1993 ; Martin et al, 2001)

Table 1.5: Oesophageal phase

Process	Neurological activity
Cricopharyngeus and upper oesophageal sphincter opens. The airway closes.	Bolus passes through the oesophagus.

(Ertekin & Aydogu, 2003; Martin & Sessle, 1993; Martin et al, 2001)

1.4 What is “dysphagia”?

Feeding, eating and drinking are highly complex activities. Effective eating and drinking require good posture, an integrated motor, sensory and autonomic nervous system, healthy gastrointestinal and cardio-respiratory systems, and access to social communication (Bochner & Jones, 2003; Colodny, 2001; Fiese & Schwartz, 2008; Harding et al 2010a; 2012b; Harris et al, 2003; Illingworth & Lister, 1964; Martin-Harris et al, 2005; Reix et al, 2006; Thach, 2005; Shiao et al, 1995). The term “dysphagia” refers to a disorder that prevents effective feeding, eating and drinking at all phases of the

swallow and can impact on the successful integration of all the skills described which are necessary for safe eating and drinking (Kennedy et al, 1997; Logemann, 1983; Martin-Harris et al, 2005). Dysphagia can arise due to congenital, acquired or progressive problems (Harding & Wright, 2010; Logemann, 1983; Willing et al, 2004). Ineffective eating can lead to malnutrition, and other health problems associated with aspiration (Arvedson et al, 1994; Lefton-Grief & Arvedson, 2008). Some of the papers included in this thesis focus directly on these issues (Harding & Wright, 2010; Harding et al, 2015).

1.4.1 The caseload

Problems with early feeding development have been identified in 25 – 45% of a typically developing population (Bernard – Bonnin, 2006). Feeding difficulties that have serious and long term consequences associated with aspiration are more likely to be found with children who have had a traumatic early history (Arvedson, 2008). Furthermore, increased incidence of dysphagia within paediatric groups is due also to improved neonatal care because higher survival rates are achieved (Kakodkar & Schroeder, 2013; Lefton-Grief & Arvedson, 2007; Miller & Willging, 2003).

Estimates of feeding difficulties in these groups can be as high as 99% (Calis et al, 2008). For children with specific congenital disorders such as cerebral palsy, aspiration difficulties have been identified as being between 31% - 99% in the population studied (Calis et al, 2008; Mirrett et al, 1994; Reilly et al, 1996; Wright et al, 1996). Table 1.6 summarises some estimations of eating and drinking difficulties identified in specific paediatric populations. The range of percentages estimating problems with aspiration risk vary greatly, making generalisation of this information limiting. Populations studied have varied aetiologies, are small, or include a population of young children, or children immediately post trauma where the problems potentially may change and not persist. In addition, this variation could be questioned in terms of either an over or under estimation of the problems by clinician - researchers (Leslie et al, 2003). Interpretation

and descriptions of swallowing difficulties are also likely to vary according to the clinical experience and experiences of the assessing SLTs (Bateman et al, 2007; Leslie et al, 2003; Martino et al, 2004).

Table 1.6 Prevalence of dysphagia in paediatric populations

Diagnosis	Estimate of the % who have dysphagia	Authors
Severe traumatic brain injury - acute phase of care	72 % 68 %	Morgan et al, 2004a Rogers et al, 1994
General neurodevelopmental disabilities	26% 37.5% 44% 21% 34%	Arvedson et, 1994 Morton et al, 2002 Taniguchi and Moyer, 1994 Newman et al, 2001 Weir et al, 2011
Premature infants	40% 26.8 % (VLBW infants)	Uhm et al, 2013 Lee et al, 2011
Acute viral illness	25%	Khoshoo & Edell , 1999
Infantile Pompe disease	38%	Jones et al, 2010
CHARGE syndrome	60%	Dobblesteyn et al, 2008
Cerebral palsy	99% 68.2% 90% 27% 31.25%	Calis et al, 2008 Mirrett et al, 1994 Reilly et al, 1996 Waterman et al, 1992 Wright et al, 1996
Down's syndrome	57. 7%	O'Neill & Richter, 2013
Presence of endotracheal tube	28%	Amantea et al, 2004
Tracheostomy in infants	7%	Leder et al, 2010
Neonatal arterial ischemic stroke	25%	Barkat-Masih et al, 2010
Post cardiac surgery	79%	Sacheva et al, 2007
Open heart surgery	24%	Yi et al, 2013
Unexplained respiratory problems	57.9%	Lefton-Grief et al, 2006
Ataxia telangiectasia	27%	Lefton-Grief et al, 2000
Infants with no known disorders	11.6%	Sheikh et al, 2001
Posterior Fossa tumour re-section	23%	Newman et al, 2006

Within a typical caseload of infants, children and young people with dysphagia, it is likely that there will be additional learning, communication, sensory, behavioural and physical needs (Field et al, 2003; Hawden et al, 2000). The majority of cases are congenital and may have specific syndromes, but a smaller number are acquired disorders (Arvedson, 2008; Clark et al, 2000; Field et al, 2003; Lefton-Grief & Arvedson, 2008; Lindgren et al, 2000; Miller et al, 2005; Morgan et al, 2003; O'Reilly & Lacioni, 2001; Pickler et al, 2010; Quartino, 2006; Samejia et al, 2007; Sandy, 2003; Sugar – Mann – Isaacs et al, 2003; Thommessen et al, 1992; White et al, 2014). Many children may have periods of requiring tube feeding given the nature of their difficulties and this can impact on successful transition to oral feeding as well as the development of communication and consistent interaction during mealtimes (Bazyk, 1990; Reyna et al, 2006; Wilken, 2012). In addition, children with congenital disorders are at higher risk of poor health aside from the swallowing difficulties (Cook & Kahrilas, 1999; Harding & Wright, 2010; Hollins et al, 1998; Kerr et al, 2003). Dysphagia increases with the degree of physical disability as postural instability and abnormal muscle tone can impact on each of the phases of the swallow (Dahl et al, 1996; Del Giudice et al, 1999; Hardwick, 1993; Parkes et al, 2010; Rosenbaum et al, 2007; Selley et al, 2000). People who have severe learning disabilities and cerebral palsy have a higher level of eating and drinking difficulties, poor weight gain and risk associated with dysphagia (Arvedson et al, 1994; Benfer et al, 2012; Bohmer et al, 1999; Dahl et al, 1996; Erasmus et al, 2012; Fung et al, 2002; Himmelmann et al, 2009; Rogers, 2004; Rogers et al, 1994; Stallings et al, 1993; Stevenson et al, 1994). Therefore, across the lifespan, those with impaired cognition, severe communication difficulties and reduced independence are at higher risk of dysphagia, partly because of health, but also because interpreting the non – verbal signs of people with learning disabilities maybe harder during mealtimes which may make mealtime management more difficult (Halper et al, 1999; Huxley at al, 1978; Yimaz et al, 2004).

Dysphagia in association with learning disabilities is an important consideration because a high proportion of a paediatric dysphagia

caseload will have a learning disability and vice versa: one study identified that 57% within a group of people with learning disabilities had some level of nutritional difficulties (Kerr et al, 2003). Feeding, eating and drinking problems are common in children who have congenital disorders, and many within this group are of high risk of missing important developmental stages for taste and texture development and may also develop subsequent aversions to food (Birch & Marlin, 1982; Blissett & Harris, 2002; Cass et al, 2005). These difficulties may be further exacerbated by reflux which can influence both appetite and gut absorption (Bhatia & Parish, 2009; Billeaud et al, 1990; Ertkin et al, 2010; Glinanain et al, 2011; Khoshoo et al, 2000; Kirby & Noel, 2007; McClean & Fink, 1980; Schwartz et al, 1980; Strudwick, 2003).

Infants who are born prematurely can have difficulties establishing successful feeding due to an inability to sequence the suck-swallow-breathe cycle (Rommel et al, 2003; Ward & Beachy, 2003). Premature infants are also are vulnerable to increased risk of morbidity, respiratory problems, readmission to hospital in the first year of life and difficulties establishing feeding (Bell & Aper, 2007; Blaymore – Bier et al, 1993; Eichenwald et al, 2001; Gunville et al, 2010; McAnulty et al, 2009; Regev et al, 2003; Raju et al, 2006; Shiao et al, 1996; Ward & Beachy, 2003). Feeding problems are one of the most common reasons for hospital re-admission for this group (Escobar et al, 2006).

The number of infants and children with eating and drinking difficulties is not clearly quantified as they do not comprise a homogenous group. In addition, studies vary in use of definition as to whether the eating and drinking difficulties are just oral or pharyngeal, or if they are a combination. Field et al (2003) noted five areas that a practitioner was likely to encounter; food refusal, food selectivity by type, food selectivity by texture, oral motor delay and neurological swallowing problems. The reasons for these difficulties are multi-factorial and may be due to lack of a normal feeding experience, an interrupted development of eating skills, differences in muscle tone that impair the development of feeding and differing neurological and physiological composition that impact on development (Birch & Marlin, 1982;

Blissett & Harris, 2002). Although less prevalent on paediatric dysphagia caseloads, there are examples of acquired disorders through head injury plus other health problems such as cancer, a stroke or a brain tumour (Cherney & Halper, 1989;1996; Mackay et al, 1999; Morgan et al, 2004a). Depending on the site of the lesion, dysphagia may be temporary (where there is a period of tube feeding in place) or permanent (where alternative feeding needs to be implemented) (Morgan et al 2002; 2003).

Traditionally, dysphagia within paediatrics has been split between organic (medical and nutritional problems) and non-organic (behavioural and psychological problems) types of disorders (Bithony et al, 1989; Budd et al, 1992). However, professionals who work with children with dysphagia argue that the adequacy of how feeding, eating and drinking difficulties are classified is misleading (Rommel et al, 2003). The classification of feeding difficulties into organic and non-organic disorders is not useful as it does not lead naturally to straightforward solutions to the management of these problems (Wittenberg, 1990; Douglas & Byron, 1996). Such a rigid division does not account for the aetiology of the disorders requiring intervention and therefore does not allow appropriate or effective treatment plans to be formulated. The implication within clinical cultures is that the aetiology perhaps should inform treatment , although the reality is that feeding, eating and drinking disorders are often more complicated with considerable overlap between the medical , psychosocial and behavioural needs of children and their families (Hawden et al, 2000; Harris & MacDonald, 1992; Rommel et al, 2003).

1.5 Summary

This thesis evaluates and discusses issues relevant to SLT assessment and intervention within a paediatric population of infants and children who have dysphagia. It suggests that the current evidence base to support many strategies is limited. There is a complex interaction between the current evidence base to support competent assessment and intervention as well as variable practitioner understanding of the neurology and physiology of the

disorders seen clinically. Additionally, the cultural values of practitioners and the integration of goals whilst managing family and multi-disciplinary relationships create a complex clinical environment. Salient points in this thesis are substantiated by papers published in peer reviewed journals. The papers that have been written evaluate different aspects of assessment and intervention from a SLT perspective. A continuous theme throughout this research is to identify the rationale underpinning therapy assessments and approaches to intervention and how these link to established theories relevant to a group that has a high number of congenital disorders. The following paragraphs summarise the topics discussed.

Chapter 1: Introduction: this chapter introduces the background concepts relevant to this thesis. It includes a description of typical development of feeding, eating and drinking skills that infants and children experience. It also considers problems that may be experienced, and the prevalence of these difficulties. Many infants and children with dysphagia are highly likely to have some level of learning disability which means that management of eating and drinking will be life-long. The challenges related to this are discussed in the Harding & Wright (2010) paper. Given that many children are likely to have communication needs alongside their dysphagia, the mealtime environment from an interactive perspective is explored. The contribution that changes in communication style can make in the management of dysphagia is discussed in two papers (Harding et al, 2010; Harding et al, 2012b).

1. Harding C. & Wright J. (2010). Dysphagia: The challenge of managing eating and drinking difficulties in children and adults who have learning disabilities. *Tizard Learning Disability Review Journal: Vol.15 (1) January, 4-13*
2. Harding C., Lindsay G., O'Brien A., Dipper L. & Wright J. (2011). The challenges of implementing AAC to children with profound and multiple learning disabilities: A study in rationale underpinning intervention. *Journal of*

Research in Special Educational Needs, Vol: 11 (2) p 120 - 129; doi:
10.1111/j.1471 - 3802.201001184

Chapter 2: Assessment: SLTs use a variety of informal, formal and instrumental assessments to make clinical judgments. This chapter reflects on current practice and discusses the challenges in developing new concepts and ways of thinking to help establish more accurate decisions. It also reflects on the neurological differences that are occurring when assessing a child's skills both outside of and within a functional eating and drinking context. The straw paper is a normative data collection of differing drinking straw speeds. This was collected for use as a clinical reference data base for children with progressive muscle disorders as it provides information about normal straw drinking speeds in relation to age and gender in a group of children aged from 4 years to 11 years of age. As this is a large sample, it provides a substantial body of data to support clinical assessment and also provides a platform to develop further methods of evaluating change in a population of children who have changing muscle tone, e.g. myotonic dystrophy. Discussion considers the value of such data and its contribution to more informed assessment.

Harding C; Aloysius A (2011) Drinking speed using a valved Pat Saunders straw TM, wide bore straw and a narrow bore straw in school age children. *The International Journal of Evidence Based Health Care* 9; 435 – 439; doi: 10.1111/j.1744-1609.2011.00241.x

Chapter 3: Intervention to manage dysphagia: many strategies used to support dysphagia management have a limited rationale to support them. One of the papers in this chapter has attempted to examine the therapy skills used to help children with a complex history of feeding problems wean off gastrostomy tube feeds (Harding et al, 2010c). Each element of the intervention is linked to appropriate evidence where possible, and this

chapter discusses how the gaps in intervention literature for paediatric literature could be approached. The second paper focuses on pre- and post-dysphagia training for staff in a special school context (Harding & Halai, 2009). Working with support workers and carers is a large part of dysphagia management. The findings from this paper highlight some important issues relevant to how SLTs enable significant others to carry out strategies on a daily basis. This paper also discusses the importance of using communication in specific ways during mealtimes to promote positive eating experiences as well as a method of identification of risk.

Harding C. & Halai V. (2009). Providing training for carers of children who have profound and multiple learning disabilities. *British Journal of Developmental Disabilities*, 55(1), 33-47

Harding C., Faiman A., Wright J. (2010). A pilot project to evaluate an intensive desensitisation, oral tolerance therapy and hunger provocation programme for children who have had prolonged tube feeds. *The Journal of Evidence Based Health Care* December (8); 268 – 276

Chapter 4: Non-nutritive sucking intervention techniques; this chapter discusses NNS as an intervention in more detail. The papers in this chapter include two commentaries on NNS as a strategy (Harding, 2008; Harding, 2009), a single case study (Harding et al, 2012a) a randomised controlled trial which critiques the rationale for using NNS (Harding et al, 2014) and a small sample of infants with neurodisability who have used NNS, but who have not all achieved full oral feeding (Harding et al, 2015). The themes in these papers have been discussed earlier and include; the importance of differentiating between non -nutritive and nutritive activation when implementing strategies and the importance of communication in the management of infant feeding development.

Harding C. (2008). Issues around non-nutritive sucking. *Developmental Medicine and Child Neurology*, 50(1) 76-80

Harding, C. (2009). An evaluation of the benefits of non-nutritive sucking for premature infants as described in the literature. *Archives of Disease in Childhood*, 94(8), 636-640

Harding C., Frank L., Dungu C., Colton N. (2012) The use of non-nutritive sucking to facilitate oral feeding in a term infant: A single case study. *Journal of Pediatric Nursing* 27; 700 - 706

Harding C., Frank L., Van Someren V., Hilari K., Botting N. (2014) How does non-nutritive sucking support infant feeding? *Infant Behavior and Development* 37; 457 – 464

Harding C., Frank L., Cockerill H., Van Someren V., Botting N., Hilari K. (2015) Assessment and management of infant feeding. *Submitted to Infant. Accepted for publication and in press.*

Chapter 5: Conclusions: this chapter summarises the papers presented in chapters 1 to 4. It explores the challenges within each of the papers, and critically evaluates them. It also considers the themes in the thesis, namely the findings from the NNS research and its differences in comparison to the other papers published in this area the role of communication as a potential strategy in the management of feeding disorders. It also discusses the contribution that the papers have made to research in the area of paediatric swallowing disorders.

1.6 Research findings completed by the author for Chapter 1

1. Harding C. & Wright J. (2010). Dysphagia: The challenge of managing eating and drinking difficulties in children and adults who have learning disabilities. *Tizard Learning Disability Review Journal: Vol.15 (1) January, 4-13*

This paper provides a summary overall of the issues relevant for people with learning disabilities across the lifespan. Of particular note is the description of the strategies used that are often used for people with learning disabilities to support their eating and drinking and the small evidence base evident to support these strategies. This is a theme that is reiterated throughout this thesis. This paper also highlights the importance of carers and training as well as the risks of poor outcomes associated with poor understanding of swallowing disorders.

2. Harding C., Lindsay G., O'Brien A., Dipper L. & Wright J. (2011a). The challenges of implementing AAC to children with profound and multiple learning disabilities: A study in rationale underpinning intervention. *Journal of Research in Special Educational Needs, Vol: 11 (2)120 - 129* ; doi: 10.1111/j.1471 - 3802.201001184

This paper is not specifically about dysphagia. However, it does consider a method of how to improve communication using AAC for children with profound and multiple learning disabilities. One of the environments targeted in the study was mealtimes where both participants significantly improved their communication responses and initiation skills. The most important aspect of this paper is that it attempts to provide an evidence based rationale where possible. This is important as this is the approach undertaken with all the intervention papers in this thesis.

3. Harding C., Wade C., Harrison K. (2012b) Communication between children and carers during mealtimes; what can we learn to improve communication opportunities for children with learning disabilities? *Journal of Research in Special Education Needs*; 13(4) 242 – 250

There is very little research on typically developing populations of children during mealtimes. This paper explores the communication of six children with their carers during a typical mealtime. The final section of the paper discusses how this information could be used when considering the mealtime communication of children who have disabilities and makes suggestions about how this may be completed.

1. Harding C. & Wright J. (2010). Dysphagia: The challenge of managing eating and drinking difficulties in children and adults who have learning disabilities. *Tizard Learning Disability Review Journal: Vol.15 (1) pp 26 - 35*



Feature

Dysphagia: the challenge of managing eating and drinking difficulties in children and adults who have learning disabilities

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Abstract

This review explores some of the key issues relevant to children and adults who have dysphagia, or eating, drinking and swallowing difficulties, and a learning disability. It explores the methods for attempting to identify this area of difficulty effectively, and reflects on some of the other issues that may affect management, such as carer support and training and use of appropriate communication strategies to support and enable participation from the client with learning disability.

Key words

dysphagia; eating, drinking and swallowing difficulties; learning disabilities; unmet health needs

Introduction

People with learning disabilities have been identified as having a number of unmet health needs (DRC, 2006; NPSA, 2004; DH, 2001). They range from general health screening check-ups such as vision and audiology tests to more significant medical needs that require acute intervention in a hospital setting (Kerr *et al*, 1996; Mencap, 2007). *Valuing People* (pp59–69) discussed the issues in improving health for people with learning disabilities. Methods to develop

improvements included suggestions such as health facilitators working with people with disabilities to identify health needs (by 2003), ensuring that people with disabilities were registered with a local GP (by June 2004) and ensuring people with learning disabilities had a health action plan (by June 2005).

The Mencap report *Death by Indifference* (2007) highlighted issues related to 'institutional discrimination', where the needs of people with learning disabilities were misunderstood,

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2. Harding C., Lindsay G., O'Brien A., Dipper L. & Wright J. (2011). The challenges of implementing AAC to children with profound and multiple learning disabilities: A study in rationale underpinning intervention. *Journal of Research in Special Educational Needs, Vol: 11* (2)120 - 129 ; doi: 10.1111/j.1471 - 3802.201001184

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Implementing AAC with children with profound and multiple learning disabilities: a study in rationale underpinning intervention

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Key words: Profound and multiple learning disabilities, functional communication, augmentative supports, communication opportunities.

There is a developing research base to support the rationale underpinning augmentative and alternative communication (AAC) for people with learning disabilities. However, there is a paucity of research examining the process involved in implementing AAC support for people who have profound disabilities. This paper seeks to explore the processes involved in planning and implementing AAC systems to support the communication of two 6 year olds with profound and multiple learning disabilities. Following assessment, a plan of intervention involving specific implementation of objects of reference, gestures and signs was implemented to enhance communication opportunities for both children. Both children improved their communication skills through use of specific AAC supports. Results suggest that important aspects to include when planning intervention are understanding the level of each child's cognition in relation to their receptive abilities and a consistent, collaborative approach where strategies are agreed between team members. Specific challenges are discussed.

Introduction

This paper seeks to explore the processes involved in planning the development of augmentative and alternative (AAC) systems for two children who are described as having profound and multiple disabilities (PMLD). Aside from the processes involved, it will consider the evidence base underpinning the selection of AAC materials, and it will attempt to consider the strategies that are necessary when developing appropriate supports for these children.

AAC is described as an area of clinical practice that attempts to compensate (temporarily or permanently) for the impairment and disability patterns of individuals with severe disorders of communication (Beukelman and Mirenda, 1992). It is acknowledged that AAC users typically use a range of modes to support their communication, for example, facial expression, gesture, objects, symbols, speech approximations, signs, communication passports

and electronic devices (Binger, Light and Drager, 2007; Light, Collier and Parnes, 1985). However, the evidence and methodology underpinning the process of implementing AAC support for people with PMLD are unclear.

The term 'profound and multiple disabilities' or PMLD is used to describe individuals who have a profound cognitive impairment alongside multiple disabilities including physical, sensory and/or health-related difficulties (Cartwright and Wind-Cowie, 2005; World Health Organization, 1992). Consequently, those with PMLD are likely to be pre-verbal communicators and may require carers and significant others to interpret their non-verbal communication signals as well as use touch, natural gesture and objects with them to support their language and communication opportunities within the environment (Bloom, 1993; Brooks and Metzloff, 2005; Franco, 1997; Green and Reid, 1996; Guess, Roberts and Siegel-Causey et al., 1993; Locke, 1997).

Difficulties with communication place children who have PMLD at risk of becoming excluded and may often lead to 'social and educational isolation as well as significant frustration' (Ronski and Sevcik, 2005, p. 176). In this study, we present the methods and approaches for implementing a programme to develop AAC to support two children with PMLD in an attempt to reduce isolation and promote choice.

Traditionally, children who are thought of as having PMLD are provided with access to multi-modal forms of AAC support, and this is considered to be good practice [Royal College of Speech and Language Therapists (RCSLT), 2006]. Such supports may also include training others to interpret non-verbal communication including whole body movement, using tactile supports, promoting access to materials for those with complex physical needs or using specific systems such as objects of reference (Park, 1997; Thompson, McKerchar and Dancho 2004; Trief, 2007). Some children may have access to switches where specific sounds or target vocabulary are included. However, it is hypothesised that there are many challenges in implementing and using AAC with children who have such complex communication and physical needs as they are likely to find initiating and maintaining an interaction difficult.

3. Harding C., Wade C., Harrison K. (2012b) Communication between children and carers during mealtimes; what can we learn to improve communication opportunities for children with learning disabilities?
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Communication between children and carers during mealtimes

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Key words: Mealtime social language, parent language style, application for children with learning disabilities.

Mealtimes are identified as an important learning environment where socialisation and language development takes place. Caregivers can facilitate the structure of a child's learning in the mealtime setting. The aim of this study was to gain an understanding about the nature of communication in a normal population during mealtimes. This is important to help understanding about the nature of communication and interaction in children with disabilities during mealtimes.

Participants were six typically developing preschool children aged from 8 months to 3;05 years. Caregivers of the children supported their child having a typical meal at home. Each mother-child dyad was video-recorded by the researchers during a typical meal for up to 30 minutes. Each recording was transcribed by the researchers, and specific communicative features were counted and coded; caregiver comments about appropriate mealtime behaviour, child verbal and nonverbal initiation, caregiver questions and comments about meal enjoyment, caregiver praise of child, and caregiver repetition to coax feeding. A caregiver questionnaire was also completed to obtain information about the child's feeding, any early history of feeding difficulties and typical mealtime routine.

The results indicated that the most considerable difference were between the dyads who had reported early feeding difficulties and those who had not reported any. Carers who supported children who had a history of early feeding difficulties used more language to manage and guide the child's behaviour during the mealtime. Caregivers who reported early feeding difficulties appeared to be more concerned with how their child was presenting at the meal (i.e., appropriate behaviour and meal enjoyment). This information has important implications for supporting children with complex needs during mealtimes.

2001). It is also a time where young children can learn to develop their oral motor skills by being introduced to new textures and tastes in a familiar and safe environment where caregivers can provide encouragement through the use of visual modelling and verbal prompting (Aukhurst and Snow, 1998; Ferm, Ahlsen and Bjork-Akesson, 2005). Communication during the meal may focus on developing independent eating and drinking skills, maintaining appropriate eating abilities or discussion of important events meaningful to the caregiver and the child (Aukhurst and Snow, 1998).

This paper examines normal mealtime communication with six preschool children aged between 8 months and 3;05 years of age. A normal preschool population was selected to gain a baseline of the type of language that caregivers would use with children who have been developing language skills and who may also be using mainly preverbal communication. Gaining this information can provide valuable insight into natural communication during an everyday functional context.

Normal language development

The process of language acquisition begins at birth with the infant's nonverbal skills acting as a pragmatic platform to stimulate interaction between caregiver and baby (Bochner and Jones, 2003). Feeding times as well as other routine events such as nappy changing, bath time and so on provide opportunities for interaction through use of eye contact, facial expression and the use of non-specific vocalisations that caregivers respond to and use reciprocally. Such skills offer important precursor strategies of joint attention, gaze following and later tracking and following gesture (Tomasello, Carpenter and Liszkowski, 2007). These skills of shared attention and interest in gesture are recognised as important in the acquisition of word knowledge and first words (Tomasello et al., 2007). Turn taking, both at the preverbal and verbal stage relies on interaction both for shared experience and for social interaction (Bochner and Jones, 2003).

Mealtime socialisation

Some studies have explored the nature of communication during the mealtime context. Family mealtimes can vary from between 20 minutes to over 45 minutes, depending on the context and age of the child (Ferm et al., 2005; Fiese

Introduction

Mealtimes provide an important opportunity for the development of independent skills, social interaction and language learning for children (Bowerman and Levinson,

1.7 Implications, recommendations and concluding remarks

The studies presented here focus on identification of dysphagia (Paper 1; Harding and Wright, 2010) relevant to infants and children who have dysphagia. The first is that although practitioners are aware of the signs of aspiration, and although Table 1 in Paper 1 differentiates between differing levels of risk signs, the reality is that in a clinical context the demarcation between risk features is not clear. Although this paper focuses on learning disability across the lifespan, the issues commented on are still appropriate to consider for children with congenital disorders that impact on swallowing. These issues are that further research is needed into congenital disorders where there is an associated dysphagia need so that an increased understanding into the signs and risks of aspiration are better understood. In addition, this paper states that research also needs to develop more robust methods of evaluating strategies for children with congenital needs as well as developing better methods of training and supporting carers of children with complex eating and drinking needs. These points are referred to throughout this thesis.

Kayser-Jones and Schell (1997) highlighted the importance of verbal prompting and a social experience during mealtimes in developing effective outcomes for people with dementia. Other researchers within the field of elderly care have identified that improved oral intake and quality of life can arise due to the targeted use of communication (Curle & Keller, 2010; Paquet et al, 2008). For children with dysphagia, mealtime communication has not been studied very substantially. The second paper (Harding et al, 2010a) focuses on two familiar children who had more targeted use of their AAC supports in a range of context including mealtimes where significant improvements in use of communication and initiation from the children was noted. Whereas it is not possible to conclude from this study that improved communication management during mealtimes

improved all aspects of eating and drinking management, it is interesting to speculate as to why both participants improved significantly in this context. Child participant K only made significant improvements with his communication during mealtimes, although not the other two targeted activities. This paper is not specifically about dysphagia, but it is important as it illustrates the problems of using AAC and communication management for children who need help to access and use their communication. However, it does show that change is possible, and what future research projects need to explore is the link between communication management and eating and drinking management. Paper 3 (Harding et al, 2012b) describes how research should consider making clearer the links between use of appropriate communication strategies and risk reduction in the discussion section. In addition, it highlights specific, practical strategies that can be applied to assist children with eating and drinking difficulties in relation to improving their experience of the mealtime but increased positive participation as well as setting up a consistent method of communication that supports the child's abilities during the meal. Using AAC more proficiently during the mealtime will not make the aspiration problems "disappear", but it could possibly reduce risk through pacing, reading a child's non-verbal signs and responding to risk signs. Communication in relation to use of specific types of language used by parents can support eating development as highlighted by Harding et al (2010b) in Chapter 3. It is already known that any attempt at independent feeding can reduce risk to a degree (Pinnington & Hegarty, 2000) as the child has some control over the pace of the meal; if pace has been shown to be important in this respect then it can be assumed that the same outcomes may arise with a more focused use of the child's own communication strategies. This paper stresses that it does not seek to recommend replication of social communication during mealtimes as for children who do not have eating and drinking or learning difficulties. Rather, it suggests that

communication is used in a functional , consistent and structured way so that there are some social and learning opportunities, and so the child can have some further control over the pace and rhythm of the meal. This consistency should promote some risk reduction, but further research is needed as suggested by the work presented here to provide more specific detail about what the actual benefits of communication management for children with dysphagia actually is.

CHAPTER 2

ASSESSMENT

CHAPTER 2: Assessment

2.1 Introduction to Chapter 2

This chapter considers complex issues associated with the assessment of swallowing. These issues are varied and this chapter discusses the disparity between what is known about swallowing such as the timing and coordination of muscle movement and which functions SLTs aim to assess. As with treatment and intervention of dysphagia, the vast majority of papers that evaluate normal function are with adults rather than infants and children (Brodsky et al, 2012; Daniels & Foundas, 2001; Hiss et al, 2001; Lederle et al, 2012). Interestingly, many of these papers use a wide range of methods to collect data, which vary from very practical observations, through to more complex instrumental measures. This chapter raises the importance of developing simple yet effective ways of quantifying and reporting what is seen and how this contributes towards more accurate clinical assessment.

Norm-referenced data is often used during swallowing assessments for congenital as well as acquired disorders (Bateman et al 2007; Martino et al, 2004). It has to be questioned as to what the benefits are of comparing oral motor and pharyngeal skills of a congenital or a progressive disorder to a typical population. Future research needs to establish how findings, particularly both temporal measures and norm – referenced data can be applied, if relevant, to a clinical assessment context. Some of these questions have already been discussed in chapter 1 in the third paper, (Harding et al, 2012) where the authors consider that mealtimes are important for oral motor and social development. However, they do not recommend that a standard template of typical mealtime behaviours be applied to children with eating, drinking and learning needs, but that a child's environment should be maximised to reduce any risks from eating and drinking difficulties and to enhance communication opportunity relevant to the context (Harding et al, 2012b). The paper concluding this chapter evaluates straw drinking in typically developing children aged from 6 -11 years (Harding & Aloysius, 2011). This information was obtained so that the normative data could be used comparatively with children who have progressive disorders. Children with progressive muscle disorders are likely to develop normally in early life, but as

the disorder emerges, changes begin to occur that may impact on a child's ability to safely maintain a full diet through eating and drinking. Using data from a normal population in this instance is potentially beneficial in that changes in skills can be monitored more efficiently and quickly using a very simple method. At the end of the paper, some clinical applications are discussed in relation to the findings.

2.2 Information gathering, observation and oral-motor examination

This section discusses the range of observations and assessment methods used with infants, children and young people who have dysphagia.

2.2.1. Case history

Information gained through discussion with carers is essential in understanding the nature of the problems affecting eating and drinking as well as in considering any strategies recommended post assessment (Bateman et al, 2007; Hendrix, 1993; Pettigrew & O'Toole, 2007). Gaining the carer perspective can also help establish a positive collaborative relationship (Hendrix, 1993). Parent and carer reporting can be influenced by the emotional associations with the child's eating and drinking problems and the impact on daily life activities (Sloper et al, 1991; Sloper & Turner, 1993). Parents often underestimate the problems and risks associated with their child's eating and drinking (Craig & Higgs, 2012; Sellers et al, 2014a; 2014b; Sullivan et al, 2000). It is uncertain as to why parents and carers underestimate feeding problems. It could be that they value the experience of oral feeding highly and that they feel that they may be viewed negatively by professionals, or they fear that any statements associated with difficulties could lead to significant changes, e.g. tube feeding, and therefore a sense of loss of an intimate time for interaction with their child (Craig et al, 2003b). As certain clinical conditions have a high correlation with dysphagia, many children assessed are at risk of eating and swallowing problems (Dodrill, 2011; Field et al, 2003; Harding & Wright, 2010). Knowledge of demographic characteristics can help inform and support accurate case history taking and improve planning for preventative strategies to reduce aspiration. It can also promote accurate and appropriate goal setting through an informed hypothetical

process (Hendrix, 1993). However, a risk is that an over-focus on diagnostic attributes of a condition and an over-reliance on the ecological validity of instrumental assessments such as videofluoroscopy can lead to decisions that are not perceived to reflect the child's feeding abilities in real life and therefore increase conflict with carers (Craig & Higgs, 2012).

2.2.2 Observation

Assessment requires the observation and evaluation of a number of different aspects both environmental and physiological so that a full and accurate picture of a child's eating and drinking needs can be obtained (Harding & Wright, 2010; Lefton-Grief & Arvedson, 2008; Logemann et al, 1999; Martino et al, 2000; Schwartz et al, 2001). In association with observation of swallowing function, non-verbal skills, in particular, those associated with oral readiness or aspiration are considered as an important part of assessment (Gill et al, 1992; Harding & Wright, 2010). For premature infants, observation of and helping the infant to develop oral readiness signs are important when preparing for the introduction of oral feeding, usually at around 34 weeks (McCain, 2003; McCain et al, 2001; McCain & Garside, 2002; McGrath & Bodea Braescu, 2004; McGrath & Medoff-Cooper, 2002; Siddell & Froman, 1993). Alertness and non-nutritive sucking competence are often assessed in combination with a review of successful weight gain, respiratory stability, general physiological stability and the development of alertness and hunger signs before a tube feed (McGrath & Medoff-Cooper, 2002; Pinelli & Symington, 2005)

During assessment, observations might include evaluation of swallowing through observation of movement after drinking sterile water as well as listening to voice quality (which is indicative of aspiration) (Bateman et al, 2007; De Pippo et al, 1992; Martino et al, 2004; Pettigrew & O'Toole, 2007; Suiter & Leder, 2008; Ramsay et al, 2003; Teismann et al, 2011). Although SLTs may use a variety of assessment methods, most would consider completing an oral – motor examination or "bedside clinical assessment" (Bateman et al, 2007; Kennedy, 1992; Martino et al, 2004; Pettigrew & O'Toole, 2007; Price et al, 1997) as well as an observation of a typical mealtime (Bateman et al, 2007; Lefton-Grief & Arvedson, 2008; Martino et al, 2004; Pettigrew & O'Toole, 2007). Oral-motor examination may involve manipulating the jaw and tongue and

looking at oral sensation (Bateman et al, 2007; Kennedy, 1992; Martino et al, 2004; Pettigrew & O'Toole, 2007). Assessing the gag reflex is used by some SLTs as part of their oral -motor examination as it gives some indication of sensation rather than swallow competence. Activation of the gag is different from initiation of a cough; the gag utilises glossopharyngeal sensory input (cranial nerve XI) and vagal motor output (cranial nerve X) which is different from the cough reflex as this involves superior laryngeal (vagal) sensory input with recurrent laryngeal motor and glottic closure (Cichero & Murdoch, 2006; Love & Webb, 2001). Because the gag reflex and swallowing reflex are not activated by the same neurological pathways many clinicians argue that assessing the gag gives little information about the safety of the swallow and do not use it in assessments (Bateman et al, 2007; Logemann et al, 2008). With acquired disorders though, the absence of a gag is used as a predictor of the likelihood of non-oral intake and if lack of a gag persists beyond four weeks it is regarded as being an indicator of significant dysphagia (Ertekin & Aydogdu, 2003; Makoto et al, 2010; Ramsey et al, 2005). A literature search from 1970 - 2014 found that there were no paediatric studies that indicated the importance of the gag with either congenital or acquired conditions (Appendix 1). Sixteen studies were identified from the search, but none were suitable for discussion in this thesis. This is because two papers were single case studies of adults with complex acquired needs (Choi et al, 2006; Villarejo - Galende et al, 2003); five discussed adult stroke cases (Hughes & Wiles, 1996; Kolb & Broeher, 2009; Nishiwahi et al, 2005; Ramsey et al, 2005; Somasundaram et al, 2014); four focused on instrumental assessment with adult acquired cases (Bleach, 1993; Bours et al, 2009; Kaye et al, 1997; Leder & Espinosa, 2002); two explored oral motor difficulties experienced by adults without congenital disorders requiring medication (Chaumatin & Lachaux, 2012; Mangilli et al, 2009) and two evaluated bedside clinical assessment methods (Gonzalez- Fernandez et al, 2011; Leder et al, 2002). Only one paper referred to a paediatric population, but this was about managing foreign body materials in the oesophagus and therefore was not focusing specifically on dysphagia (Roderiguez et al, 2012). Although the gag does not provide specific information about the swallow it can provide sensory information and give an indication of any changes that are occurring in a

person's neurological status (Ertekin & Aydogdu, 2003). A similar issue is related to palatal function, and during observation and assessment the SLT may, for example, ask the client to say "ah" so that palatal functional and voice quality can be assessed, or ask the client to swallow their saliva prior to attempting a dry swallow. Clients may also be asked to demonstrate a range of tongue movements both inside and outside the oral cavity. There is therefore a reliance on client cognition to be able to comply with basic commands, but there is also an expectation that actions carried out outside of a functional context will provide information that has direct relevance to the process of eating and drinking. However, the neurological activation for these varied skills is different, and this is discussed later (Bennett et al, 2007; Broussard & Alschuer, 2000; Hamdy et al, 1999a; 1999b; Jean, 1984; 2001; Kern et al, 2001; Kessler & Jean, 1985; Koga & Bradley, 2000; Martin et al, 2004; Mosier & Brenznaya, 2001; Murray et al, 1998; Perry et al, 2002; Suzuki et al 2003).

Assessment may additionally involve other methods such as cervical auscultation. This is a method of subjectively evaluating the pharyngeal function by listening to breathing and swallow sounds during a swallow (Logan & Bosma, 1967; Takahashi et al, 1994). Although acoustic analysis of swallow sounds has produced results for swallow sound duration with peak intensity recordings and associated gender differences (Youmans & Stierwalt, 2005) and specific duration of laryngeal and pharyngeal sounds associated with movement (Moriniere et al, 2008) this type of data has not become integrated into mainstream assessment (Bateman et al, 2007; Kennedy, 1992; Martino et al, 2004; Pettigrew & O'Toole, 2007). One reason could be that practitioners may interpret sounds as either being a swallow "click" or breath sound, or alternatively, may not hear all sounds consistently (Borr et al, 2007; Leslie et al, 2004). Similar difficulties in interpretation have been identified with swallow sounds in a population of healthy children (Almeida et al, 2008). Another reason could be that agreement between practitioners is not strong. Stroud et al, (2002) evaluated agreement in identification of swallow sounds using sixteen recordings. Only three of the recordings were examples of aspiration. Agreement between raters was only fair (0.28 kappa). In a similar study using recordings of dysphagic stroke adults,

Leslie et al, (2004) had poor inter-rater reliability on normal swallows (0.02 kappa) and poor inter-rater reliability on abnormal swallows (0.18 kappa). These findings currently suggest that this tool remains an adjunct to assessment rather than core in decision making about the identification of aspiration or penetration. Studies on cervical auscultation have additionally been criticised in the literature because of design limitations and unclear criteria for participant selection (Collins & Bakheit, 1997); poor comparison with instrumental evaluation such as videofluoroscopy (Lim et al, 2001); small sample sizes (Sellars et al, 1998) and poor inter-rater reliability (Leslie et al, 2004; Stroud et al, 2002).

Another assessment tool is pulse oximetry which is used to monitor heart rate and level of oxygen saturation during a mealtime or oral trial of fluid or food (Leder et al, 2011; Morgan et al, 2001; 2004b; Smith et al, 2000). An increase in respiratory effort can interrupt the swallow process and lead to aspiration or an aspiration event which is indicated by oxygen desaturations (Dozier et al, 2006; Leder, 2000; Lederle et al, 2012). Morgan et al, (2001) evaluated nine children (mean age 14 years, range 9;7 – 15;11 years) with chronic neurological disability and compared them to nine health controls with the same mean age (range 9;5 years – 16;0 years). A statistically significant difference was found in oxygen saturation levels between the two groups during oral intake. Only three children demonstrated oxygen desaturation during their meal. The authors acknowledge that this was only a small sample, and that further data needs to be collected on larger samples of children with a wider range of difficulties associated with dysphagia.

Both cervical auscultation and pulse oximetry remain part of clinical assessment and would not be used on their own to identify aspiration. Having access to equipment which can make calibrated measures of oral and pharyngeal function is not readily available, and as a result, clinicians rely on observation and use of additional procedures such as those described (Perlman et al, 2000; Smith et al, 2000). The conclusions drawn and measurements taken during observation / clinical assessment including cervical auscultation and pulse oximetry are not consistent as there is no one agreed format or methodology in use, and the recordings obtained,

particularly for pulse oximetry, are not always accurate (Dozier et al, 2006; Lederle et al, 2012).

A few studies have evaluated the normal development of eating and drinking in terms of amount of fluid ingested, numbers of spoonfuls of food taken, types of foods tolerated and general oral motor skill development (Gisel, 1988; Gisel et al, 1986; Harding & Aloysius, 2011; Hudspeth et al, 2006; Potter & Short, 2009; Van den Engel – Hoek et al, 2014). The development of differing methods and variety in assessment could be multi-factorial. One reason, particularly in paediatric dysphagia is that a small number of SLTs who work with children specialise in this area and this impacts on the development of widely used methods (Bailey et al, 2008). A narrow definition of “dysphagia” has been suggested as being one reason for the inconsistency in the development of core dysphagia assessment skills (Leslie et al, 2003). Because of the inconsistency in the availability of this information and limited application to clinical practice, much expertise with assessment relies on practitioner knowledge and experience of normal versus deviant feeding, eating and drinking abilities and application of this to an observational context (see Table 1, p 7 ; Harding & Wright, 2010).

2.2.3 Checklists used in observation

The number of specific dysphagia assessments available for infants, children and young people are limited in number. However, there are some commercially available assessments specifically designed for a paediatric caseload (Brindley, et al, 1996; Evans-Morris & Dunn-Klein, 2000; Meyer-Palmer, 1993; Reilly et al, 1995; Skuse et al, 2000; Sellers et al, 2014a; 2014b). Most of these assessments have had inter-rater and intra-rater reliable measures completed (Brindley, et al, 1996; Meyer-Palmer et al, 1990; Reilly et al, 1995; Skuse et al, 2000; Sellers et al, 2014a; 2014b). Only one is a specific checklist which highlights key areas that a practitioner would be evaluating during assessment (Evans-Morris & Dunn-Klein, 2000). The Neonatal Oral Motor Schedule (NOMAS; Meyer-Palmer, 1993) is specifically for infants in acute care settings. The NOMAS is a clinical tool that categorises oral-motor patterns that underlie feeding behaviour in neonates and it involves evaluation of both non-nutritive and nutritive sucking. It describes 13 characteristics of tongue

and jaw movement; Meyer-Palmer (1996) recognises the importance of the movement of the jaw in relation to the tongue. The characteristics of both the jaw and the tongue are divided into categories of normal, disorganised and dysfunctional patterns of behaviour (Meyer Palmer, 1993). Disorganised features tend to be immature movements of the jaw and tongue, and features described on the checklist include elements such as "inconsistent degree of jaw depression", "arrhythmical jaw movements", "incordination of suck /swallow and respiration", "nasal flaring, head turning", and "extraneous movement". These patterns are used to describe the oral motor movements attempted by premature infants. The third category is referred to as "dysfunctional"; this includes terms on the checklist such as "excessively wide excursion" of the jaw; and descriptions of the tongue such as "flaccid" and "retracted". For both the tongue and jaw, practitioners are required to make a percentage judgement about the movement of the articulators; this is a subjective opinion as no specific guidance is provided as to how to give an overall percentage measure (Meyer - Palmer, 1993).

Similarly, the Paediatric Oral Skills Package (POSP) (Brindley et al, 1996) provides a structure to observe oral motor skills during assessment for the 0 -16 year old group. It requires informal and clinical observation, and argues that it uses objective measures. It is not necessary to complete all the sections, and the SLT decides which aspects require specific and detailed assessment. Sections cover: Breathing, Voicing, Oro-facial structure & function, Eating, Drinking, Movement, Articulation, Teeth/Dentition, and Saliva Control. Each section requires an overall rating of the movement being assessed from 1 -3 (where 1 = normal, 2 = some difficulties and 3 = significant difficulties) which requires clinician knowledge of developmental norms of function in these areas. If a score of three is gained indicating significant difficulties, a further subjective rating of between 1 – 5 is made (where 1 = least severe, and 5 = most severe). Imitation of tongue movement, for example involves asking the child to stick their tongue out, move it back into the oral cavity, lick the upper and lower lip, and other movements both within and outside of the oral cavity; descriptors such as "perseveration" and "weak movement" support the evidence collected during assessment. Grading enables a SLT to make an evaluation of the severity of the problem. The authors explain that the

assessment is not standardized, but is '... a clinical tool, which has been developed in clinical situations' (p. iii). It can be argued that the overall rating of movement from 1 to 3, and the further ratings of 1 to 5 still rely on a combination of clinical experience and subjective evaluation. This issue can also be relevant for the NOMAS (Meyer - Palmer, 1993) where judgements about whether something is "flaccid" or "immature" still require clinical experience to make a decision.

The Schedule for Oral Motor Assessment (SOMA) (Reilly, et al, 1995; Skuse et al, 2000) is described by its authors as an objective evaluation of the skills of pre- school children. Oral motor function is assessed with a focus on a range of food textures. The schedule is based on a sample of 127 children; it has a predictive validity of 97% positive predictions of validity and 85% sensitivity to identify oral motor dysfunction (Reilly et al, 1995; Skuse et al, 2000). The SOMA has four main components which are ; i) oral motor challenge categories, ii) functional areas, iii) functional units/activity of the muscle groups, and iv) discrete oral motor behaviour. Solids, for example evaluate lip, jaw and tongue movement during eating and require the clinician to consider if the jaw moves in a graded way, how the lips move during eating, especially in relation to utensils, self feeding attempts and other areas relevant to functional oral motor skills (Brindley et al, 1996; Meyer - Palmer, 1993; Reilly et al, 1995; Skuse et al, 2000).

Sellers et al, (2014b) have commented that despite the evidence to support inter- and intra- rater reliability for some assessments (Brindley et al, 1996; Meyer-Palmer, 1993; Reilly et al, 1995; Skuse et al, 2000), there are no reliable or valid scales in existence that classify functional eating and drinking abilities for children and adults with cerebral palsy. They identified problems in many assessments with variation in use of terminology to describe the phases of the swallow. In addition, they commented that few addressed content validity or intra - / inter - rater reliability. This is in contrast to the Gross Motor Functional Classification System used to describe level of physical disability within the population of people who have cerebral palsy as this has good content validity and rater-reliability and is in mainstream use (Eliasson, 2007; Palisano et al, 1997; 2008). Sellers et al (2014a) considered the problems raised and designed a method of classifying the eating and drinking abilities of

children and people with cerebral palsy, The Eating and Drinking Ability Classification System (EDACS) (Sellers et al, 2014b). The EDACS has a high level of reliability, with SLTs showing absolute agreement at 78%.

Interestingly, when considering all the available rater-reliable assessments, only the NOMAS requires practitioners to re-new their reliability skills on a regular basis so that rater reliability can be maintained. Despite these assessments having inter - and intra - rater reliability measures completed on them, they still require a number of clinical skills which not all SLTs, particularly those less experienced, will have. These clinical skills include experience of the developmental norms for eating and drinking; experience of evaluating different types of muscle tone and formulating an opinion about muscle movement, an awareness of specific problems to look out for within particular groups of disabilities and making general subjective judgements about what is being observed.

2.3 Instrumental assessment

In many instances where aspiration is suspected, a more formal instrumental assessment may be needed. A videofluoroscopy is one such procedure and involves the use of radiation. It provides a recorded image of a client's swallowing status and lateral view of the oral preparatory, oral and pharyngeal phases of the swallow (Furia et al, 2000; Hiorns & Ryan, 2006; Kendall et al, 2000; Olsson et al, 1997). It is therefore possible to see aspiration and penetration of food and fluid during the swallow process (Furia et al, 2000; Hiorns & Ryan, 2006; Kendall et al, 2000; Olsson et al, 1997). Inter - rater-reliability between peers as to whether a client is showing signs of aspiration or penetration when completing an interpretation of videofluoroscopy results remain controversial with some interpreters disagreeing as to the level of aspiration or penetration occurring (Bryant et al, 2012; Ekberg et al, 1998; Gibson & Phyland, 1995; Kidd et al, 1993; Kuhlemeier et al, 1998; Martin-Harris et al, 2000; McCullogh et al, 1999; 2001; Perry & Love, 2001; Robbins et al, 1999; Scott et al, 1998; Stoeckli et al, 2003; Wilcox et al, 1996). Early studies claimed that inter - rater-reliability was high between clinicians for identification of client aspiration, penetration or safe swallow (Gibson & Phyland, 1995; Wilcox et al, 1996). One multi-centre study focused on a single

specific clinical population, clients with Parkinson's disease, so it could be argued that there would be less variety with types of expected oral and pharyngeal difficulties and therefore increased rater-reliability (Gibson & Phyland, 1995). In comparison, another study (Wilcox et al, 1996) involved 10 raters, seven out of the ten being SLTs. It is possible that these practitioners were used to working together and supporting each other's interpretations of results (Wilcox et al, 1996). Kuhlemeier et al (1998) also had a mixed group of SLTs and doctors rating swallowing on videofluoroscopy recordings across five consistencies. Unlike the Wilcox et al (1996) study, they found that agreement of specific swallowing difficulties were due mainly to chance, with the highest level of agreement being for aspiration of solid food, and the lowest level of agreement being for the timing of the swallow. McCullogh et al (2001) also found that agreement between clinicians as to what is being seen on the videofluoroscopy recording was poor to fair. Poor levels of agreement in interpretation of assessment of children with cerebral palsy in videofluoroscopy(39%), salivagram results(56%) and milk scan results(6%), suggest that the problems in identifying aspiration are not exclusive to adult populations (Baikie et al, 2005). Indeed, the interpretations of assessment results from instrumental evaluation vary greatly (Mathers-Schmidt & Kurlinski, 2003).

Aspiration of solids appears to have a high rater-reliability with adult studies, although fluids have a low level of agreement as to the degree of aspiration (Kuhlemeier et al, 1998; Scott et al, 1998). In contrast, SLTs rating problems with swallowing *fluids* safely with paediatric videofluoroscopy cases have a high inter - rater reliability, compared to poor inter - rater reliability with *solids* (de Matteo et al, 2005). This is interesting to consider further. More studies need to be carried out on practitioner interpretation of instrumental studies such as videofluoroscopy across a wider range of paediatric teams to study inter - rater reliability further. In particular, interpretation of aspiration in contrast with penetration with differing textures would be interesting to consider. Should the findings of the de Matteo et al (2005) be supported, then there would be a case to suggest that paediatric cases, which are largely congenital, have differing presentations to adult acquired populations. This may also be useful in understanding the neurology of and also determining

specific difficulties experienced by children who have congenital swallowing disorders. However, the reason why SLTs who work with children are more competent in identifying aspiration with fluids more accurately is likely to be because most children are more likely still be taking fluids rather than solids at the time when swallowing difficulties are identified.

Scales to guide clinical interpretation have been devised to support interpretation of videofluoroscopy recordings (Robbins et al, 1999; Rosenbeck et al, 1996). Robbins et al, (1999) devised an 8 point scale to attempt to evaluate and quantify elements of penetration and aspiration. A sample of 98 normal, healthy adults compared to 15 multiple stroke and 16 head and neck cancer participants were evaluated. The penetration-aspiration scale was able to significantly differentiate between normal/healthy and abnormal airway swallowing skills within the three populations. All normal swallows viewed received high inter - rater reliability scores. However, inter - rater reliability for the identification of aspiration and penetration was less clear with variability between clinicians as to the difference between aspiration and penetration in some examples.

Interestingly, Bryant et al (2012) compared two groups of SLTs rating the same videofluoroscopy recordings; one group rated the videofluoroscopy recordings using a checklist, the other group completed free ratings, which means that they did not use a checklist to guide their identification of what the difficulties were. The free ratings group demonstrated a much higher rate of inter-rater reliability for aspiration and penetration. Bryant et al (2012) suggest that the checklist may have led to practitioners only thinking about features on the list and that those who were in the free ratings group demonstrated more flexible thinking enabling them to consider a wider range of possible outcomes (Bryant et al, 2012).

Similar issues with Inter - rater reliable measures have been discussed in the literature with the use of Fibre-optic Endoscopic Evaluation of Swallowing (FEES). This procedure examines the pharyngeal phase of the swallow and requires passing a fibre-optic endoscope through the nasal cavity to the oropharynx so the larynx can be seen (Langmore, 2003). The pharynx, larynx and glottis can be viewed at rest and during a swallow and although the scope does not go below the oropharynx, this technique has been argued as

being as effective as VFSS in the identification of aspiration (Colodny et al, 2002). Rater reliability studies have shown high inter- and intra-rater reliability measures with use of FEES, but one study involved only three SLTs who worked together closely and therefore collaborated frequently (Leder et al, 2005); another study noted that reliability measures increased and became more consistent on a second rating compared to the initial rating (Colodny et al, 2012). Comparing the identification of aspiration and penetration using FEES versus videofluoroscopy has indicated that SLTs perceived aspiration to be greater in FEES than in videofluoroscopy. One reason for this could be that the pharynx is being viewed from a different angle compared to the lateral view seen in videofluoroscopy and perhaps the perception is that it appears to have a greater amount of food material present than might be expected (Kelly et al, 2007; Mari et al, 1997).

2.4 Critical issues with assessment

Assessment of oral motor skills usually includes examination of the lips, cheeks, oral cavity, tongue and range of jaw movement (Bateman et al, 2007; Kennedy, 1992; Martino et al, 2004; Meyer-Palmer, 1993; Pettigrew & O'Toole, 2007). Oral structures have a range of movement speeds and have specific ways of moving (Bennett et al, 2009; Brodsky et al, 2012; Daniels & Foundas, 2001; Hiss et al, 2001; Lederle et al, 2012; Napadow et al, 2002; Spiers et al, 1988; Stierwalt & Youmans, 2007; Youmans et al, 2002) and nutritive and non nutritive oral motor movements differ (Bennett et al, 2007; Broussard & Alschuer, 2000; Hamdy et al, 1999a; 1999b; Jean, 1984; 2001; Kern et al, 2001; Kessler & Jean, 1985; Koga & Bradley, 2000; Martin et al, 2004; Mosier & Brenznaya, 2001; Murray et al, 1998; Perry et al, 2002; Ramsay et al, 2003; Suzuki et al 2003). Despite these differences, many SLTs when assessing oral motor skills do not consider that tongue movement increases with increased bolus volume with discreet variations in movement (Pouderoux & Kahrilas, 1995; Ramsay et al, 2003), or that small bolus amounts may cause someone to use more varied and less consistent tongue movements due to weaker sensory feedback (Tasko et al, 2002). There are also age, gender and isometric pressure differences with tongue movement and sensation, but these factors are rarely considered when assessing clients (Bennett et al 2007;

Clark & Solomon, 2012; Crow & Ship, 1996; Dworkin & Aronson, 1986; Hirai et al, 1991; Logemann et al, 2002; Napadow et al, 2002; Nicosia et al, 2000; Robbins et al, 1992; Smith et al, 2006; Stierwalt & Youmans, 2007; Youmans & Stierwalt, 2005; 2006;2011; Steele & van Lieshout, 2009; Tasko et al, 2002). Tongue movement for speech across the age span remains the same but not for swallowing with movement of the tongue slowing down when eating (Bennett et al, 2007). One reason for this could be that the tongue is required to be more flexible and adaptable for food than for speech and with aging there are changes in oral sensory processing during swallowing (Tasko et al, 2002).

There are fewer studies which investigate children's oral motor abilities for eating, drinking and swallowing. Vaiman et al (2004) found a mean volume amount of a swallow in children aged 4 – 8 years(mean volume of casual single swallow = 6.1 cm³, mean volume of one swallow during continuous drinking = 4.8 cm³); children aged 9 -12 years(mean volume of casual single swallow =9.6 cm³, mean volume of one swallow during continuous drinking = 7.2 cm³ and adults up to 30 years of age(mean volume of casual single swallow = 16.6 cm³, mean volume of one swallow during continuous drinking = 12.7 cm³). Potter & Short (2009) evaluated tongue strength in 150 typically developing children aged 3 -16 years. Males showed a slight though not significant increase in tongue strength compared to females at 14 and 16 years of age. Tongue strength increased with age and increases were significant at ages 3-4, 5-6 and 6-8 years. Children aged 3 – 6 years showed greatest variability in tongue strength and this variation coincides with the development of texture management and tolerance (Gisel, 1988; Potter & Short, 2009). The refinement of tongue skills during oral motor development has also been noted in an earlier study where the tongue movements of 103 typically developing children aged between 2 – 8 years were evaluated (Gisel, 1988). With maturation, forward tongue positioning and more open jaw swallowing was noted in 2 - 4 year olds, but this disappeared by 5 years of age. Clinical application using the data from this study could be challenging as the terminology used is not in mainstream usage and the descriptions of the position of the tongue are hard to

conceptualise visually. Consequently, replication could be difficult. In a different study, Gisel et al, (1986) compared tongue movement patterns of typically developing 2 – 5 year olds with children who had a diagnosis of Down's syndrome. Children who had Down's syndrome aged 4 years old were less skilled at lateralisation of the tongue compared to their typically developing peers, and used fewer compensatory strategies such as tilting the head, rolling the tongue or using fingers to manipulate food in the oral cavity. Again, this study would be hard to replicate for the same reasons as for the 1988 study by Gisel as these studies use specialist equipment, or have results recorded using percentages so it would be hard to compare new results accurately. These studies on children highlight that oral motor movements are hard to measure during clinical assessment as some of these movements are fast with wide variation. However, SLTs will decide if there is any impairment of movement from observation. This decision is likely to be subjective. The importance of having had clinical experience and its relationship to decision making in dysphagia has an impact on observations made as well as how inter-rater reliable assessment measures are interpreted (Brindley et al, 1996; Bryant et al, 2012; Kuhlemeier et al, 1998; Meyer - Palmer, 1993; Reilly et al, 1995; Scott et al, 1998; Skuse et al, 2000; Stoeckli et al, 2003; Van Schroyen Lantman de - Valk et al, 1997; Wilcox, 1996).

There are a number of issues that need to be considered in relation to assessment of dysphagia. The first is that as SLTs focus on the identification of aspiration and penetration, they tend to overestimate risks associated with swallowing compared to other professionals. This can mean that the relationship between aspiration and compromised health is sometimes contested by members of the team (Cass et al, 2005; Craig & Higgs, 2012). Secondly, SLTs and other professionals who work with the same groups of infants, children and young people use observational skills and also tend to refer to normal developmental skills as a benchmark. As described, the tongue and jaw are assessed at rest. Neurologically, swallowing is complex with cortical activation of swallowing for voluntary and involuntary swallowing being distinctly different, and different again for motor- speech activity (Bennett et al, 2007; Broussard & Alschuer, 2000; Hamdy et al, 1999a;1999b; Jean, 1984; 2001; Kern et al, 2001; Kessler & Jean, 1985; Koga & Bradley, 2000;

Martin et al, 2004; Mosier & Brenznaya, 2001; Murray et al, 1998; Perry et al, 2002; Suzuki et al 2003; Wise et al, 2001). This has implications for assessment, especially when SLTs ask a child to swallow their saliva or attempt a dry swallow as opposed to observing sequential swallowing during a meal. Already it is known that there are key differences with movements within and aside from eating and drinking; tongue movements in swallowing are slower and more variable than in speech (Bennett et al, 2007; Mortimore et al, 1999); differences in labial muscle force are noted between cup, straw and non-nutritive labial muscle movement (Murray et al, 1998; Wohlert & Smith, 2002); there are gender differences in oral amounts (Nascimento et al, 2010); palatal elevation varies for swallowing and for speech, thus highlighting a contrast in movement types (Perry et al, 2002). This suggests that use of traditional methods of oral examination during assessment have a questionable value, or rather, the rationale underpinning why an oral motor examination is carried out in many situations needs to be much clearer without assuming that there is a link between the oral movements utilised in nutritive and non – nutritive movements (Bennett et al, 2007; Broussard & Alschuer, 2000; Hamdy et al, 1999a; 1999b; Jean, 1984; 2001; Kern et al, 2001; Kessler & Jean, 1985; Koga & Bradley, 2000; Martin et al, 2004; Mosier & Brenznaya, 2001; Murray et al, 1998; Perry et al, 2002; Suzuki et al 2003).

2.5 Summary

This chapter has highlighted that there is wide variation in clinical practice when assessing people who have dysphagia (Bateman et al, 2007; Kennedy, 1992; Martino et al, 2004; Meyer-Palmer, 1993; Pettigrew & O'Toole, 2007). Research into congenital disorders, particularly children is limited (Harding & Cockerill, 2014). Some outcomes from research such as the differences between nutritive and non – nutritive activation does not appear to influence clinical assessment skills (Bennett et al, 2007; Broussard & Alschuer, 2000; Clark & Solomon, 2012; Crow & Ship, 1996; Dworkin & Aronson, 1986; Gisel, 1988; Gisel et al, 1986; Hamdy et al, 1999; Hirai et al, 1991; Jean, 1984; 2001; Kern et al, 2001; Kessler & Jean, 1985; Koga & Bradley, 2000; Martin et al, 2004; Mosier & Brenznaya, 2001; Murray et al, 1998; Nicosia et al, 2000; Perry et al, 2002; Potter & Short, 2009; Poudroux & Kahrilas, 1995; Suzuki et al

2001; Smith et al, 2006; Steele & van Lieshout, 2009; Tasko et al, 2002; Vaiman et al, 2004; Youmans & Stierwalt, 2005; 2006 ;2011). Experience also has an impact on clinical decision making during assessment (Brindley et al, 1996; Bryant et al, 2012; Kuhlemeier et al, 1998; Meyer - Palmer, 1993; Reilly et al, 1995; Scott et al, 1998; Skuse et al, 2000; Stoeckli et al, 2003; Van Schrojenstein Lantman de - Valk et al, 1997; Wilcox, 1996).

The following paper evaluates straw use in a population of typically developing children. The aim was to provide specific data that could be applied in an assessment context. Rather than using percentages or instrumental assessment it provides actual amounts that can be easily calibrated in a clinical context, therefore providing important information about bolus management and sequential swallowing. The paper discusses the application of this tool for children with progressive disorders.

2.6 Research findings completed by the author

The following paper presents data collected from a normal population of children and discusses the relevance for clinicians who work with children who have progressive disorders. Using normative data for this population is useful as a means of evaluating change. The method described is simple and uses data which can be easily replicated in a clinical context. It can be an important adjunct to clinical assessment.

Harding C; Aloysius A(2011)Drinking speed using a valved Pat Saunders straw TM, wide bore straw and a narrow bore straw in school age children. *The International Journal of Evidence Based Health Care* (9); 435 - 439; doi: 10.1111/j.1744-1609.2011.00241.x

Harding C; Aloysius A(2011)Drinking speed using a valved Pat Saunders straw TM, wide bore straw and a narrow bore straw in school age children. *The International Journal of Evidence Based Health Care* (9); 435 - 439; doi: 10.1111/j.1744-1609.2011.00241.x



EVIDENCE UTILISATION

Drinking speed using a valved Pat Saunders straw, wide bore straw and a narrow bore straw in school-age children

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Abstract

Background To understand the nature of straw drinking in relation to a group of children with specific eating and drinking difficulties, it is first necessary to ascertain the range of normal function. Straw drinking is often recommended as a method that can support children with eating and drinking difficulties.

Method This study looked at straw drinking performance in a normal population of 125 children aged between 6 and 11 years of age. Three types of straws were used: a valved Pat Saunders straw, a wide bore straw and a narrow bore straw. Children drank 40 mL of water for each straw tested.

Results Children increased their speed of intake significantly for all straw types as they matured. Drinking speed was quickest for the wide bore straw followed by the narrow bore and slowest for the valved Pat Saunders straw. This was supported by qualitative feedback from the children with most finding the wide bore straw the easiest one to use and the valved Pat Saunders straw the hardest. There were significant differences in speed of flow between the valved Pat Saunders straw and wide bore straw, between the valved Pat Saunders straw and the narrow bore straw and between the wide bore straw and the narrow bore straw. There were no significant differences between straw flow or straw type and gender.

Conclusions This normative data for straw drinking in a paediatric population can be used to develop baseline measures for clinical assessment.

Key words: equipment evaluation, normal data range, sequential drinking, straw drinking.

Introduction

Drinking fluid using a straw is one method of maintaining hydration. It involves a complex interaction between the facial and tongue muscles to move the liquid through the mouth into the pharynx and into the oesophagus.¹ This paper evaluates the functional straw drinking skills of a normal population of children, and discusses clinical applications of these data.

Drinking skills

During the process of eating and drinking, the lip muscles provide stability for utensils used. In a small study of 11

women aged 18–25 years, a higher level of labial muscle activation occurred when a straw was being used compared with the force required for speech or facial expression. Force was significantly more for fluid intake via a straw in comparison to when a spoon or cup was used.¹ Normal straw drinking involves a rapid, sequential movement of the pharyngeal and laryngeal structures. Partial laryngeal elevation occurs as the epiglottis inverts between swallows. After the swallow sequence is complete, the larynx lowers and the epiglottis returns to an upright position.^{2–4} Airway closure during the passage of the bolus through the pharynx results in brief period of apnoea during the swallow. During straw drinking, an extended duration of apnoea is evident when laryngeal excursion occurs during sequential swallowing.²

Daniels and Foundas³ examined straw drinking in 15 healthy males aged 30 ± 3 years. When taking fluid from a straw sequentially, the mean volume per swallow was 11.53 ± 5.9 mL (range 3.54–26.39 mL). In a further study

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2.7 Implications, recommendations and concluding remarks

Decision making for both informal and more formal assessment of dysphagia rely on a practitioner's clinical expertise and skills, previous knowledge, inter-rater reliability for certain assessment methods such as videofluoroscopy and judgements based on experience to decide whether function is normal or impaired in its movement. The same issues apply to the use of more formalised assessment tools such as the NOMAS (Meyer-Palmer, 1993) POSP (Brindley et al, 1996) and the SOMA (Reilly et al, 1995; Skuse et al, 2000). Most notably, clinical knowledge is necessary with observing the non verbal signs infants and children show during mealtimes, e.g. demonstration of hunger cues or risk signs, and this is discussed further in chapter 4 (McGrath & Braescu, 2004). Such interpretation relies on experience and ability to "read" the child's signals in a timely way (Gill et al, 1992). As with the more formalised assessments described, subjective decision making interacting with experience help guide the clinician towards planning and intervention.

There is still a pervasive clinical idea that producing oral motor movements outside of a functional process of eating and drinking will provide essential information. However, nutritive and non nutritive activation is distinct (Aziz et al, 1996; Broussard & Alschuer, 2000; Devinsky et al, 1995; Hamdy et al, 1996a; 1996b ; 1999; Jean, 1984; 2001; Kern et al, 2001; Kessler & Jean, 1985; Martin & Sessle, 1993; Martin et al, 1999; 2001; Mosier & Brenznaya, 2001; Shuler et al, 2001; Suzuki et al 2003). Some studies have identified quantifiable measures from typical populations such as; duration of swallow and upper oesophageal sphincter sounds using cervical auscultation (Moriniere et al, 2008; Youmans & Stierwalt, 2011); timing of the component features of the pharyngeal phase, such as vocal fold closure, hyoid elevation and timing of the swallow (Daniels & Foundas, 1997; 2001; Hartl et al, 2002; Hiss & Huckabee, 2005; Inamoto et al, 2011; Kim & McCullogh, 2008; Leonard et al, 2000; Leonard & McKenzie, 2006; Roubreau et al, 2008; Zhang et al, 2012); palatal movement during eating and drinking compared to speech (Perry et al, 2002); pressures for tongue movement (Bennett et al, 2007; Crow & Ship, 1996; Nicosia et al, 2000; Potter & Short, 2009; breast and bottle sucking pressures (McGrath & Medoff - Cooper, 2002; Mizuno & Ueda, 2006); upper and lower pharyngeal pressure changes (Weckmueller et al, 2011); respiratory airflow

(Brodsky et al, 2012; Hiss et al, 2001); oral –facial strength using pressure measures(Clark & Solomon, 2002); pharyngeal speed of movement (Kim et al, 2005; Roubeau et al, 2008); normal saliva production during swallowing (Kuplia et al, 1984);timing of respiratory cessation during the swallow (Daniels & Foundas, 2001; Klahn & Perlman, 1999; Lederle et al, 2012);bolus amounts of fluid for normal adults with cups and straws, (Bateman et al, 2007; Lawless et al, 2003);oral filling and transit times (Weckmueller et al, 2011) and gender differences with laryngeal movement or volume of fluid ingested (Daniels and Foundas, 2001; Hartl et al, 2003;Inamoto et al, 2011; Leonard et al, 2000; Leonard & McKenzie, 2006; Logemann et al, 2002; Nascimento et al, 2010; Robbins et al 1992; Zhang et al, 2012) are evident in the literature but have not become a consistent part of an assessment routine. All these studies present data that is hard to be transferred to a clinical context as non-specific measures such as percentages are used (Gisel, 1988) or they include very fast speeds in milliseconds(Roubeau et al, 2008) or need specialist equipment to measure , such as pressure changes in the pharynx (Weckmueller et al, 2011). The measurements are too fast to be seen or felt during assessment in the usual way, or the timing or movement of what is being assessed needs such specialist and specific equipment that this excludes many practitioners who are not working in highly specialist acute contexts.

In contrast, other studies have provided data that can have a clinical application. For example, Vaiman et al (2004) provide a mean volume amount of a swallow in children aged 4 – 8 years; children aged 9 -12 years and adults up to 30 years of age. Weckmueller et al, (2011) have some data from videofluoroscopy studies that could feasibly be timed during the process in seconds. Lawless et al (2003) and Adnerhill et al (1989) report sip size amounts with fluids and Hudspeth et al (2006) provide data on speed of straw sucking with children who have muscle difficulties which could be completed in a clinical setting easily. The study reported at the end of this chapter has produced normative information that would be useful for children with progressive muscle disorders. In a clinical setting, a SLT would be able to time a child's straw drinking and refer to the information in this study to monitor change over time (Harding & Aloysius, 2011).

Further studies need to investigate the relevance of normative data to acquired, progressive and congenital groups of children who have dysphagia. The issues of inter rater reliability also need further study as the papers cited in this chapter have shown that participants can be influenced by experience or by their peers. Understanding of the risks of aspiration and identification of dysphagia is still developing with congenital conditions, and increasing understanding of the difficulties can assist in more focused assessment (Calis et al, 2008). Increasing knowledge of the potential risks could support the development of improved assessment methods.

CHAPTER 3

INTERVENTIONS USED TO MANAGE DYSPHAGIA WITH CHILDREN

CHAPTER 3: Interventions used to manage dysphagia with children

3.1 Introduction to Chapter 3

This chapter summarises the main types of intervention used by paediatric SLTs in the management of dysphagia. The next chapter will focus in more detail on one of these intervention techniques, non - nutritive sucking (NNS) which is often used with preterm infants. Research on intervention for children with dysphagia is limited and the evidence supporting many strategies used is not strong (Arvedson et al, 2010a; Arvedson et al, 2010b; Gantasala et al, 2013 ; Greene et al, 2012 ; Morgan et al, 2012). One reason why the evidence base is small could be because the term “feeding” when applied to infants and children covers a wide range of issues, from oral aversion, to pharyngeal phase difficulties. Management of feeding problems may focus on behavioural issues such as food refusal or self feeding rather than specific motor or swallowing difficulties that interrupt effective eating and drinking. However, minimising risk from aspiration, identifying appropriate strategies to meet the needs of the client, training and supporting caregivers and close liaison with the team are core to managing swallowing and feeding problems across the lifespan (Kurjan, 2000; Leslie et al, 2003; Miller et al, 2001; Puntis, 2008). Many children with dysphagia are likely to have a congenital disorder rather than an acquired problem (Cook & Kahrilas, 1999; Cass et al, 2005; Field et al, 2003). Strategies used with acquired swallowing problems may not help children with congenital disorders due to differences in the neurology and aetiology of the swallowing difficulties being remediated (Kent, 2004; Robbins et al, 2008a; Martin et al, 2001). Although there is a larger evidence base supporting some interventions for adults, many approaches, for example motor manoeuvres during the swallow such as the Mendelsohn manoeuvre (Ding et al, 2002; Kahrilas et al, 1991; Logemann et al, 1990; Robbins & Levine, 1993) and others such as electrical stimulation of the muscles (Blumenfeld et al, 2006; Freed et al, 2001; Leelamanit et al, 2002; Ludlow et al, 2007; Park et al, 1997; Power et al, 2004; 2006; Shaw et al, 2007) are still controversial. Although there is a perception that the evidence base is stronger in dysphagia acquired in adulthood, the reality is that many of the studies are inconclusive (Blumenfeld et al, 2006; Ding et al, 2002; Freed et al, 2001; Kahrilas et al, 1991; Leelamanit et al, 2002; Logemann & Kahrilas, 1990; Ludlow et al, 2007; Park

et al, 1997; Power et al, 2004; 2006; Robbins et al, 1993; Shaw et al, 2007). In the absence of studies to support interventions for feeding and swallowing, SLTs have used strategies developed for adults with acquired disorders. This reasoning is perhaps not appropriate as the strategies developed for adults rely on a past history of normal eating and drinking. Additionally, some strategies may require some level of cognition and receptive language ability that enables a person to understand and carry out a specific therapy strategy. For children with learning disabilities or for those who are not yet cognitively able to initiate strategies for themselves this is not an option.

Another important factor to consider with children is the anatomical and growth changes that occur within the first year of life. The larynx is sited high in the neck close to the soft palate and epiglottis in an infant. Due to the closeness of these structures, the soft palate and epiglottis act as a protective mechanism during the process of swallowing. The larynx descends at between 4 – 6 months of age in conjunction with substantial postural, language and cognitive development (Bosma, 1963a; 1963b; 1967). During these changes, infants and children pass through critical periods for development with both tastes and textures which adults have already established (Cichero & Murdoch, 2006; Skuse, 1993).

The chapter ends with two research papers. One paper focuses on the training of education staff who work with children and young people who have dysphagia and complex needs (Harding & Halai, 2009). A training programme to increase knowledge of dysphagia in a specialist school setting was carried out, and staff participants completed before and after questionnaires about their knowledge of swallowing difficulties. As discussed later in chapter 3, this paper raises some important points about carer understanding of dysphagia and risks from poor swallowing. The second paper presents a multi – disciplinary behavioural feeding intervention received by two children who needed to wean off gastrostomy tube feeding and develop oral motor competence with food textures and tastes typical for their developmental ages. The therapy plan, composed of SLT, dietetic and clinical psychology components is presented. An important aspect of this study was to support the structure of the behavioural feeding intervention with relevant evidence from the literature (Harding et al, 2010c).

3.2 A summary of approaches to dysphagia management

Table 3.1 summarizes the main types of approaches taken across the lifespan when managing dysphagia. These tend to be divided into; motor with swallow (using a motor action during eating and swallowing), motor without swallow (oral motor exercises), sensory interventions, compensatory strategies (posture, texture modification) and managing the environment. There are also some behavioural approaches with children who present with persistent food refusal (Ahearn et al, 1996; Blackman & Nelson, 1987; Burmucic et al, 2006; Byars et al, 2003; Clawson et al, 2007; Davies et al, 2009; Douglas, 2002; Freeman et al, 1998; Kelley et al, 2003; Kindermann et al, 2008; McGrath Davies et al, 2009; Patel et al, 2001). However, these are not considered as part of this dissertation as any underlying dysfunctional swallow aetiology is not the main focus of these behavioural studies. Indeed, differentiation of different types of approaches into specific categories is difficult. The following paragraphs summarize briefly the main types of approaches used with infants and children categorizing the main areas as described above.

3.2.1 Motor with swallow

Adults with acquired disorders can be trained to use specific motor techniques during swallowing to help manage the way a bolus of food passes through the cricopharyngeus. Specific movements that alter pharyngeal opening during swallowing can help reduce the risk of aspiration (see Table 3.1)(Bulow et al, 1999; 2001; Ding et al, 2002; Ekberg et al, 1986; Ertekin et al, 2001; Groher, 1984; Hammer et al, 2013; Kahrilas et al, 1991; Lazarus, et al, 1993; 2002; Lewin et al, 2001; Logemann et al, 1992; Logemann & Kahrilas, 1990; Olsson et al, 1997; Poudroux et al; 1995 ; Robbins & Levine, 1993; Shanahan et al, 1993; Welch et al, 1993). Use of electromyography with modeling and visual feedback (biofeedback) can help people with acquired swallowing problems attempt conscious movements when carrying out maneuvers during eating and drinking (Bryant & Bryant, 1991; Crary 1995; 1997; Crary et al, 2007; Crary & Groher, 2000; Huckabee & Cannito, 1999). Children tend not to use these approaches unless they have had an acquired or progressive disorder and if they can demonstrate the cognitive ability to be able to carry out the required action. As many children with dysphagia are likely to either be very young or have significant learning difficulties, being able to carry out these required motor actions throughout a mealtime would be challenging (Harding & Cockerill, 2014). Such techniques also rely on the client having had a previous

awareness of the sensations involved in eating and drinking, therefore providing them with some form of reference point on which to base their motor with swallow attempts. Children with congenital disorders will not have had this previous experience and this can have a significant impact on the development of goals to improve oral and pharyngeal problems; the child will have no knowledge of what it is those encouraging him wish to develop and experience (Harding & Cockerill, 2014).

A small number of studies have evaluated attempts to support motor with swallow approaches such as reducing tongue thrust or tongue strengthening during a mealtime for children with learning disabilities (Ganz, 1987; Harden & Rydell, 1984; Lamm et al, 2005). These studies have used a range of behavioural and direct methods of reducing the tongue thrust or developing a range of tongue movements including massaging the facial and oral motor muscles both outside of and during the mealtime. Outcomes from these studies have been variable and have not been repeated in more recent research and therefore need to be treated with caution. Motor with swallow techniques tend to be used less with children.

Table 3 .1: Main therapy strategies utilised in dysphagia management

Type of approach	Method of applying approach	Clinical Group	Evidence
<p>Motor with swallow: <i>Development of a specific motor action during a functional swallow to reduce swallowing dysfunction.</i></p>	<p>Examples include the head tilt / head rotation (helps a bolus move down the stronger side), chin tuck (enables the valleculae to widen and the epiglottis to close more effectively), effortful swallow (increases tongue base posterior motion during the pharyngeal swallow so bolus clearance is improved); the supraglottic swallow (closes the airway at the level of the true vocal folds before and during the swallow); the super supraglottic swallow (closes the airway entrance before and during the swallow).</p>	<p>Adults with acquired disorders or who have had head and neck surgery. These clients have previously had cognition within the normal range, and have also had experience of normal eating and drinking.</p>	<p>Bryant & Bryant, 1991; Bülow et al, 2001 ; 2002 ; 2003; Huckabee & Cannito, 1999; Lewin et al ,2001 ; Logemann, 1986 ; 1989 ; 1993; 1997; Logemann et al, 1992; Welch et al, 1993</p>
<p>Motor without swallow : <i>Use of oral-motor exercises outside of an eating and drinking context.</i></p>	<p>a) Non-nutritive sucking; used in the [Motor without swallow] context to facilitate quicker transfer to full oral feeding.</p>	<p>a) Infants, mainly those who are premature, but also those with neurodisability.</p>	<p>a)Bache et al, 2014 ; Barlow et al, 2008; Boiron et al, 2007; Fucile et al, 2002; 2005; 2011; 2012; Gaebler & Hanzlik, 1995; Hwang et al, 2010; Liu et al, 2013; Lyu et al, 2014 ; Poore et al, 2008; Pimenta et al, 2008; Rocha et al, 2007; Rochat et al, 1997; Vojta & Peters, 1992 ; Zhang et al, 2014</p>

	<p>b) Oral-motor exercises for children; used in many contexts to develop oral skills for both speech and eating and drinking.</p>	<p>b) Children with congenital disorders.</p>	<p>b) Beckman, 1988 ; Ottenbacher et al, 1981 ;1983; Rosenfeld-Johnson, 1999 ; Sjogreen et al, 2010</p>
	<p>c) Manoeuvres to support adults: the Masako manoeuvre (used to improve anterior pharyngeal wall movement towards base of tongue); the Shaker manoeuvre (used to elevate and tilt larynx forward and improve cricopharyngeous functioning); the Mendelsohn manoeuvre (increases the extent and duration of laryngeal elevation, increases the duration and width of cricopharyngeal opening).</p>	<p>c) Adults with acquired disorders or who have had head and neck surgery. These clients have previously had cognition within the normal range, and have also had experience of normal eating and drinking.</p>	<p>c)Carroll et al, 2008; Fukuoka et al 2013 ; Hammer et al, 2013; Lazarus ,1993 ; 2006; Lazarus et al 2000 ; 2003 ; 2006 ; 2007 ; Mendelsohn ,1993; Robbins et al 2005 ; 2007; 2008b ; Shaker et al, 2002 ; Shanahan et al, 1993</p>
	<p>d) Non – oral feeders may have some oral care activities to manage oral hygiene.</p>	<p>d) Oral care programmes are used across the lifespan, and are used with clients who have congenital, acquired and progressive disorders.</p>	<p>d) Cocks & Ferreira, 2013; Logemann et al, 2008 ; Pollens, 2004; Scannapieco, 2006; Wilken, 2012</p>

<p>Sensory : <i>Strategies that attempt to enhance or reduce sensation in the head and neck region due to some perceived problem or neurological imbalance with sensory abilities.</i></p>	<p>a) Vibration, massage and temperature, used mainly to stimulate muscle function and alter sensation in some way.</p>	<p>a) Mainly adults who have had acquired condition, although Barlow et al, 2008;2014; Mattes et al, 1996; Poore et al, 2008 and Yildiz & Arikan, 2011 mention that NNS with premature infants is specifically an oral sensory approach.</p>	<p>a) Bartostruck et al,2003; Barlow et al, 2008;2014; Duffy, 2007; Edwards et al, 1972; Garcia et al, 2008; Hamdy et al, 1997;1998; 2003; Hedenberg, 1970; Lazzara et al,1986 ; Mattes et al, 1996; Micholovitz, 1986; Miglietta, 1973; Ottenbacher et al, 1981; 1983; Poore et al, 2008; Regan et al, 2010; Robbins et al, 1992; Rosenbek et al, 1991;1996; Sciortino et al, 2003; Weber & Brown, 1996; Yildiz & Arikan, 2011</p>
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	<p>b) Electric stimulation of the muscles, is sensory stimulation using low voltage on the mylohyoid muscle and the thyrohyoid muscle to trigger muscle fibre contraction, maintain muscle function, preserve function and stimulate new neural pathways post trauma. b)</p>	<p>b) Mainly adults who have had acquired condition.</p>	<p>b) Barikroo & Lam, 2011; Blumenfeld et al, 2006; Carnaby –Mann & Crary, 2007; Crary, 1995; 1997; Crary et al, 2007; Crary & Groher, 2000; Christiaanse et al, 2011; Curren & Mann, 1983; Dantas & Dodds, 1990; Ding et al, 2002; Freed et al, 2001; Furuta et al, 2012; Humbert et al, 2006; Kieger et al, 2006; Leelamanit et al, 2002; Ludlow et al, 2007; Othman et al, 2007; Park et al, 1997; Power et al, 2004; 2006; Shaw et al, 2007</p>
	<p>c) Developing improved oral sensation to help with oral-motor planning for eating through use of an intra-oral appliance.</p>	<p>c) Children with a diagnosis of cerebral palsy.</p>	<p>c) Gisel, 1994; 1996; Gisel, et al, 1995a; 1995b; 1996; 1999; 2001; Harberfellner et al, 2001; Korbmacher et al, 2004</p>
<p>Compensatory : <i>Strategies where a specific feature is changed or utilised such as food texture, posture or a piece of equipment. The client is not expected to perform any specific motor activities as in [motor with</i></p>	<p>a) Posture, where whole body postural stability is maximised pre-a meal so that risk of aspiration is minimised, or altering the position so that better swallowing can be facilitated, e.g. chin tuck.</p>	<p>All clients, both acquired and congenital.</p>	<p>Bulow et al, 2001; 2002; Clark et al, 2007; Ekberg, 1986; Einasson – Baches et al, 1993; Ertekin et al, 2001; Lewin et al, 2001; Macie & Arvedson, 1993; Mootosamy & Dietrich, 2002; Morton et al, 1993; Okada et al, 2007; Shanahan et al, 1993;</p>

swallow].	b) Texture modification is sometimes implemented so that food can be sucked or chewed and swallowed more safely.	b) All clients, both acquired and congenital.	b) Adeleye & Rachal, 2007; Atherton et al, 2007 ; Bosscher et al, 2003; Bulow et al, 2003 ; Chadwick et al, 2002;2003;2006; Clayton, 2002; Crawford et al, 2007 ; Croft, 1992 ; Dantas et al, 1989 ; 1990 ; Daniels, 2008; Dewar & Joyce, 2006; Ertkin et al, 1997 ; Finestone et al, 2001; Garcia et al, 2005 ; 2008 ;Groher et al, 2006 ; Gumbley et al, 2008 ; Igarashi et al, 2010 ; Khoshoo et al, 2000; Kuhlemeier et al, 2001 ; Logemann, 1986; Lotong et al, 2003 ; Matta et al, 2008; Patch et al, 2003; Smith et al, 2004; Snider et al, 2011 ; Sopade et al, 2008 ;Steele & Van Lieshout, 2004; Stuart & Motz, 2009; Taniguchi et al, 2008 ; Vivanti et al, 2009; Walden & Prendergast, 2001; Whelan, 2001 ; Ying-Ju et al, 2007
	c) Equipment used that promotes safer intake for the client, or which enables safer, and where possible, independent eating and drinking.	c) All clients, both acquired and congenital across the lifespan.	c) Chang et al, 2007; Harding & Aloysius, 2011; Harding, Fitzpatrick, Morris & Aloysius, 2014; Lau & Schandler, 2000; Mathew, 1998;1990; Walden & Prendergast, 2000

<p>Environmental : <i>Strategies where the environment is considered as an important tool in management, e.g. use of communication & behaviour management.</i></p>	<p>a) Communication & providing support in everyday settings</p>	<p>a) All clients, both acquired and congenital, but the literature has tended to focus on infants and children.</p>	<p>a) Harding 2009; Harding et al, 2006; 2010a; 2012a; 2012c ; 2014;2015; Hill, 2005; Mathisen, 2001;McGrath & Medoff-Cooper, 2002; Pickler et al, 1995; 2006; Veness & Reilly, 2007; White-Traut et al, 2002</p>
	<p>b) Behaviour modification</p>	<p>b) The literature has tended to focus on children with persistent eating and drinking difficulties, mainly those who are averse to eating or to attempting a wider range of textures.</p>	<p>b) Ahearn et al, 1996 ; Blackman & Nelson, 1987; Burmcic et al, 2006; Byars et al, 2003; Davies et al, 2009 ; Douglas , 2002; Freeman et al, 1998; Kelley et al, 2003; Kindermann et al, 2008 ; McGrath Patel et al, 2001</p>

3.2.2 Motor without swallow - Oral motor therapy

Traditionally, many SLTs have implemented motor without swallow oral motor work into their treatment plans to manage dysphagia (Table 3.1). This approach has evolved from physiotherapy and occupational therapy muscle treatments where the goal is to improve and maximise muscle function (Clark, 2003). However, the limb and back muscles that tend to be remediated by physiotherapists and occupational therapists within the body have different muscle spindle fibres compared to the muscles used in swallowing (Clark, 2003; Kent, 2004; Robbins et al, 2008a; Martin et al, 2001). These therapy approaches have been based on trying to remediate muscle function through manipulation, stimulation and exercise (Boshart, 1998; Gangale, 2001; Mackie, 1996a; 1996b; Pehde et al, 1996; Rosenfeld-Johnson, 1999; Strode and Chamberlin, 1997). Intervention to change muscle tone usually is around improving muscle strength and tone (Clark, 2003; O'Sullivan, 1988; Shumway - Cook & Woollacott, 1995). Exercises tend to be active or passive. Active exercises usually require the participant to complete a range of oral motor tasks designed to stretch and strengthen muscles, with quick stretches increasing tone, and slow stretches decreasing tone (Burkhead et al, 2007). Passive exercises include massage, stroking, stimulation and using vibration on muscles to improve sensory feedback of the muscles and help normalise early oral motor reflexes (Ottenbacher et al, 1981; 1983). Passive exercises are usually completed by a carer rather than a participant (Ottenbacher et al, 1981; 1983).

There does, however, appear to be a practice view that work on oral-motor skills outside of a functional context will improve oral motor function both for speech and swallowing (Beckman, 1988; Boiron et al, 2007; Vojta & Peters, 1992). The assumption is that there will be dual benefits as the speech and swallowing centres share the same pathways, therefore oral motor exercises, including non-nutritive sucking will benefit both speech and swallowing skills (Barlow & Estep, 2006; Beckman, 1988; Rosenfeld-Johnson; 1999; Vojta & Peters, 1992). Some researchers describe non - nutritive sucking as an oral motor approach that can stimulate feeding and speech (Field et al, 1982; Measel & Anderson, 1979; Neiva et al, 2006; 2007). Non - nutritive, or oral motor work is sometimes recommended for infants and children who are unable to take nutrition orally (Table 3.1). This is mainly to help maintain good oral hygiene and improve quality of life as tube feeding is associated with increased trauma in families, a decrease in normalcy

with potentially a negative impact on the mother-child relationship (Scannapieco, 2006; Wilken 2012). Sometimes, the reasons given for non – nutritive programmes do not consider that the neurological origin for speech activation and swallowing are separate from each other and that the muscle fibres for speech and swallowing have specific differences adapted to their function (Bennett et al, 2007; Broussard & Alschuer, 2000; Hamdy et al, 1999a; Jean, 1984; 2001; Kern et al, 2001; Kessler & Jean, 1985; Koga & Bradley, 2000; Martin et al, 2001; Mosier & Brenznaya, 2001; Murray et al, 1998; Perry et al, 2002; Suzuki et al 2001).

The oral motor approach frequently used by Rosenfeld-Johnson (1999) is not based on research evidence, but a therapy manual (as is the O’Sullivan 1998 work) which describes a strengthening programme that uses drinking straws to target specific placement of the articulators, and muscle use for swallowing. It argues that straw drinking can promote tongue retraction and therefore, whilst encouraging this during straw use, the parameters for positioning of the tongue for consonant production, e.g. /r/ are set. In another study (Sjogreen et al, 2010), children with a diagnosis of myotonic dystrophy, type 1, participated in a sixteen week lip strengthening programme to improve eating skills and saliva control. Although there were improvements in lip strength, results indicated that there were no significant improvements in eating or saliva control in any of the children. Muscle force and contraction is higher for sucking than in speech, plus there is the added recruitment of muscles for lip rounding and this suggests that the similarities are not as close as suggested (Burkhead et al, 2007). Interestingly, there is a developing clinical idea that there is limited evidence to support use of oral motor exercises in relation to speech sound development but this is not pervasive to clinical work (Lass & Pannbacker, 2008). Current theoretical and research findings challenge the benefits of oral motor exercises to develop speech (Lof & Watson, 2008). The anterior cingulate cortex is important for swallowing (Moiser & Bereznyaya 2001; Devinsky et al, 1995) as well as for the processing of motor, sensory and cognitive information (Blank et al, 2002). Some functioning in this area of the brain is also related to tongue movement and vocalisation, although Martin et al (2001) stress that swallowing function appears to relate specifically to the rostral, intermediate and caudal aspects of the anterior cingulate cortex. Moiser et al (2001) found that the following areas of the brain were activated during swallowing; the sensori-motor areas in the cortex, premotor cortex, posterior parietal cortex, cingulate cortex, inferior frontal gyrus, the cerebellum, the insular,

the auditory cortex, corpus callosum, basal ganglia and thalamus. In contrast, language and speech areas are largely within the left hemisphere (Sciote et al, 2003). Of particular importance for language and speech are the parietal, occipital, temporal and some parts of the frontal lobe (Sciote et al, 2003). Differentiation between which areas of the brain are activated in relation to language and swallowing is important in understanding and developing effective therapy approaches for children with swallowing difficulties. Speech, language and swallowing are linked in that they have sequential processes involved in planning but despite the shared pathways, activation and outcomes are different (Bennett et al, 2007; Broussard & Alschuer, 2000; Clark, 2003; Dworkin, 1978; Fujju & Logemann, 1996; Hamdy et al, 1999a; 1999b; Jean, 1984; 2001; Kern et al, 2001; Kessler & Jean, 1985; Koga & Bradley, 2000; ; Lazarus et al, 1993; Martin et al, 2004; Mosier & Brenznaya, 2001; Murray et al, 1998; Perry et al, 2002; Sheppard & Fletcher, 2007; Stael et al, 2003; Sullivan et al, 1997; Suzuki et al 2001). There are many unanswered questions in relation to oral motor exercises and their relationship to swallowing. Active and passive muscle stimulation influence muscle spindles in different ways (e.g. Boshart, 1998; Gangale, 2001; Katz, 1996; Pedretti & Early, 2001; Trombly, 1983). Muscle capacity to maximize, maintain or improve skills is not clearly understood, particularly in relation to progressive and congenital swallowing disorders (Clark, 2003). Consequently, the impact of muscle training, i.e. for resistance, contraction velocity, and improving function as well as the time needed to maximize movement does not yet have a clear rationale (Clark, 2003). It seems that further research needs to be undertaken to understand the benefits, if there are any, of oral motor interventions for children who have congenital disorders, and who are highly likely to have affected muscle tone and a different neurological make up. In the absence of many approaches that therapists feel that they can use with confidence, these therapy approaches persist in being practised.

3.2.3 Sensory approaches to intervention

Sensory approaches include interventions that involve touch or massage in the oral region to desensitise a child to food textures or it may involve other forms of stimulation such as thermal-tactile stimulation, i.e. vibration, massage and temperature (Bishop 1974; 1975; Edwards et al, 1972; Hamdy et al, 2003; Hedenberg, 1970; Lazzara et al, 1986 ; Micholovitz, 1986; Miglietta, 1973;

Ottenbacher et al, 1981; 1983; Regan et al, 2010; Rosenbek et al, 1991;1996; 1998; Sciortino et al, 2003; Sobsey & Orelove, 1984; Weber & Brown, 1996), E-stim to increase or decrease sensitivity (Barikoo & Lam, 2011; Blumenfeld et al, 2006; Carnaby Mann & Crary, 2007; Curren & Mann, 1983; Dantas & Dodds, 1990; Ding et al, 2002; Freed et al, 2001; Furuta et al, 2012; Humbert, 2006; Kieger et al, 2006; Leelamanit et al, 2002; Ludlow et al, 2007; Othman et al, 2007; Park et al, 1997; Power et al, 2004; 2006; Shaw et al, 2007), or use of intra-oral appliances to improve sensory awareness of the tongue and jaw in relation to eating and drinking (Gisel, 1994;1996; Gisel, et al, 1995a; 1996; 1999; 2001;Harberfellner et al , 2001; Korbmacher et al, 2004). Non – nutritive sucking is described in some of the literature as a sensory approach to facilitate the development of oral feeding for premature infants (Mattes et al, 1996; Poore et al, 2008; Yildiz & Arikan, 2011). Others describe a combination of sensory stimulation and oral motor work (Barlow et al, 2008; 2014; Boiron et al, 2007; Bragelien et al, 2007; Coker-Bolt et al, 2012; Fucile et al, 2002; 2005; 2011; 2012; Gaebler & Hanzlik, 1995; Hill, 2005; Hwang et al, 2010; Lau & Smith, 2012; Lessen, 2011; Pimenta et al, 2008; Rocha et al, 2007; Standley et al, 2010). The sensory approach with infants is reported as being necessary to help their oral sensory development and reduce oral aversions following any tube feeding or other invasive interventions that may have a negative impact on oral feeding development (Jadcherla et al, 2010; Mathisen et al, 2000).Non – nutritive sucking will be discussed further in the next chapter.

The rationale for sensory approaches is different from oral-motor exercises in that stimulation is being performed to increase or reduce sensitivity rather than alter muscle function (Gilmore et al, 2003). Sensory approaches stimulate the sensory receptors of the relevant cranial nerves, trigeminal, (cranial nerve V), glossopharyngeal (cranial nerve IX) & vagus (cranial nerve X) nerves and therefore cause some reactivation, or sensory changes that will be beneficial (Jean, 2001). Children who have long term feeding problems are likely to have food aversions (Field et al, 2003; Mathisen et al, 2000). These may have arisen because of prolonged use of a naso - gastric tube or persistent reflux impacting on the eating and drinking process (Mathisen et al, 1991; 2000; Senez et al, 1996). Sensitivity may present as hypersensitivity or hyposensitivity. Oral hypersensitivity tends to manifest itself through a child's dislike of certain textures in the oral cavity or having their face touched. In contrast, oral hyposensitivity tends to include a

limited awareness of the amount of food in the oral cavity; diminished responsiveness to stimuli in the oral region; significant saliva loss; limited sucking and /or chewing skills and a tendency to prefer very strong flavours (Field et al, 2003; Lawless, 1985; Mathisen et al, 1991; 2000).

Children with eating and drinking difficulties may also have additional needs such as visual or hearing impairments, and these problems in addition to learning difficulties may increase the chance of developing significant eating and drinking problems (Kennedy, et al, 1997; Rommel et al, 2003; Sanders et al, 1993; 1997; Senez et al, 1996). Therapists often recommend sensory programmes to reduce oral-motor intolerance or to increase sensory awareness. A messy food play programme may be implemented, for example (Harding et al, 2010b; Senez et al, 1996). The Harding et al (2010b) paper discusses the importance of messy play as an opportunity to enable children with long term food aversions to become desensitised to unfamiliar tastes and textures in a context which is not demanding. However, it is hard to differentiate between how much is learnt behaviour compared to impaired oral sensory function. More recently, use of carbonated drinks to stimulate oral and pharyngeal areas have been recommended for adults as there is some sensory stimulation of the trigeminal, glossopharyngeal and vagus nerves (Jean, 2001; Mistry et al, 2007). Carbonated drinks stimulate greater sensation in the pharynx leading to increased movement of the hyoid bone with reduced aspiration and penetration (Bartosthuck et al, 2003; Duffy, 2007; Sdtravou et al, 2012). With children, there are issues with health such as the sugar content present in these drinks, so it tends not to be used. In addition, studies cited that support carbonated drinks and swallowing have been with acquired neurological disorders (Bartosthuck et al, 2003; Duffy, 2007; Sdtravou et al, 2012).

The unsubstantiated rationale underpinning oral-motor desensitisation programmes suggests that there has been an ineffective integration of motor and sensory skills during development, and as such, work by the therapist may help to redress this balance and allow progress to be made. Also, such programmes argue that a child can develop more coordinated oral movements alongside increased tolerance of tastes and textures in a more pleasurable play situation (Senez et al, 1996). Sensory approaches remain controversial. In addition, there have been few studies with large numbers of participants that have explored the use of sensory approaches with congenital disorders. One hesitant hypothesis

based on expert opinion suggests that use of thermal application, particularly cold stimulation or use of electrodes to stimulate muscles may not have positive outcomes for children with congenital difficulties, and may actually be detrimental as the make up of the muscles of a congenital disorder is not going to change. Circumstantial opinion suggests that using extreme temperatures such as cold thermal applications for small children could cause shock and discomfort.

3. 2.4 Compensatory strategies

i) Modification of food textures

Using specific textures (Table 3.1) to make food more manageable to eat is frequently implemented to help compensate for motor difficulties (Croft, 1992; Morton et al, 1993; Snider et al, 2011). The type of food texture required is dependent upon assessment findings as to the oral - motor and swallowing needs of the client, and which texture or bolus amount is best to help reduce aspiration risk. Thin fluids can be difficult to manage and thus be the cause of aspiration or penetration so thickeners may be used. Altering the texture of food and thickening fluids can help someone create a better food bolus, gain better oropharyngeal control, alter transit time in the pharynx and therefore reduce any risks of aspiration (Dantas et al, 1989; 1990; Gumbley et al, 2008; Igarashi et al, 2010; Steele & Van Lieshout, 2009; Taniguchi et al, 2008). Additionally, the temperature of food and the sensory feedback provided by temperature and taste can help better bolus control and manipulation (Kuhlemeier et al, 2001; Sciortino et al, 2003). Although thickening fluids and modifying food textures can help manage eating and drinking needs, there are a number of issues related to use of thickeners that are controversial and result in poor outcomes. Thickeners are often mixed incorrectly as carers do not understand the rationale of why fluids need to be thickened or the properties of how the thickener may react when mixed with other fluids (Chadwick et al, 2002; 2003; 2006; Crawford et al, 2007; Harding & Halai, 2009; Smith et al, 2006). In the first study by the author in this chapter (Harding & Halai, 2009) participants working in a special school setting commented that although they mixed thickeners in their daily management with meal preparation for the students, they were not confident with this. Advice, therefore, on how to gain differing levels of viscosity through adding thickener to fluids, and explaining to carers why thickeners are needed remains problematic. Aside from the challenges of conveying how to mix thickeners to others,

thickeners are affected by temperature. The sensory characteristics of thickeners can change over the course of a meal, so viscosity may alter in contact with saliva and as the temperature of the food changes (Dewar & Joyce, 2006; Garcia et al, 2008; Matta et al, 2006). Thickeners are often not used with premature infants as the gut is considered too immature to cope with different materials to digest and could consequently lead to serious health outcomes. (Clarke & Robinson, 2004; Lucus & Cole, 1990).

People on thickened diets rarely meet the hydration targets necessary for good health and still have a higher incidence of pneumonia compared to others who have different health needs (Finestone et al, 2001; Vivanti et al, 2009; Whelan, 2001). This suggests that although thickeners may provide some benefit in reducing risk from aspiration there are still other problems in relation to health that a thickened diet fails to address. Because of the altered state of fluids once thickeners are used, clients may have a reduced appetite (Vivanti et al, 2009). Due to these difficulties, team collaboration and working is essential to monitor the health needs of the child as well as supporting caregivers in their management of texture modification and use of thickeners.

ii) The importance of posture

An upright posture is better for competent swallow function during eating and drinking in typically developed adults as there is greater anterior displacement of the hyoid bone with almost simultaneous trigger of the swallow (Perry et al, 2012). This swallow competence is not maintained with a delay in triggering the swallow when in supine (Perry et al, 2012). Providing appropriate head control to provide whole body stability and maximise a good head and neck position during mealtimes can reduce some risk of aspiration or penetration (Table 3.1; Einasson –Backes et al, 1993; Morton et al, 1993). Having a physical disability that influences postural competence may impact on the following; i) initiation of effective oral-motor skills; ii) appropriate breathing pattern required for eating and drinking; iii) effective swallow mechanism, and iv) effective gut motility (Morton et al, 1993; Perry et al, 2012). Using other postural strategies such as jaw support or side lying during a mealtime can enable better oral phase stability and also provide passive support so that effort is not taken up with managing respiration (Boiron et al, 2007; Clark et al, 2007).

Other compensatory movements involve altering the position of part of the body, e.g. a chin tuck, rather than whole body postural management. This type of compensatory strategy can minimise the risk of aspiration by improving the biomechanics of the swallow (Bulow et al., 2002; 2003; Ertekin et al, 2001; Lewin et al, 2001; Shanahan et al, 1993). Accurate replication of this type of compensatory movement is challenging. A study identified that SLTs did not agree on the position for a chin tuck and this therefore has implications for how carers and clients are trained as well as maintaining the most beneficial physiologic effects (Okada et al, 2007). Children with learning disabilities find it hard to use compensatory postural strategies such as the chin tuck as it requires both cognitive and receptive language skills to carry out and maintain during a mealtime (Harding & Cockerill, 2014). These techniques also rely on the client having had a previous awareness of the sensations involved in eating and drinking, therefore providing them with some form of reference point on which to base their compensatory attempts. People with learning disabilities may not have had a previous positive experience with eating and drinking (Duffin, 2010). However, caregivers may focus on supporting the client physically, verbally and visually to have a specific head posture, for example, and therefore use some of the biomechanical principles outlined in the postural techniques described to aid bolus transit (Okada et al, 2007).

3. 2 .5 The environment

Mealtimes are a daily event and communication should be a central part of the management for children with learning disabilities (Table 3.1). Given the high incidence of eating and drinking problems within a caseload of children with learning disabilities parents and caregivers are likely to experience a high level of stress and this can impact on a child's eating and drinking management (Cass et al, 2005; Field et al, 2003; Hewetson et al, 2009; Peterson et al, 2006; Sleight 2005). Children may not be independent and require help from others when eating (Parkes et al, 2010; Reilly et al, 1992; 1993; 1996). Independence during mealtimes can enable children with learning disabilities to control the speed and pace of the meal; importantly, by setting the pace themselves, a bolus of food can be more effectively managed before taking the next mouthful (Pinnington & Hegarty, 2000). Using communication strategies appropriate for a child can support both their receptive and expressive skills and can help prepare

the child to manage liquid and food effectively. This could contribute to risk reduction as well as enhancing the quality of life within the routine context and many papers in this thesis have highlighted the importance of communication as part of eating and drinking management (Harding & Halai, 2009; Harding et al, 2010a; 2010b). Children may have reduced communication competence and have to rely on others to interpret their non-verbal or idiosyncratic communication when indicating that they are having difficulties; this is important especially when monitoring risk within a vulnerable population (Lace & Ouvry, 1988). Parents of premature infants find interpreting their infant's signals difficult, particularly around mealtimes (Harding et al, 2014; 2015; Shaker, 2013; Silberstein et al, 2009). This difficulty can impact on the successful introduction of oral feeding, and will be discussed in more depth in chapter 4 (Harding, 2008; 2009; Harding et al, 2012a; 2014; 2015). The Harding & Halai, (2009) paper highlighted changes in carer perceptions of the importance of mealtime communication. Before training, participants on the dysphagia training programme had not considered using communication as part of their mealtime management. After the training, there was a significant difference in opinion about the importance of integrating communication targets to support pupils. More specifically, parent – child interaction during the hunger provocation study (Harding et al, 2010b) focused on changing parent language styles to be more facilitative and enabling. On completion of the intervention, the parents used fewer reprimands with the children. Both children made significant progress with oral intake, tolerating mealtimes and reducing gastrostomy feeds in contrast to the Control child. It is hard to prove which strategies enabled improvements to emerge with such a small sample and further studies with larger samples would be needed to understand more clearly the therapeutic processes used in this study such as communication styles of both parents and children (Harding et al, 2010b).

3.3 Conflicts in intervention

Research in eight systematic reviews that supports the management of feeding and swallowing problems in paediatrics is described as having methodological limitations, and inconclusive outcomes for oral motor interventions, compensatory strategies and alternatives such as gastrostomy feeding (Arvedson et al, 2010 a; Arvedson et al, 2010b; Clark et al, 2009; Gantasala et al, 2013; Morgan et al, 2012; Pinelli & Symington, 2005; Samson-Fang,

2002). The evidence base to support paediatric strategies that minimise the risk of dysphagia therefore is still small (Arvedson et al, 2010a). This is partly due to the wide range of therapeutic methods used and the varied environmental variables involved, such as equipment, positioning and communication styles of both the child and carer (Table 3.1). More specific details about the reason for a strategy as well as how often it needs to be completed would be useful. Some of the work in this thesis has attempted to describe the various therapy intervention pathways necessary to implement change as well as the time taken to achieve this (Harding et al, 2010a; 2010b; 2012a). Quantification of how often an approach needs to be carried out and the time spent on it would be useful for both practitioners and carers. Additionally, consideration needs to be given to deciding if an intervention should be carried out during the mealtime or separate from it as with oral motor exercises (Beckman, 1988; Ottenbacher et al, 1981; 1983; Rosenfeld-Johnson, 1999; Shuler et al, 2001; Sjogreen et al, 2010). Embedding compensatory movements within a functional context to maximise function is something that SLTs frequently do. The argument is that neural plasticity will not be effective unless the action is purposeful and related to the actual function (Morgen et al, 2004; Remple et al, 2001). It is assumed that the sensory aspect of smell and texture can also provide stimulation and support to improving eating and drinking skills, and that integrating the strategy targeted within a functional context is more meaningful for a child. It is not yet clear from the current research if a therapeutic strategy would be more effective if carried out within a familiar setting so that learning is maximised or if it should be completed outside of the familiar environment so that the target movement is disassociated from its context. It may be that both approaches are necessary, and if so, it is important to explore the rationales behind each method. For children who have learning disabilities, success of a strategy is more likely to occur and have greater meaning if it is carried out within an everyday situation. Children with disabilities find generalisation of a skill into another situation hard, so exercises outside of a meaningful context may have less value or produce fewer outcomes (Merrill et al, 2003). The age of the client, the stage of neurological development of that person and the extent of neurological damage are likely to have an impact on outcomes (Morgan et al, 2003). Other research is still exploring any negative consequences of stimulation with the argument that promotion of neuroplasticity beyond the immediate area being stimulated may cause *interference* and the

possibility that stimulation may inhibit any improvement in function (Kleim et al, 2002; Kleim & Jones, 2008). These issues are explored further in chapter 4 in relation to non – nutritive sucking for infants.

Some therapy strategies used with people who have dysphagia have focused on, repetitive stimulation of muscles in a specific area. This is to enable some alternative innervation to develop some permanent functional change through plasticity (Nudo et al, 1996; Kilgard et al, 1998; Pascual - Leone et al, 1993). Repetition can be important in inducing changes in brain function, although the application of such an approach to people who have dysphagia has been variable in its outcomes (Nudo et al, 1996; Kilgard et al, 1998; Pascual-Leone et al, 1993). With non-nutritive sucking, for example, one rationale suggests that by providing oral stimulation, relevant neural pathways will be stimulated and this will help the development of feeding and later speech development (Bache et al, 2014; Barlow et al, 2008 ; 2014; Boiron et al, 2007; Boyle et al, 2006; Bragelien et al, 2007; Coker-Bolt et al, 2012; Field et al, 1982; Fucile et al, 2002; 2005; 2011; 2012; Gaebler & Hanzlik, 1995; Hill, 2005; Hwang et al, 2010; Lau & Smith, 2012; Lessen, 2011; Liu et al, 2013; Lyu et al, 2014; Mattes et al, 1996; Measel & Anderson, 1979; Neiva & Leone, 2006; 2007; Pimenta et al, 2008; Poore et al, 2008; Rocha et al, 2007; Rocaht et al, 1997; Standley et al, 2010; Taylor et al, 2000; Tideman, 2000; Yildiz & Arikan, 2012). There are variable arguments about the benefits of the intensity of neurological stimulation. One suggestion is that there needs to be a certain level of stimulation to enable change to occur although it is not clear what the threshold for stimulation would be (Luke et al, 2004; Lisman et al, 2005). Alternatively, another argument is that too much stimulation can cause no change in desired outcomes (DeBow et al, 2004). Dosage, i.e. the amount of stimulation needed has been explored in some studies (Rosenbek et al, 1991; 1996; 1998). The authors of these studies focused on tactile thermal stimulation with stroke patients looking at between 150 to 540 trials per week of stimulation. Data from these studies show that 540 trials per week was the most effective number of trials needed to facilitate significant changes with swallowing. However, these studies typically had small numbers of participants with limited periods of follow up. It is difficult to draw conclusions as to how best to deliver this intervention to a larger population with more variable neurological problems.

Promotion of neuroplasticity beyond the immediate area being stimulated is known as *transference* (Robbins et al, 2008). This involves the stimulation of

functional neurological pathways to promote compensatory movement or neurological change (Hanson & Landmesser, 2003; Kleim et al, 2008). Research into electro stimulation of the cortex in relation to swallowing has shown neuroplastic re-organisation that has improved swallowing skills (Hamdy & Rothwell, 1998; Hamdy et al, 2003; Fraser et al, 2002; Han et al, 2005). Again, this is a clinical area where further research to understand the process and mechanisms involved is important. On the other hand, *interference*, or too much stimulation can result in neurological pathways being over stimulated and therefore ineffective. One example is trans - cranial magnetic stimulation (Muellbacher et al, 2001). Inappropriate use of stimulation can lead to limited outcomes (Power et al, 2004; 2006; Fraser et al, 2002). Premature infants have a period of synaptogenesis which is important for synaptic development and synaptic pruning. Throughout this period of neurological activity, learning opportunities and environmental stimuli interact with innate cognitive abilities to modify neurones and develop cortical organisation, and these sequence of neurological events are recognised critical periods important in infant development (Cichero & Murdoch, 2006; Jadcherla et al, 2010; Kolb & Gibb, 2001; Skuse, 1993). Migration is complete at birth but premature infants are still experiencing this period of neurological development and activity; practitioners hypothesise that because of this, stimulation could be neurologically beneficial with re-generation of new , functioning synapses shaped by the stimulation received (Barlow & Estep, 2006; Craig & Boudin, 2001; Kolb & Gibb, 2001; Luciana, 2003; Yamanumura et al, 2002; Yao et al, 2001). Research into neuroplasticity has been mainly with acquired populations, or with premature infants who do not have a congenital disorder. This makes it hard to consider the best types of therapy strategies for children with congenital disorders and dysphagia as less is known about congenital neurology (Harding & Cockerill, 2014). Timing of intervention is also important, with a suggestion that long, uninterrupted periods of training are more effective than short bursts of therapy (Fisher et al, 2001).

To summarise, many therapy interventions focus on repair of damaged pathways or developing new pathways to compensate for skills lost or which have not yet developed. The level of receptive function and cognition has not often been considered in many approaches and this can lead to the wrong strategy being selected for certain conditions (Harding & Cockerill, 2014). The population of infants and children who require support and development with eating and

drinking needs to be defined more clearly, with greater attention given to the diversity of this population (Arvedson et al, 2010 a; Arvedson et al, 2010 b; Clark et al, 2009; Gantasala et al, 2013; Morgan et al, 2012; Pinelli & Symington, 2005; Samson-Fang, 2002; Sleight, 2005). There are not enough valid and reliable tools available for assessment of feeding and swallowing problems, and this makes evaluation of current methods difficult. Future research with paediatrics needs to consider the immature and congenital make up of children as well as the cognitive and environmental elements that interact with a child's management. The two papers in this chapter have focused on carer knowledge of the management of eating and drinking difficulties (Harding & Halai, 2009) and carer training to manage complex eating disorders (Harding et al, 2010b). Instead of focusing on oral motor exercises, other methods such as verbal prompting, communication style and improving oral sensory tolerance to reduce food aversion have been implemented effectively. These papers now follow this summary.

3.4 Research findings completed by the author

The following comment and two papers have been published by the author and focus specifically on two interventions. These papers are:

1. Harding C. & Halai V. (2009) Providing training for carers of children who have profound and multiple learning disabilities. *British Journal of Developmental Disabilities*, 55(1), 33-47

A dysphagia training programme was devised for staff in a school for children with severe and profound learning difficulties. Before and after questionnaire data was collected. The main purpose of the questionnaire was to ascertain staff understanding of the nature and impact of swallowing disorders that their typical classroom student might experience. Further questions evaluated changes in knowledge about eating and drinking difficulties after the training had been completed. Other topics considered included the benefits of communication during mealtimes, as well as understanding the rationale behind SLT recommendations such as texture modification. The themes here, such as identification of risk, understanding what to look for visually during a mealtime and using communication as part of the dysphagia management appear in other papers by the author, but with different populations (Harding, 2009 ; Harding et al, 2010a; 2010c; 2014)

2. Harding C., Faiman A., Wright J. (2010b) A pilot project to evaluate an intensive desensitisation, oral tolerance therapy and hunger provocation programme for children who have had prolonged tube feeds. *The Journal of Evidence Based Health Care* December (8); 268 – 276

The participants in this study all had neonatal feeding problems as a result of chronic reflux. All had had gastrostomy tubes inserted as the severity of the reflux they experienced prevented them from developing oral feeding abilities. This study examined a five day multi-disciplinary approach used to wean children off gastrostomy tube feeds. The programme of intervention is described with clear rationales citing relevant studies to support the activities. Feeding interventions for children are often criticised as the evidence base is small. This study includes only

a small sample, but it does attempt to describe why certain strategies are carried out, and what the benefits are. One aspect of the intervention was exploring parent – child language used during the mealtime using video materials. Communication styles were included in the goals developed with parents, and therefore, communication strategies were an important part of the therapeutic management to encourage increased oral intake and reduced gastrostomy tube dependence. Many papers presented in this thesis comment that communication is an important part of the management of eating and drinking difficulties (Harding, 2009; Harding & Halai, 2009; Harding et al, 2010a; 2010b; 2014; 2015).

1. Harding C. & Halai V. (2009). Providing training for carers of children who have profound and multiple learning disabilities. *British Journal of Developmental Disabilities*, 55(1), 33-47

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PROVIDING DYSPHAGIA TRAINING FOR CARERS OF CHILDREN WHO HAVE PROFOUND AND MULTIPLE LEARNING DISABILITIES

Celia Harding and Varsha Halai

Introduction

People with learning disabilities are frequently dependent on the support of others both to interpret health needs and to evaluate health status (Lace and Ouvry, 1998). Lace and Ouvry (1998) also comment that many people with learning disabilities, and particularly those with profound and multiple learning disabilities (PMLD), have unmet needs; in particular, they mention that nursing staff have often overlooked the medical needs of the clients they care for. Emerson and colleagues (Emerson *et al.*, 2001) report that 'Studies have shown that people with learning disabilities not only have a high level of unrecognised illness, but also reduced access to generic preventative screening and health promotion procedures,' (p 25).

Eating and drinking difficulties are often undiagnosed or untreated within the learning disabled population and as a result health difficulties may arise from undetected aspiration or lack of adequate

nutrition. In a study where 507 participants were assessed, 22% were perceived to be overweight and 14% underweight, with 21% had "other difficulties" such as problems with chewing, aspiration difficulties and specific issues related to the oral preparatory phase, oral phase and /or pharyngeal phase (Kerr *et al.*, 1996). Aspiration risk and death from aspiration pneumonia within the learning disabled population has been highlighted in the Mencap report, "Death by Indifference", (Mencap, 2007). This report drew attention to six clinical cases where it was felt that people with learning disabilities were not accessing health services in an equitable way, and that health care professionals also displayed lack of understanding regarding the nature of the communication needs of the clients, thus making intervention challenging.

The issues about supporting the health of children and adults with learning disabilities are multifactorial. One issue is the ability of the person to communicate

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EVIDENCE UTILISATION

Evaluation of an intensive desensitisation, oral tolerance therapy and hunger provocation program for children who have had prolonged periods of tube feeds

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Abstract

Background Some children with feeding difficulties may require nasogastric tube feeding or insertion of a percutaneous endoscopic gastrostomy (PEG) from a young age. A small cohort of these children can develop severe oral aversions that can delay the re-introduction of oral feeding. Multidisciplinary approaches that provide an intensive approach are deemed the most effective method of intervention to reduce nasogastric and PEG dependency.

Methods Two children and their parents received an intensive approach to reduce PEG feeds (Child A and Child B), while one child and her parents elected to receive a traditional feeding clinic approach (Child C). The mean age of the participants was 4 years 4 months.

Results Child A initially took 2090 kJ (44% daily nutritional requirement) via her PEG before the intensive program, and Child B took 100% daily nutritional requirement via his PEG. Three months post the intervention, Child A took 100% of her nutritional requirements orally and Child B had reduced PEG requirement significantly to 38% of daily nutritional requirement. Child C showed no changes in PEG versus oral intake.

Children who received the intervention were able to remain focused on mealtimes for longer, with fewer instances of leaving the table. Parents altered their language styles post coaching on the intensive intervention using fewer reprimands. No changes with these behaviours were noted with Child C.

Conclusions Although this was a small pilot study, there are some strategies used within an intensive multidisciplinary context that can enable children to reduce their reliance on PEG feeds significantly.

Key words: food aversion, hunger provocation, increased oral intake, prolonged tube use.

Introduction

Feeding, eating and drinking problems (dysphagia) within a paediatric population are complex and varied, and many children with such difficulties require multidisciplinary intervention from healthcare professionals to overcome these issues.¹

Some infants and children may have complex difficulties that can lead to alternative feeding methods including nasogastric (NG) tube feeding sometimes leading to percutaneous endoscopic gastrostomy (PEG) insertion feeding.²⁻⁵

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There is a small cohort of children who have a PEG inserted early in their life, but who make progress medically (such as children in whom chronic reflux has resolved), and who *should* no longer require PEG feeding. These children can be highly resistant to oral feeding and maintain dependence on PEG feeding.

This paper seeks to explore an intensive approach within a Paediatric Gastroenterology Team that developed oral feeding tolerance with children who had had prolonged periods of PEG feeding.

Prevalence

Some studies have attempted to quantify the types and range of difficulties that children may have. Predictions vary, but Babbitt *et al.*⁶ report that there are up to 25% of children

3.5 Implications, recommendations and concluding remarks

The two studies completed by the author have considered typical therapy environments including training parents and caregivers to carry out an intervention and evaluating how a strategy links to the current evidence base. These studies have explored why SLTs carry out an intervention and how effective it is.

Paper 1 focuses on carer training in a special school for children with severe and profound learning difficulties. Paper 2 considers a small group of children with oral aversion and long term tube use and uses a range of approaches used by SLTs in collaboration with other members of the multi-disciplinary team. Both papers considered using communication as part of the eating and drinking management. Carers of children with severe and profound learning disabilities had not considered communication as an essential part of mealtime management before their training (Harding & Halai, 2009). Parents in the second study were encouraged to change their language and communication style with their child to improve the amount eaten, and to provide some verbal guidance with the mechanics of eating and drinking (Harding et al, 2010b). The importance of communication is highlighted both in this chapter and in chapter 1 (Harding et al, 2010a; 2010b). Language use is not a tangible concept for many and is frequently underrated as a strategy as has already been discussed in Chapter 1. These papers show that communication could be given greater prominence in intervention, though future research could examine more specifically how. Communication is an important consideration as children with dysphagia often have disrupted interaction with a carer at this time (Davies et al, 2009). Mealtimes for children with dysphagia are effortful (Welch et al, 2000), stressful because carers may be concerned about amounts of food taken (Davies et al, 2009) and may not have an consistent routine due to a child's varying responses when eating and drinking (Reilly et al, 2000). In one study of children who had cerebral palsy, protests were the most prevalent communicative initiation made by the children participating (Veness & Reilly, 2007). Veness & Reilly, (2007) go on to suggest that further studies of typical mealtimes are needed so that the negative eating and drinking experience of children with complex needs can be reduced. However, Harding et al, (2012b) argue that attempting to reduplicate a typical experience can give some important information about helping gain a more comprehensive understanding of the link between social communication during

meals and managing a child's eating and drinking. However, a typical mealtime template will not necessarily suit a child with complex eating and drinking needs. Further observations would be useful to explore how communication can benefit the child's eating and drinking style as well as the carer's quality of life. It would be useful to study the various communication methods children use, both non-verbally and verbally to examine if certain communication behaviours are associated with specific physiological or motor difficulties during the meal. Evaluation of the benefits of communication could also be studied, in particular, how communication can help to set the pace of a meal or the differences in a child's ability to manage a meal according to the use of verbal prompts. A study that explores parent training to interpret the early non-verbal communication of premature infants is presented in chapter 4, and some of these issues are discussed again (Harding et al, 2014; 2015).

Carers receiving dysphagia training in the school were experienced, yet still were unsure of certain concepts related to swallowing disorders (Harding & Halai, 2009). This could be because they did not understand why they had to use some mealtime therapy strategies, or it could be because they did not feel the approach had any value or benefit for the child. Given the research about non-compliance with therapy goals for compensatory strategies it would be important to explore practitioner communication skills and carer values in greater depth to understand the process of engagement with implementation of therapy goals into everyday situations (Crawford et al, 2007; Chadwick et al, 2002; 2003; 2006) How practitioners give advice and share information with carers can influence whether advice is acted on (Sleigh, 2005). Therefore, the way SLTs demonstrate and communicate therapy strategies, is likely to have a major impact on whether they are used or not.

The review of intervention in this chapter has highlighted that the evidence base to support research into managing paediatric dysphagia is small but developing (Arvedson et al, 2010 a; Arvedson et al, 2010 b; Clark et al, 2009; Gantasala et al, 2013; Morgan et al, 2012; Pinelli & Symington, 2005). The caseload experienced by SLTs who work in this area is very complex and wide ranging (Field et al, 2003). The evidence for many approaches to eating, drinking and swallowing disorders is polarised and variable in content and for oral motor exercises outside of a functional setting the evidence base is weak (Arvedson et al, 2010a; Arvedson et al, 2010b ;Gantasala et al, 2013 ; Greene et al, 2012 ;

Morgan et al, 2012). A greater understanding of the muscle aetiology and the neurology of the infant and child with feeding difficulties needs to be clarified within research. There appear to be benefits for therapy approaches that incorporate strategies into functional, everyday situations but the populations studied need to be defined more clearly with differentiation between congenital and acquired disorders so that the clinical applications can have maximum efficacy. Greater discussion as to the benefits of a very intensive and potentially invasive approach to oral stimulation for the neonate for example would be productive in understanding the reality of what the benefits should be and the perceived advantages if there are any (Bache et al, 2014; Barlow et al, 2008; 2014; Bernbaum et al, 1983; Boiron et al, 2007 ; Boyle et al, 2006; Fucile et al, 2002; 2005; 2011;2012; Hill, 2005 ; Hwang et al, 2010; Liu et al, 2013; Lyu et al, 2014; Measel & Anderson, 1979 ; Poore et al, 2008; Rochat et al, 1997; Rocha et al, 2007 ; Rosenfeld-Johnson, 1999 ; Standley et al, 2010; Yildiz & Arikan, 2012; Zhang et al, 2014). Information on the participant's communicative and cognitive capacity is an important issue and the research presented in this thesis is suggesting that considering communicative interactions during mealtimes of people who have complex eating and drinking needs or focusing on infant pre-intentional communication during feeding is an area that requires further exploration.

The focus of therapy needs to shift considerably to meet the needs of infants, children and young people with feeding, eating and drinking difficulties. Rather than making children passive recipients of interventions that are being "done" to them and participating in exercises that appear to have little relevance to the situation, they need to be involved as much as possible so that they can have some control over what is happening and also possibly develop some independence in managing their difficulties. Therapy goals could perhaps take account of the fact that a child with a congenital disorder will probably not have had a positive early experience with eating, and will possibly not achieve "normal" movement of his lips, cheeks, tongue and jaw. They also need to account for the fact that caregivers will be the main source of support for the children, and realistically, strategies need to be easily transferable so that parents and significant others can utilise these strategies effectively. Making therapy goals a part of the context and therefore ensuring they are functional is essential. Reducing risk is vital, but quality of the experience on a daily basis is also important. The papers here attempt to highlight the fact that caregivers are

important in that they carry out specific approaches on a regular basis and need to be an integral part of future research (Harding, 2008; Harding, 2009).

Interventions also need to be adapted appropriately to meet the needs of infants, children and young people with complex needs and perhaps consider the environment more. Where possible, children need to be active collaborators in the implementation of their goals so that they can understand clearly what is happening and be as independent as possible, whilst appropriate strategies to minimise risk from swallowing difficulties are implemented into their eating and drinking programmes on a daily basis (Harding et al, 2010b ;Harding & Wright, 2010).

CHAPTER 4

NON – NUTRITIVE SUCKING INTERVENTION TECHNIQUES

CHAPTER 4: Non-nutritive sucking intervention techniques

4.1 Introduction to Chapter 4

This chapter discusses the rationale underpinning non-nutritive sucking (NNS) as a principle strategy for promoting oral feeding in premature infants. There is a developing body of literature that argues that NNS is beneficial for a variety of skills, most commonly to trigger the development of functional nutritive sucking. However, gaining positive outcomes in the development of oral feeding are varied (Bache et al, 2014; Barlow et al, 2008; 2014; Boiron et al, 2007; Boyle et al, 2006; Bragelien et al, 2007; Coker-Bolt et al, 2012; Field et al, 1982; Fucile et al, 2002; 2005; 2011; 2012; Gaebler & Hanzlik, 1995; Harding, 2009; Harding et al, 2006; 2012a; 2014; 2015; Hill, 2005; Hwang et al, 2010; Lau & Smith, 2012; Lessen, 2011; Liu et al, 2013;Lyu et al, 2014; Mattes et al, 1996; Measel & Anderson,1979; Neiva & Leone, 2006; 2007;Pimenta et al, 2008; Poore et al, 2008; Rocha et al, 2007; Rochat et al, 1997; Sehgal et al, 1990; Standley et al, 2010; Yildiz & Arikan, 2012; Zhang et al, 2014). The reason for using NNS as an intervention is described in this chapter in relation to its benefits for feeding development. Some research argues that NNS is a sensory stimulation and / or oral motor programme that is used to develop functional sucking (Bache et al, 2014; Barlow et al, 2008; 2014; Boiron et al, 2007;Bragelien et al, 2007;Coker-Bolt et al, 2012; Field et al, 1982;Fucile et al, 2002; 2005; 2011; 2012; Gaebler & Hanzlik, 1995; Hill, 2005; Lau & Smith, 2012; Lessen, 2011; Liu et al, 2013; Lyu et al, 2014; Mattes et al, 1996; Measel & Anderson, 1979; Neiva & Leone , 2006;2007; Poore et al, 2008;Pimenta et al, 2008;Rocha et al, 2007;Rochat et al,1997; Sehgal et al, 1990; Standley et al, 2010; Yildiz & Arikan, 2012;Zhang et al, 2014) whilst other research recommends the use of NNS to enhance oral readiness, reduce pain by oral stimulation leading to neurotransmitter production of natural analgesics and provide comfort in medical procedures, reduce reflux, support weight gain or reduce the risk of Sudden Infant Death Syndrome (SIDS)(Boyle et al, 2006;Bueno et al, 2013; Butt et al, 2000; Carbajali et al, 1999; Cichewicz ; 2004; De Kun et al,

2005;Ernst et al, 1989;Harrison et al, 2005; Heaton et al, 2007; Kramer et al, 2001;Liaw et al, 2013; Liu et al, 2010; Orenstein, 1998; Pickler & Frankel, 1995; Rush et al, 2005; Sehgal et al, 1990; South et al, 2005; Stevens et al, 1999; 2013; Sundaram et al, 2013; Zhu et al, 2014). All the studies described comment that NNS has many benefits and refer to diverse theories to support the rationales underpinning the approaches (Table 4.1).In addition, the methods used for the studies vary greatly.

This chapter presents what is important in infant development, approaches to care for vulnerable infants, non-nutritive sucking and the research evidence to date, and final discussions and conclusions on the future of NNS as a therapy approach. The final paper in this section is a randomized controlled trial that evaluates NNS and draws together some of the discussion points raised here. It puts forward a proposal for a more realistic rationale and suggests an appropriate method of how and when to use NNS.

4.2 Premature infants

Feeding is an intimate time where there are many opportunities for interaction between the mother and the infant as well as learning and developing new skills (Bochner & Jones, 2003; Dodrill, 2001; Jonasson & Clinton, 2006; Kelly et al, 2007; Rutter, 1979; Tomasello & Carpenter, 2007). Sucking in particular is vital in the early development of the infant whether it involves breast or bottle-feeding (Bosma, 1986). Feeding is essential for receiving nutrition, of providing stability in distress and also a means of exploring the environment (Kelly et al, 2007). As discussed in Chapter 1, there are two types of sucking, nutritive sucking (NS) and non-nutritive sucking (NNS). Both bottle fed and breast fed infants have similar rates of NNS and NS, although there are differences with tongue and laryngeal movements and intra-oral sucking pressures as discussed in Chapter1, page 12 (Geddes et al, 2012; Mizuno & Ueda, 2006). The tactile experience that occurs with breast feeding can also enable a mother to engage with her infant and stimulate milk expression (Whitelaw et al, 1988).

Premature infants are born at or before 37 weeks post menstrual age (AAP, 2004). They are fragile as their nervous systems are immature and are still growing

and developing. Motor development occurs both at fetal and infant level and this is important as movement activates mechano-receptors and sensory feedback that supports infant learning (Hanson & Landmesser, 2004). When aged 40 weeks post conceptual age (PCA) premature infants have less grey-matter differentiation and less myelination of the brain compared to term infants (Huppi et al, 1996). Premature infants tend to be over – represented in populations of children who have feeding difficulties as are children who have had significantly low birth weight for gestational age (Pickler et al, 2012; Pridham et al, 2007; Rommel et al, 2003).

Premature infants are not adequately equipped in the range of skills necessary to function when born (Als, 1986; Anderson & Vidyasagar, 1979; Bingham et al, 2009; Ludwig, 2007; Simpson et al, 2002). They have to develop autonomic stability, motor tone and muscle stability, state regulation, interaction and attention skills as well as self regulation abilities. The autonomic system involves breathing, circulation and digestive skills. Typically, feeding requires coordination of sucking, swallowing and breathing (Kelly et al, 2007; Thoyre et al, 2005). The brain stem central pattern generators are stimulated by feedback from chemosensory and tactile reactions to milk ingested by the infant (Amaizu et al, 2008). In the development of early infant feeding, stable swallowing appears before a rhythmical suck pattern emerges (Gewolb et al, 2001). Premature infants often have difficulty in learning to coordinate the suck-swallow-breathe sequence necessary for successful feeding, and this pattern is rarely established before 34 weeks (Bingham et al, 2009; Craig et al, 1999; Da Costa et al, 2008; Koenig et al, 1990; Stumm et al, 2008). Establishing the suck – swallow – breathe cycle, particularly respiration, may be further impaired by the infant's need for a naso – gastric tube (Shiao et al, 1995). Weak pharyngeal pressure due to immature upper oesophageal sphincter function can also inhibit the initiation of successful oral feeding, and subsequently this can have an additional negative impact on sequential sucking development (Rommel et al, 2011). Ineffective suck - swallow - breathe cycles can lead to variable oxygenation and irregular patterns of breathing which in turn impacts on digestion (McGrath & Bodea Braescu, 2004; Pinelli & Symington, 2005; Tronik et al,

1990; Vanden Berg, 1990). These problems with co-ordination tend to occur when premature infants are learning to bottle feed and can cause hypoxia, apnoea and / or bradycardia (da Costa et al, 2010a; Eichenwald et al, 2001; Gewolb & Vice, 2006; Ludwig, 2007; Shiao et al, 1996; Thoyre & Carlson, 2003). Problems with gut absorption can additionally impact on feeding development, and milk formulas may be necessary to support nutritional requirements (Carlson et al, 1991; Lucas & Cole, 1990; McClean & Fink, 1980). Poor motor skills and limited muscle tone in the premature infant can contribute to weak sucking pressure, a decreased sucking cycle, variable pressure throughout the feed and reduced oral intake (Matsubara et al, 2005). As premature infants are more fragile, they may have more health needs; this may impact on the development of consistent feeding skills and therefore on the establishment of a consistent suck-swallow-breathe cycle and motor and sensory development during a period of critical brain development (Bingham et al, 2009; da Costa et al, 2010b; Mizuno et al, 2007; Rommel et al, 2003; Ross & Philbin, 2011a; Stumm et al, 2008).

The state system or the behavioural state shown by the infant represents maturing skills and this provides information about infant brain development (Als et al, 2004; Kinnear & Beachy, 1994). Infant behavioural states include the ability to indicate active sleep, quiet sleep, quiet alert, active alert, drowsiness, crying and indeterminate states as well as showing awareness of significant others (Als et al, 2003; Als, 1986; Ludwig, 2007; Parmelee & Stern, 1972). Responding to stimuli and developing skills to regulate and organize the self are important. The ability to organize behavioural states improves as the infant matures. Maturation occurs as the infant acquires skills through interaction with the environment (Bowlby, 1969; 1973; Parmelee & Stern, 1972). As the infant acquires more skills, there is an increase in the *quiet alert* state (Holditch-Davis, 1990). Developing the *quiet alert* state is important for premature infants in the development of feeding; this state is seen in normal term infants before a feed, but in only 1.1% of premature infants (Bingham et al, 2010; Holditch-Davis, 1990; Parmelee & Stern, 1972). Practitioners often identify the *quiet alert* state as important for the development of oral feeding (McCain & Gartside, 2002; McCain, 1992; 1997; McCain et al, 2001). Pickler et al, (2006) found in their analysis of 95 infants that infants who were more

active generally as well as being alert tended to feed better in relation to both volume and efficiency. However, this perhaps illustrates that there is lack of consistency in the identification of infant states when encouraging oral feeding (Crowe et al, 2012). Recognizing the variety of infant states is not just important for early oral readiness signs, but also for learning how to interpret early infant non-verbal communication (Harding, 2009; Harding et al, 2012a; Harding et al, 2014; Harding et al, 2015). Communication is frequently seen as a nebulous concept, and up to half a sample of mothers of premature infants interviewed commented that interaction during feeding was not important (Thoyre, 2000). Accurate parent interpretation of both pre - feeding and feeding behaviours can have serious consequences in relation to the establishment of positive oral feeding and early interaction (McGrath & Medoff-Cooper, 2002; Pickler et al, 1993; 1996; 2006; White-Traut et al, 2002). If feeding style and interaction are not managed consistently, negative experiences associated with mealtimes can arise and become a long term problem (Cerro et al, 2002; Hawden et al, 2000; Pickler et al, 2012; Pridham et al, 2005; 2007). This can result in the development of interaction styles which are not facilitative and less adaptive to an infant's needs (Silberstein et al, 2009). Parent stress can influence the development of sustained positive interaction opportunities and the neonatal unit environment can exacerbate parent feelings of anxiety (Carr-Swift & Scholten, 2009). It is therefore important that parents are taught to recognize early non - verbal communication signs and infant states when interacting with their infant (Bell et al, 1995; Dodrill, 2011; Harding et al, 2014; 2015; Rioradan et al, 2001; Shaker, 2013).

Parents report that they feel unsure of the "rules" in a neonatal setting which makes it difficult for them to anticipate what to do or how to manage. They also report that conflicting nursing advice on how to manage their infant's feeding as well as nursing staff feeding the infant rather than enabling parents to do so impacts on their confidence (Carr-Swift & Scholten, 2009; Hoddinott & Roisin, 2000). Some parental anxieties can become focused on the amounts of food an infant is taking rather than enjoyment of the social and interactive opportunities within a mealtime (Cerro et al, 2002). Other anxieties involve

concerns about prolonged tube feeding and its perceived impact (Mason et al, 2005), or difficulties establishing breast feeding (Bell et al, 1995; Jensen et al, 1994; Nyquist et al, 1996; Rioradan et al, 2001). Managing parent anxiety and uncertainty is important to consider when helping parents to learn how to manage completing everyday care activities for their infants (Carr-Swift & Scholten, 2009). The parents in the case study described by Harding et al, (2021a) were anxious about beginning oral feeding with their infant daughter. This paper describes how the parents were involved in the early feeding intervention which involved work on both NNS and interaction. In this study, NNS was used as a tool to monitor changes in oral motor function as well as being part of a programme to increase parent confidence with the interpretation of Baby H's infant states. The mother in this study commented that using NNS as part of the programme gave her confidence to interact and respond to Baby H suggesting that NNS can be important in helping parents to learn to identify infant states and early nonverbal signs. This idea is extended further in the randomized controlled trial reported at the end on this chapter where parent training in using NNS to help infants reach a state suitable for oral feeding trials decreased time spent in hospital (Harding et al, 2014) and in a smaller study where infants with congenital disorders were studied (Harding et al, 2015).

There have not been any studies which have investigated the reliability of the terms used to represent infant states. Supporting the premature infant using the principles of Developmental Care (Als, 1986; Als et al, 2004) and using strategies that take account of the infant's vulnerabilities, e.g. NNS to help guide an infant towards a *drowsy* or *quiet alert* state for feeding are important for orientating the baby and developing early learning opportunities (McCain & Gartside, 2002; McCain et al, 2001).

Oral readiness is one of the important early stages of infant development but has variable recognition and usage as a mechanism for determining oral feeding ability (Als et al, 2003; Dodrill et al, 2004; McGrath & Medoff - Cooper, 2002; Shaker, 2013). Sucking ability both non-nutritively and nutritively is often used as an indicator of an infant's oral-motor status and can also be used to give important information about behavioural states (Amaizu et al, 2008; Pickler

& Frankel, 1995). Alertness, as mentioned, is an important behavioural state that is linked to an infant's ability to interact with the environment; this ability to actively focus prior to a motor event has also been linked to later cognitive development (Columbo, 2001; Parmalee & Stern, 1972; Thoman et al, 1976; Wolff, 1959). Premature infant alertness is different from the alertness of a term infant; in term infants, the intensity of the sucking is positively correlated with infant responsiveness and the important *quiet alert* state necessary for feeding (Medoff-Cooper & Ray, 2004; Pickler & Frankel, 1995). Thus, if the infant is irritable, then the sucking is likely to be less consistent and more erratic (McGrath & Bodea Braescu, 2004). Greater oral feeding success in premature infants is associated with the gradual development of the *quiet alert* state (Medoff - Cooper & Ray, 2004; Mizuno et al, 2000). Premature infants can achieve the *drowsy* or *quiet alert* state before a feed, but have difficulties in maintaining this because of the other problems they may have due to immaturity, such as weak muscle tone which impacts on the maintenance of a stable suck-swallow-breathe pattern (McCain, 1997). The *quiet alert* state can be increased by use of NNS prior to a feed, and it has been noted that if infants are helped to achieve this state prior to the implementation of full oral feeding, then they develop more mature NNS patterns (Bingham et al, 2010). Feeding is one of the early, routine activities when mothers feel that they are close to their infants and that they are able to develop some interaction with them (Holditch-Davis et al, 2003; Thoyre, 2000). A combination of attributes contributes towards feeding success; one is the gestational age of the infant as well as his or her stability in relation to motor control, physiologic status and general ability to demonstrate behaviours (Als et al, 2003; Medoff-Cooper & Ray, 2004; McCain et al, 2001; McCain & Garside, 2002; Shaker et al, 1992). Stability of the suck-swallow-breathe cycle, along with the ability to demonstrate hunger cues, alertness and good health all contribute to the development of oral readiness for the first oral feed. Thoyre et al (2005) also recognize the challenge of identifying oral readiness in relation to an infant's stamina when this involves sucking, oral motor function, physiological stability and coordination of the suck-swallow-breathe cycle. These authors have created a checklist that identifies oral readiness signs, the Early Feeding Skills

Assessment (EFS) (2005). This checklist that comprises of 32 items used to guide observation is described as being “*designed to standardize the measurement of feeding skills of preterm infants*” (p 2). It is uncertain as to whether this can be achieved as the checklist itself relies on interpretation based on experience of working with neonates, and it only utilizes four of the Als (1986) physiological state descriptors. Another checklist, Supporting Oral Feeding in Fragile Infants (SOFFI – Ross & Philbin, 2011b) uses algorithm resources to guide practitioners through decision making about oral readiness. It is specifically for bottle fed, fragile infants. However, although it describes use of non-nutritive sucking, pacing and oral states, it is less clear on defining these concepts, and therefore practitioner competence and experience may assist with interpretation. Other, less familiar resources include scales and ratings which are dependent on practitioner experience and knowledge; The Preterm Infant Nipple Feeding Readiness Scale (PINFRS) (McGrath, 2003), and an 18 item preterm infant oral feeding instrument (Fuginaga, 2007). The Preterm Infant Nipple Feeding Readiness Scale Ten item scale that scores items such as gestational age, post-conceptual age, colour and activity, state regulation, hunger cues and tone. Now updated and known as the Feeding Readiness and Progression in Preterms Scale (FRAPPS) (McGrath, 2008 cited in Crowe et al, 2012). The combination of signals and signs that contribute to decisions about oral readiness remain ambiguous and not all practitioners who work with infants may be effective in consistently differentiating between all of the identified infant behavioral states (Braun & Palmer, 1985; Case-Smith et al, 1987; Dodrill et al, 2004; Jordan, 1998; Zimmerman & Barlow, 2009).

4. 2. 1 Developmental care: an approach to support premature infants

Developmental Care (Als, 1986; Als et al, 2003; 2004; McAnulty et al, 2009) is the acute care provided that aims to create the most nurturing environment for the infant. This approach aims to compensate for the disadvantage of being born too early. The philosophy that supports Developmental Care (Als, 1986) relies on the interpretation of infant behaviour and identifying the infant’s non-verbal communication so that positive early development can be facilitated.

The parents are seen as being key to learning to interpret the infant's early signals. Goals include promoting opportunities for the development of physiological functions, developing times for both sleep and for alertness, social interaction, self-regulation, i.e. responsiveness to different situations and the establishment of successful feeding. Infants are recognized as demonstrating key behavioural states as already described (Als, 1986; Als et al, 2003; McAnulty et al, 2009; White-Traut et al, 2002).

Several theories support Developmental Care (Als, 1986) and these include Transactional Theory (Berne, 1964; Sameroff & Fiese, 1990), Neurobiological Theory (Anastasiow, 1990), Psychoanalytic Theory (Bowlby, 1969; 1973; Stern, 1977; Winnicott, 1960) and Synactive Theory (Als, 1986; Als et al, 2004). Transactional Theory (Berne, 1964; Sameroff & Fiese, 1990) recognizes the importance of the environment in relation to a child and the learning opportunities. Neurobiological Theory (Anastasiow, 1990) focuses on the notion of neuroplasticity and that critical periods of development must not be missed or need to be compensated for in some way. Psychoanalytic Theory (Bowlby, 1969; 1973; Stern, 1977; Winnicott, 1960) describes the importance of the infant's developing understanding of the world through relationships with others. Synactive Theory (Als, 1986; Als, 1997; Als et al, 2003; 2004) is the amalgam of the three theories with the focus centered on the vulnerable infant.

4.3 Comparing the key non-nutritive sucking studies

4.3.1 Introducing the key concepts relevant for using NNS

This section focuses on studies that have evaluated NNS, their rationales and outcomes. The studies discussed will be those that have considered NNS as a method of improving and developing either oral motor and / or feeding skills (Table 4.2; Appendix 2). The studies described in Table 4.2 (Appendix 2) were obtained from a literature search. Databases searched were MEDLINE, EMBASE, psycINFO, CINAHL and WEB OF SCIENCE. The search terms used were:
Non nutritive sucking AND
Premature infants AND

Feeding AND

Days to full oral feeding AND

Neonatal AND

Oral motor

English language publications were sought from January 1980 to December 2014. Further papers were obtained searching the reference lists of already identified papers. Papers were included when the aim of the intervention described involved primarily the development of oral feeding though not necessarily days to full oral feeding. In order to ensure as many relevant papers as possible were included, all types of study including randomized controlled trials, smaller matched pairs designs, case studies and commentaries were sought. The maximum number of publications identified by a search amounted to 569. Papers were excluded if they were not in English, did not have the attainment of oral feeding as a main goal, were focused on dentistry, pain or gastric management, were animal studies or with participants who were children, not infants. No quality criterion was applied for the main papers discussed in this chapter.

A total of 41 papers were identified as being relevant in that they focus specifically on the development of oral feeding. These 41 papers are compared to the author's own findings in this chapter.

Table 4.1: Terminology used in Table 4.2, (See Appendix 2):

Table 4. 2: Studies that use non – nutritive sucking to support oral readiness and feeding with infants mentioned in this chapter, (See Appendix 2):

Some of the programmes discussed may not be perceived as considering all of the principles of Developmental Care (Als, 1986; Als et al, 2003; 2004); for example the high therapeutic intensity that some infants receive in programmes provided by a researcher or practitioner (Fucile et al, 2002; 2005; 2011; 2012) (Table 4.3). Programmes where an adult who is not the parent, but a researcher or healthcare professional is stimulating the infant's oral sensory and / or motor

skills out of a functional context comprise of the majority of studies on NNS (Bache et al, 2014; Barlow et al, 2008 ; 2014; Boiron et al, 2007; Boyle et al, 2006; Bragelien et al, 2007; Coker-Bolt et al, 2012; Curtis et al, 1986; Ernst et al, 1989; Field et al, 1982; Fucile et al, 2002; 2005; 2011; 2012; Gaebler & Hanzlik, 1995; Hill, 2005; Hwang et al, 2010; Lau & Smith, 2012; Lessen, 2011; Liu et al, 2013; Lyu et al, 2014; Mattes et al, 1996; Measel & Anderson, 1979; Neiva & Leone, 2006; 2007; Poore et al, 2008; Pimenta et al, 2008; Rocha et al, 2007; Rochat et al, 1997; Seghal et al, 1990; Standley et al, 2010; Yildiz & Arikan, 2012; Zhang et al, 2014). Only Harding, (2009), Harding et al, (2006; 2009; 2012a; 2014; 2015) and Gaebler & Hanzlik (1995) involve parents in the intervention. A programme which does not involve the parents could be seen as in conflict with the principles of Developmental Care (Als, 1986; Als, 1997; Als et al, 2003). It could also increase the risk of alienating the parents from developing confident skills when caring for their infant (Carr-Swift & Scholten, 2009). Non - nutritive sucking is carried out in a variety of different ways. It may involve encouraging sucking on a pacifier or finger in a simple way, or by using a more detailed programme such as one as devised by Fucile et al (2002; Table 4.3) which can be completed between 12 - 15 minutes.

Table 4. 3: Fucile et al (2002) NNS programme (see Table 4.2 for how NNS is implemented in the studies)

<p><i>Peri-oral stimulation (Rationale – to improve muscle intractability, strength and orientation reflexes)</i></p> <ul style="list-style-type: none">• Cheeks x 4 (2 minutes)• Upper lip x 4 (1 minute)• Lower lip x 4 (1 minute)• Upper and lower lip curl x 2 each lip (1 minute)• Upper gum x 2 (1 minute) (rationale = to stimulate swallow & improve suck)• Lower gum x 2 (1 minute) (rationale = to stimulate swallow & improve suck)• Internal cheek x 2 each cheek (2 minutes)• Lateral borders of the tongue x 2 each side (1 minute)• Mid-blade of the tongue x 4 (1 minute) (rationale = to stimulate swallow & improve suck)• Elicit a suck with finger (no frequency specified) (1 minute) (rationale = improve suck and soft palate activation)• Elicit a suck with pacifier (no frequency specified) (3 minutes) (rationale = improve suck and soft palate activation) <p>TOTAL TIME = 15 minutes</p>

In the literature, NNS has many uses (Table 4.4). For the vast majority of studies, it tends to be used to develop sensory awareness in the oral cavity and pharynx, reduce hypersensitivity in combination with motor stimulation of the oral musculature, as a way of increasing the range of motion and strength of the muscles, to increase oral motor organisation and to activate oral reflexes through use of an exercise programme with the aim of developing oral intake (table 4.3) (Bache et al, 2014; Barlow et al, 2008; 2014; Boiron et al, 2007; Case-Smith, 1987; Coker-Bolt et al, 2012; Field et al, 1982; Fucile et al, 2002; 2005; 2011; 2012; Gaebler & Hanzlik, 1995; Hill, 2005; Hwang et al, 2010; Lau & Smith, 2012; Liu et al, 2013; Lessen, 2011; Lyu et al, 2014; Mattes et al, 1996; Measel & Andersen, 1979; Neiva & Leone, 2006; 2007; Poore et al, 2008; Pimenta et al, 2008; Rocha et al, 2007; Rochat et al, 1997; Sehgal et al, 1990; Standley et al, 2010; Yildiz & Arikan, 2012; Zhang et al, 2014). It could be argued that such a physically intensive programme could over stimulate an infant and therefore could cause states to emerge which make it harder to re-orientate and self-regulate. Over

stimulation may increase heart rate, cause excessive caloric loss, increase oxygen desaturations and other destabilizing infant behaviours (Case-Smith, 1987; Long et al, 1980). Not all papers suggest that NNS is important for sensory or oral motor function and development. Some focus on weight gain, nutrient intake, pain management and absorption (Boyle et al, 2006; Bueno et al, 2013; Butt et al, 2000; Cichewicz, 2004 ; Harrison et al, 2005 ; Heaton et al, 2007 ; Kramer et al, 2001 ; Liaw et al, 2013; Liu et al, 2010; Rush et al, 2005; Sehgal et al, 1990; South et al, 2008 ; Stevens et al, 1999; 2013 ; Sundaram et al, 2013; Zhu et al, 2014) some on reflux management (Widstrom et al, 1988; Orenstein, 1988) or minimizing the risk of SIDS (De Kun et al, 2005). Non - nutritive sucking could be a more plausible strategy within the Neurobiological Theoretical framework (Anastasiow, 1990) as there is a possibility that some neuro - plastic stimulation is occurring. However, consideration is still needed regarding the fact that the neurological movements being stimulated are not necessarily going to contribute to the development of functional NS skills since the neurological origins of both NNS and NS are different as with oral motor stimulation generally (Broussard & Alschuer, 2000; Hamdy et al, 1999; Jean, 1984; 2001; Kern et al, 2001; Kessler & Jean, 1985; Martin et al, 2001; Mosier & Brenznaya, 2001; Suzuki et al 2003).The Harding et al (2010a) single case study highlights an example where the development of NNS did not automatically trigger NS skills to emerge. This infant took 17 months to achieve full oral feeding.

Stable swallowing occurs before sequential sucking (Gewolb et al, 2001), so working on sucking first could have few benefits, even though authors suggest that some of the exercises they are undertaking are to develop both sucking and swallowing. Exploring the current range of studies may help to develop more ideas for supporting premature infant transition to full oral feeding safely with the support of parent – led approaches. One paper has actually considered the idea that stable swallowing develops before consistent sucking (Lau & Smith, 2012). Lau & Smith (2012) randomly assigned very low birth weight infants to one of three groups; Control, Swallow therapy and use of NNS. Swallow therapy involved the implementation of 0.05 – 0.2 mls of milk on the back of the tongue 30 minutes pre a feed 5 times a week , and NNS therapy consisted of sucking on

a pacifier with initiation of sequential sucking by the researchers manipulating the pacifier teat in the oral cavity. This study does not discuss how oral readiness was determined, although infants had a mean PMA of 34 weeks at the onset of the intervention. Outcomes showed that there were no significant differences between the Control infants and the NNS infants with the Control infants taking 21 ± 2 days, and the NNS infants taking 19 ± 2 days to move onto full oral feeding. In contrast, the Swallow therapy group infants moved onto full oral feeding significantly more rapidly than their peers, taking 15 ± 2 days. Lau and Smith (2012) discuss that NNS as an exercise to promote the development of oral feeding is not useful in the development of oral feeding. They suggest that swallow exercise is more effective as it is related to the sensory processing of milk passing in the oro-pharynx and that the success is more likely to be attributed to the pharynx being ready to manage what it is designed to do at the right time. Harding et al (2014; 2015) also state that NNS does not necessarily promote quicker access to full oral feeding, and that the benefits of NNS are not necessarily nutritive. In the randomized controlled trial study, there were no significant differences between the NNS groups in comparison with a Control group, but the benefits of NNS as a strategy were discussed in this study (Harding et al, 2014). The smaller study completed by Harding et al, (2015) highlights the importance of NNS as an assessment tool for practitioners, a method of engaging and training parents as well as a way of managing good oral care. Other studies identify that NNS does not significantly improve progress to full oral feeding (Bache et al, 2014; Bragellien et al, 2007; Di Pietro et al, 1994; Gaebler & Hanzlik, 1995; Harding et al, 2014; Hwang et al, 2010; Liu et al, 2013; Mattes et al, 1996; McCain et al, 1995; Neiva et al, 2007; Pickler et al, 2004). Interestingly, recent papers are still focusing on the use of NNS to achieve full oral feeding rather than the swallow, but it could be that researchers feel that this is still an important outcome to evaluate as the current evidence is varied (Bache et al, 2014; Liu et al, 2013; Lyu et al, 2014; Zhang et al, 2014).

4. 3. 2 Inclusion and exclusion criteria for studies about non - nutritive sucking

Most of the studies included infants who were an appropriate size for their gestational age, but excluded those with chronic medical problems stipulating that they must not have congenital abnormalities or chronic medical issues such as Intraventricular haemorrhages III or IV, periventricular leukomalacia or necrotizing enterocolitis (Bache et al, 2014; Barlow et al, 2008; 2014; Bingham et al, 2010; Boiron et al, 2007 ; Boyle et al, 2006; Bragelien et al, 2007; Field et al, 1982; Fucile et al, 2002; 2005; 2011; 2012 ; Gaebler & Hanzlik, 1995; Harding et al, 2006; 2014; Harding, 2009 ; Harding et al, 2014; Hill , 2005; Hwang et al, 2010; Lau & Smith, 2012; Lessen, 2011; Liu et al, 2013; Lyu et al, 2014; Mattes et al, 1996; Measel & Anderson, 1979; Neiva et al, 2006 ; 2007; Poore et al, 2008; Rocha et al, 2007; Sehgal et al, 1990; Standley et al, 2010; Yildiz & Arikan, 2012; Zhang et al, 2014). Including infants with chronic medical problems could be challenging principally because of parents stress, the diversity of the problems and ethical issues although Harding et al (2010a; 2015) focus on infants with neurodisability, Coker - Bolt et al (2012) infants requiring heart surgery, Barlow et al, (2014) infants with lung disease, and Liu et al,(2013) infants with poor sucking compared to their peers. These papers are rare in that they focus on infants with more complex needs. Some authors include more explicit criteria around weight e.g. average size for gestational age (Gaebler & Hanzlik, 1995) or more specifically being born between 24 – 33 weeks gestation (Lau & Smith, 2012), an average of 28 weeks gestational age (Hwang et al, 2010) or 26 – 29 weeks post- menstrual age (Lessen, 2011); having a body weight greater than or equal to 1,250g (Mattes et al, 1996); more than 1,000g birth weight & between 28 -34 weeks gestational age (Measel & Anderson, 1979); adequate weight for gestational age <1,500 g for infants of 26 -32 weeks gestation(Pimenta et al, 2008); " *healthy preterm infants*" (p 517) aged 3.9 ± 1.0 weeks old with weight around 2066 ± 84 g (Widstrom et al, 1988); born after 28 weeks gestation and before 34 weeks gestation with a birth weight of 1,000g minimum (Yildiz & Arikan, 2011). The range of participant characteristics and the range of gestational ages of infants included in the studies are summarised in Table 4.2. It is noted that gestational

age on onset of implementation of the programme is included in some tables, but not clearly stated in the methodology.

Table 4. 4: Types of approaches for NNS

Approach	Parent involvement	Authors
Sensory + oral motor	No Yes: Gaebler & Hanzlik, (1995)	Bache et al, 2014; Boiron et al, 2007 ; Bragelien et al, 2007 ; Coker-Bolt et al, 2012; Fucile et al, 2002; 2005;2011;2012; Gaebler & Hanzlik, 1995; Hill, 2005; Hwang et al, 2010; Lau & Smith, 2012;Liu et al, 2013; Lessen, 2011;Lyu et al, 2014; Pimenta et al, 2008 ; Rocha et al, 2007 ; Rochat et al, 1997; Sehgal et al, 1990; Standley et al, 2010 ; Ziang et al, 2014
Pain relief	No	Boyle et al, 2006; Bueno et al, 2013; Butt et al, 2000 ; Cichewicz, 2004 ; Harrison et al, 2005 ; Heaton et al, 2007 ; Kramer et al, 2001 ; Liaw et al, 2013; Liu et al, 2010; Rush et al, 2005 ; South et al, 2008 ; Stevens et al, 1999; 2013 ; Sundaram et al, 2013; Zhu et al, 2014
Digestion	No	De Curtis et al 1986; Ernst et al 1989
Regulation	No	De Kun et al, 2005
Oral Motor	No	Field et al, 1982 ; Measel & Anderson, 1979; Neiva et al, 2006;2007
Oral readiness and communication	Yes	Harding et al, 2006; Harding; ,2009; Harding et al, 2014; Harding et al, 2015
Sensory stimulation	No	Barlow et al, 2008 ; 2014 ; Mattes et al, 1996; Poore et al, 2008 ; Yildiz & Arikan, 2012
Reflux management	No	Orenstein, 1988 ; Widstrom et al , 1988

4. 3 .3 How long and how often are the non - nutritive sucking programmes carried out?

There is no clearly defined protocol based on research evidence that suggests an optimum time for NNS stimulation in the literature. This has led to various interpretations as how NNS should be stimulated. Programmes vary from 15 minutes (Bache et al, 2014; Bragelien et al, 2007; Coker-Bolt, 2012; Fucile et al, 2002; 2005 ; 2011; 2012; Lyu et al, 2014; Pimenta et al, 2008; Rocha et al, 2007; Standley et al, 2010; Zhang et al, 2014) through to short periods of sucking in a pacifier with no additional intra-oral stimulation (Bernbaum et al, 1983; Di Pietro et al, 1994; Field et al, 1982; Gill et al, 1992; Harding et al, 2006; 2012; 2014; 2015; Hill, 2005; Mattes et al, 1996; Measel & Anderson, 1979; McCain et al, 1995; Pickler et al, 1996; 2004; Sehgal et al, 1990; Rochat et al, 1997 ; Yildiz & Arikan, 2012). A few studies use an NTrainer as a method of applying NNS stimulation through use of an electronic device for 3 minutes 3 - 4 times daily (Barlow et al, 2008; 2014 ; Poore et al, 2008). All of the NNS studies included for discussion about the development of nutritive skills have a variety of methods for implementing NNS (see Table 4.2). Some studies do not define a clear time for when to carry out the intervention, (Field et al, 1982; Measel & Anderson, 1979; Rocha et al, 2007; Rochat et al, 1997) whereas others just specified that a pacifier be used for each scheduled feed for a set period from the infant demonstrating oral readiness signs for around 7 -10 days whilst oral feeding was being established (Bernbaum et al, 1983; Di Pietro et al, 1994; Field et al, 1982; Gill et al, 1992; Harding et al, 2006; 2012; 2014; 2015; Hill, 2005; Mattes et al, 1996; Measel & Anderson, 1979; McCain et al, 1995; Pickler et al, 1996; 2004; Rochat et al, 1997; Sehgal et al, 1990; Yildiz & Arikan, 2012). Other studies use NNS to make a judgment about an infant's potential to progress to oral feeding (Bingham et al, 2010).

There is wide variety in the way that NNS is stimulated. Fucile et al, (2002; 2005; 2011; 2012) have provided a programme that many other studies have also either adapted or used (Bache et al, 2014; Boiron et al, 2007; Bragelien et al, 2007; Coker-Bolt, 2012; Fucile et al, 2002; 2005 ; 2011; 2012; Hwang et al, 2010; Lessen, 2011; Lyu et al, 2014; Pimenta et al, 2008; Rocha et al, 2007; Standley et

al, 2010; Zhang et al, 2014). The vigorous programme devised by Fucile et al, (2002; 2005; 2011; 2012, see Table 4.3) has been altered in its implementation over the last few years; in the 2002 study the programme was administered once a day, for 15 minutes on 10 consecutive days, 15/30 minutes before a tube feed. The next study (2005) quotes the 2002 study in terms of protocol; "*both were administered 15 – 30 minutes before a tube feed*" (p 159). However, it is not clear if the approach is carried out once or twice a day. Finally, the 2011 and 2012 studies remain the same approach which is twice a day for 15 minutes each. There is no clear discussion between the 2002 and 2005 papers as to why there is a progression in the number of times the programme is completed and additionally, there is no further discussion as to the theory supporting the approach in the latter two papers. The Fucile et al, (2002; 2005; 2011; 2012) papers have had a major impact on other studies which have used exactly the same therapy approach or adapted the approach to suit their populations (Bache et al, 2014; Boiron et al, 2007; Coker-Bolt et al, 2012; Hwang et al, 2010; Lyu et al, 2014; Pimenta et al, 2008; Rocha et al, 2007). Bache et al (2014) and Lyu et al (2014) use the Fucile et al (2002) programme 10 days before oral feeding is introduced for once a day, 15-30 minutes prior to a tube feed. Both Boiron et al, (2007), Gaebler & Hanzlik, (1995) Hwang et al, (2010) & Zhang et al (2014) do not utilize fully the Fucile et al (2002; 2005; 2011; 2012) programme, but use some elements of facial and oral massage only. No clear reason is given by these authors as to why this has been altered. Whereas Fucile et al (2002; 2005; 2011; 2012) cite the work of Beckman (1988) as the evidence base to support the use of NNS as a method of developing NS skills, other authors use similar programmes. Bragelien et al, (2007) cite the work of Vojta & Peters (1992), which, like Beckman refers to a text book that includes oral-motor exercises which recommends that the procedure is carried out for 15 minutes once a day. Lessen (2011) has developed a method of carrying out oral stimulation for infants known as the Premature Infant Oral Motor Intervention (PIOMI) which is also based on an updated version of Beckman's principles (1988). Pimenta et al (2008) recommends the Fucile NNS programme (Table 4.3). Non nutritive sucking was stimulated daily for 15 - 30 minutes once a day for an average of 10 days until

infants were on full oral feeding (Pimenta et al, 2008). In a music therapy programme NNS was used with music as a stimulation to improve the development of oral feeding. Infants received NNS for 15 minutes or 3 times a day within a 5 day period to be completed 30 minutes before a feed for once a day at the same time at between 4 –5 pm (Standley et al, 2010). Other authors used an NTrainer which is an electronic device which stimulates NNS in a more consistent way than perhaps an adult can (Barlow et al, 2008; Poore et al, 2008). The infants received stimulation from the NTrainer 3 – 4 times daily (Barlow et al, 2008; 2014; Poore et al, 2008).

The studies all have different methods of when and for how long NNS should be stimulated as described in Table 4. 2. Some NNS interventions are completed before or during each tube feed, and others are once a day (Table 4. 2). Other studies imply that the intervention is performed for each tube feed; Barlow et al, (2008; 2014) recommend 3 minutes of stimulation provided during tube feeds to facilitate association between sucking and satiation ; Gaebler & Hanzlik, (1995) suggest use of NNS 3 times a day, 5 days a week; Neiva & Leone, (2006; 2007) describe using the programme daily, 5 days a week, 10 minutes a day during tube feeds 3 times daily which is similar to Yildiz & Arikan, 2012; Lau & Smith (2012) recommend use of NNS once a day for 15 minutes, 30 minutes prior to oral feeding and tube feeding; Hwang et al (2012) use a cross over design of NNS for 2 days prior to oral feeding attempts 30 minutes prior to the feed time. Although Coker-Bolt et al, (2012) use the Fucile et al (2002) programme with infants who have had heart surgery, they recommend that NNS is carried out only once pre-surgery, then immediately following surgery for x 6 days a week yet they do not discuss the rationale for this. Harding et al (2014) focused on NNS on onset of a tube feed, compared with NNS within 30 minutes before a tube feed to evaluate if there were any differences with timing of using NNS. The two groups receiving the NNS showed no significant difference in number of days to achieve oral feeding compared with each other and with the Control group. It was also noted that in more recent studies, no significant differences between Control and Experimental (i.e. NNS) groups was noted (Bache et al, 2014; Bragellen et al,

2007; Harding et al, 2014; Hwang et al, 2010; Liu et al, 2013; Mattes et al, 1996; Nevia et al, 2007; Pickler et al, 2004).

Different times and ways of using NNS have been evaluated in other studies. The Harding et al (2006), Harding (2009) and Sehgal et al, (1990) studies evaluate 10 minutes of NNS on onset of tube feeding with clear discussion around the importance of the bonding aspect of the infant and caregiver. The programme is to support infant organisation and state during tube feeds as a method of pre-feeding preparation and was to be completed for a minimum of three feeds a day when the parents were in. The same strategy was used in the later randomized controlled trial where parents implemented the NNS three times a day either on onset of oral feeding or within 30 minutes prior to a tube feed (Harding et al, 2014). Lessen (2011) recommended that when the infant reached 29 weeks post menstrual age (PMA), they would begin the 5 minute programme then continue for once a day for 7 consecutive days ending at when the infant was 30 weeks post menstrual age. Each intervention was separated by minimum of 9 hours and a maximum of 36 hours but no specific neurological or physiological reason was given as to why this would be the specified timing for the NNS programme. The paper also suggests that oral feeding be attempted at 30 weeks post menstrual age; not all premature infants would have the sucking and swallowing coordination to be able to cope with oral feeds at this stage in their development. Mattes et al, (1996) studied the use of a pacifier provided for all gavage feeds for approximately 14 days or until the infants were able to tolerate full oral feeds. Sucking was also evaluated weekly before midday feed with a 4 minute trial followed by a one minute rest, using a pacifier. Sucking pressures were also measured.

Researchers are aware that NNS has benefits, but the reasons why it is beneficial are complex and hard to define. On examining the outcomes in table 4.1 combined with how often and how long the intervention is produces very varied results in relation to outcomes such as days to full oral feeding, weight, rate of sucking and so on. This suggests that there are still many unanswered questions about why NNS is useful.

4.3.4 Oral - readiness and feeding regimes of the infants

"Oral readiness" is an important precursor skill for deciding when to start oral feeding (Thoyre et al, 2005). It is not clearly defined in any of the NNS studies referred to overall although onset of intervention is specified in most studies and tend to coincide with oral readiness times around 34 weeks GA (see specified ages for intervention in Table 4.2). Studies use various terms to describe an infant's age, such as gestational age and post menstrual age, and this can influence how results are interpreted. This issue of reporting of infant age is discussed later. Some studies were not clear in the specification of age for NNS intervention (Barlow et al, 2008; 2014; Fucile et al, 2005; Lyu et al, 2014), or were very non-specific in defining the age as with Bragelien et al, (2007) where the authors state that all infant participants were aged less than 36 weeks. In other studies, information is available, but not clearly defined; Fucile et al (2011; 2012) who use the same sample to focus on two different research questions related to early infant feeding suggest onset for the interventions is 32 weeks. In their earlier study, Fucile et al (2002) enroll infants into their study at 34.6 ± 1.7 gestational ages for the Experimental group and 34.5 ± 1.5 gestational ages for the Control group. Other studies follow a similar age with Bingham et al (2009) evaluating infants at $33.3 \text{ weeks} \pm 0.8 \text{ weeks}$; (range 32.0 – 36.3 weeks), Boiron et al, (2007) involving infants at between 32 and less than 34 weeks at a chronological age of more than 4 days, with full nasogastric tube feeds, and Barlow et al (2014) involving infants born 23 – 36 weeks GA when they were aged around 34 weeks PMA. Other studies start to include infants at 29 weeks post menstrual age (Lesser, 2011) or at 31 - 34 weeks (Bache et al, 2014; Gaebler & Hanzlik, 1995 ; Harding et al, 2006; 2014; Harding , 2009; Hill, 2005 ; Pimenta et al, 2008 ; Standley et al, 2010 ;Yildiz & Arikan, 2012). Older infants with a starting age of 35.2 ± 1.7 weeks were included in the Rocha et al, (2007) study. Only one study looking at NNS in relation to feeding focused on term infants (Coker-Bolt et al, 2012) whilst the other studies do not require oral readiness to be a specific indicator in relation to the programme as they are researching reflux or risks from SIDS (Boyle et al, 2006; De Kun et al, 2005; Orenstein, 1988; Widstrom et al, 1988). It is interesting to note, that oral readiness, such an essential indicator

communicated by the infant in a number of ways is not more prominent in the literature. More needs to be researched in terms of rater-reliable measures that examine the infant states, changes that occur with these states as infants develop, and the links between specific states with oral readiness and feeding.

Pickler et al, (1996) have defined oral readiness in their study with preterm infants and state that feeding stability and progress can only emerge once an infant is physiologically stable. They identified that the transfer from tube to oral feeding takes approximately 10 – 14 days on average, and that progress, in particular the suck-swallow-breathe cycle may be difficult to establish due to immaturity and poor coordination (Pickler et al, 2006). Oral readiness is often based on subjective evaluation based on behaviour state, post conceptual age and presence of any complicating disorders. Many neonatal practitioners see if an infant can manage one feed a day, then increase feeds gradually at the infant's pace. Pickler et al (1996) suggest that oral / feeding readiness is to do with the inter-relationship between morbidity, maturity, behavioural state at the start of a feed and feeding experience.

Pickler et al (2006) investigated oral readiness in a sample of 95 infants who were premature. The participants were born between 24 – 32 weeks gestational age (mean 29.3 weeks; SD = 2.0), but were enrolled onto the programme aged 30 - 32 weeks. Weights ranged from 550g – 2390g at birth (mean 1290.6 g; SD = 379). Behaviour state changes were measured using the Anderson Behaviour State Scale (ABSS); this measures sleep, wakefulness, deep sleep and crying on a scale of 1 – 12. Observations were made 30 minutes before the feed then during the feed. The percentage of formula taken in the first 5 minutes of the feed was also measured. The amount consumed was calculated as a percentage of prescribed formula consumed orally over feeding time, and efficiency was the volume taken per minute. This study indicated that there is a clear relationship between feeding readiness indicators and feeding performance outcomes. Feeding readiness indicators include maturity of sucking skills and behavioural state and feeding performance indicators are proficiency of feeding performance and amount consumed. The typically linear development suggests maturation. Maturity depends upon experience, so increased opportunities to

feed should increase proficiency. Quiet states are not always optimal for feeding according to some research (McCain & Gartside, 2002); rather the "active" infant, "drowsy" or "quiet alert" infant is more likely to develop increased proficiency and efficiency in comparison.

Oral readiness is rarely accounted for in the majority of the papers discussed. Some papers did not discuss any clear methodology in terms of identification of key features but focused on gestational age, with 32 - 34 weeks being an appropriate time to start (Bache et al, 2014; Barlow et al, 2008; 2014; Bingham et al, 2009; Boiron et al, 2007; Fucile et al, 2002; 2005; 2011; 2012 ; Hill, 2005 ; Lessen, 2011;Liu et al, 2013; Lyu et al, 2013; Mattes et al, 1996 ; Measel & Anderson, 1979 ; Neiva et al, 2006; 2007 ; Poore et al, 2008 ; Pimenta et al, 2008; Rocha et al, 2007 ; Sehgal et al, 1990; Standley et al, 2010 ; Yildiz & Arikan, 2012 ; Zhang et al, 2014). In some instances, a few studies did attempt to quantify cues for feeding; Bingham et al (2010) carried out observations just before implementation of full oral feeding at 32 weeks post menstrual age with inclusion of those infants showing cues such as wakefulness for feeding followed by a set protocol, i.e. Level 1, infants who had managed 5 mls orally offered x 3 daily feeds; Level 2, feeding trial every 6 hours x 4 daily once up to 10mls. Fucile et al, (2002; 2005) began intervention 48 hours post cessation of nasal CPAP, but do not clearly specify gestational age. The Fucile studies completed in 2011 and 2012 do not describe a clear protocol for oral readiness. Gaebler & Hanzlik (1995) comment that oral readiness was determined by nursing staff, usually when the infants were approximately 34 weeks post conceptual age in a stable medical condition, with a weight of approximately 1500g. The infants were expected to be able to suck on fingers or pacifier and not more than 1 cc of residual formula left in the stomach from the previous feeding and a weight gain of at least 0.5 ounce per day. Similarly, both Pimenta et al (2008) and Rocha et al, (2007) identified tolerance of 100 mls/kg/day but do not refer to other oral readiness markers. Other studies where NNS was used to remediate other difficulties did not refer to oral readiness as this was not relevant to the goals of the studies (Boyle et al, 2006; Orenstein, 1988; Widstrom et al, 1988). The importance of using NNS in relation to the development of more appropriate feeding states is described as

an outcome in few papers (Harding et al, 2014; Hwang et al, 2010; Lau & Smith, 2011; Pickler et al, 1996; 2004). Hwang et al (2010) do discuss the need for the development of quiet-alert states and drowsy states for feeding success and that NNS was important in the development of this. It was found that using the NNS pre-feeding programme improved infant levels of drowsy and quiet alert states suitable for feeding from 42% to 82% between the start and end of the programme. A disadvantage of this study is that the first author did the majority of bottle feeds and it is not clear who made the judgments about the infants' states when preparing for feeds and how these judgments were made.

4. 3. 5 NNS outcomes in relation to oral feeding

Most studies that focused on using NNS to improve oral intake report that NNS supports the development of feeding (Table 4.2). The studies where NNS was stimulated by an NTrainer found that infants who had had this approach were significantly better at taking increased amounts of milk orally compared to their Control peers (Barlow et al, 2008; 2014; Poore et al, 2008). These three studies did not specify the number of days to achieve full oral feeding as they were all focused more on the maturation of NNS patterns. They comment that the full oral feeding process took approximately 7 – 10 days. Some studies found no significant differences in use of NNS as an intervention (Bache et al, 2014; Harding et al, 2014; Pickler et al, 2006; Sehgal et al, 1990; Smith & Lau, 2012), though a trend may have been noted (Bragelien et al, 2007; Harding et al, 2006; Harding 2009; Mattes et al, 1996; Liu et al, 2013; Neiva & Leone 2007; Pimenta et al, 2008). Some studies commented on the maturation noted with the development of NS skills (Barlow et al, 2008; 2014; Bingham et al, 2010; Coker-Bolt et al, 2012; Gaebler & Hanzlik, 1995; Harding, 2009; Harding et al, 2006; 2014; 2015; Hill, 2005; Lyu et al, 2014; Mattes et al, 1996). Two studies commented that NNS helped infants develop more mature skills to be able to cope with the development of breast feeding in comparison to their Control peers (Bache et al, 2014; Pimenta et al, 2008). Pickler et al (2006) suggest in their study that NNS has no effect on the development of the suck-swallow-breathe cycle as respiratory patterns do not change during NNS stimulation. They identified more

consistent sucking patterns on onset of NS, but concluded that NNS cannot support the development of NS as there are qualitative differences specifically with different NS and NNS intra – oral pressures. Harding et al, (2006) found that there were significant differences in NOMAS scores between the Intervention and Control group post intervention, showing that NNS potentially had some specific benefits in assisting with the development of the ability to organize more mature sucking. This could be due to the sensory feedback and the development of more appropriate behavioural states that support oral intake gained from the pacifier or it could be that parents were more confident at interpreting their infants. Significant differences in NOMAS scores were also identified by Gaebler & Hanzlik, (1995) but there were no differences in increased oral intake between the groups. The increase in milk intake in the first 5 minutes of oral feeding that the authors predicted in the Intervention group was based on another study where infants were reported as having an increase in oral intake during the first 5 minutes of a feed post NNS stimulation (Trykowski et al, 1981).

Coker-Bolt et al, (2012) used NNS with term infants awaiting heart surgery; the Treatment group who used NNS only achieved full oral feeding two days sooner (not significant) than the Control group, and given that no other specific measures in terms of infant orientation and comfort are made, it is hard to evaluate the outcomes when the gains are small compared to outcomes for maturing premature infants. In contrast to the other studies that focus on the benefits of NNS in relation to the development of oral feeding, developing swallowing through use of 0.05 – 0.2 mls was shown to be more effective than NNS in one study , with a four day difference in progression to full oral feeding between the NNS and swallowing groups (Lau & Smith, 2012). The authors state that the swallowing intervention was more beneficial as an infant's swallow develops stability before sucking matures and therefore it can be concluded that the intervention was more effective compared to NNS as it was suited more to an infant's predicted level of functioning; they go onto state that " *A similar exercise consisting of sucking on a pacifier has no benefit*" (page e269).

Bingham et al, (2010) identified the post menstrual age of infants at introduction of oral feeding when they were taking 5mls orally and the post menstrual age once fully orally feeding which tended to be 35.3 weeks which is similar to many of the studies in Table 4.1. Full oral feeding was defined as no tube feeds for 48 hours and the ability to take at least 100mls/kg/day. More organized NNS patterns were significantly indicative of shorter transition to full oral feeding, and the transition to oral feeding usually took 15.8 ± 6.6 days (range 5.0 – 38.0 days). Boiron et al, (2007) achieved a transition of 5.6 days to oral feeding with their [Oral Stimulation and Jaw Support] group, 6.5 days to achieve oral feeding with the [Jaw Support] alone group, 7.8 days with the [Oral Stimulation] group and 11.2 days with the [Control] group. The [Oral Stimulation and Jaw Support] group and [Jaw Support] group made statistically significant progress towards full oral feeding compared to the [Oral Stimulation] and [Control] groups. The authors found that NNS accelerates increased sucking pressure and both the [Oral Stimulation and Jaw Support] group the [Oral Stimulation] group (not the [Jaw Support] group which made quicker progress to oral feeding) had the highest sucking pressures indication that NNS sucking pressure is not the same as the pressure applied in NS. This example could be useful in the argument that NNS and NS have distinct differences in relation to the development of oral feeding. Jaw support has been identified as supporting infants to develop fewer and shorter pauses during sucking, and therefore more effective sucking skills; significant differences have been found between infants who have had this support compared with those who have not (Hill, 2005). Fucile et al (2002; 2005) initially achieved oral feeding within 11 days on average, compared with the Control groups who took up to 18 days. Other studies show varying outcomes; Bache et al (2014) found no significant differences between the Intervention and the Control groups with days to achieve oral feeding. Infants from both groups took 16.0 ± 6.9 days. In contrast, Lyu et al (2014) who administered the same programme designed by Fucile et al (2002; 2005) did have significant differences between the Intervention and Control groups. The NNS group took 9.56 ± 4.43 days to achieve full oral feeding compared to 13.9 ± 6.18 days for the Control group infants. These studies compare favorably with Harding et al , (2006) &

Harding (2009) who found that infants receiving NNS took between 9 -21 days to take all of their feeds orally compared to the Control group who took 11 - 25 days. The later Harding et al (2014) study found a greater range in the time taken for infants to achieve full oral feeding. Number of days ranged from 8 - 50 days. This wide variation perhaps highlights the range of additional problems which delays feeding development premature infants may experience, such as reflux (Field et al, 2003; Rommel et al, 2003). Fucile et al, (2011) record that the transition to full oral feeding can take 10.10 days using tactile / kinesthetic approaches as well as oral motor stimulation compared to a Control group that took up to 20.7 days, thereby indicating transition to oral feeding 9 -10 days sooner in the intervention groups compared to the Control infants. Interestingly, Rocha et al, (2007) have replicated the work of Fucile et al (2002; 2005; 2011; 2012) but have achieved slightly different outcomes, with those receiving the NNS sensory-motor oral stimulation beginning oral feeding 8.2 days sooner than the Control group. Full oral feeding for the intervention group was attained at 38±16 days (mean + SD) compared to the Control group where oral feeding was achieved at 47±17 days (mean + SD).

Measel & Anderson (1979) had a NNS Treatment group which moved onto bottle feeding 3.4 days earlier than the Control group. The Treatment group also received 27 fewer tube feeds; gained 2.6g more weight per day (not significant) and were in hospital for 4 days less. The number of days to achieve full oral feeding ranged from 5 – 40 days. The Standley et al, (2010) study suggested that use of music from a pacifier-activated-lullaby system (PAL) enables infants to wean off tube feeding more rapidly with time taken to tube feed noted as 35.17 days (mean) for PAL compared to 58.88 days (mean) in the Control group at 34 weeks, compared to 21.48 days (mean) for PAL and 67.71 days (mean) for the Control group at 36 weeks of age. It was interesting to note that at 32 weeks, the Control group was significantly faster moving off tube feeding compared to the other 2 groups. Significance was noted at 34 weeks with PALS, but no significant difference was evident at 36 weeks. It could be that perhaps at 32 weeks the stimulation was too much for the infants to respond to. In a similar study using music, it was the Pacifier(NNS) group that made the quickest transition to oral

feeding, than the Lullaby - music group feeding hours, and finally the Control group (Yildiz & Arikan, 2012). Hwang et al (2010) do not specify the number of days to achieve oral feeding; rather, one of the outcomes focused on was the relationship between oral stimulation and sucking ability in the initial five minutes of feeding; they concluded that there was no significant effect on functional sucking ability from carrying out an oral motor programme.

The number of days taken to achieve full oral feeding using the same programme as in Table 4.3 varies depending on the gestational age of the infant on onset of the intervention but is usually approximately 5 – 40+ days (e.g. Bache et al, 2014; Boiron et al, (2007) ; Bragelien et al, 2007; Coker-Bolt et al, (2012); Fucile et al, (2002; 2005; 2011; 2012); Gaebler & Hanzlik, (1995); Hill, (2005); Hwang et al, (2010); Lau & Smith, (2012); Lessen, (2011);Lyu et al, 2014; Pimenta et al, (2008); Rocha et al, (2007) ; Sehgal et al, 1990; Standley et al, (2010); Zhang et al, (2014). It could be that populations of infants in studies have greater numbers of either lower or higher gestational ages within the samples used in the intervention, and perhaps infants with lower gestational ages take longer to establish consistent oral feeding due to their complex needs (Hawden et al, 2000; Koenig et al, 1990; Rommel et al, 2011). It is also not clear what state the infant is in when the intervention is carried out, i.e. are they drowsy or alert as this could potentially influence outcomes. The researchers carrying out the NNS programmes described could be completing it in varying ways between countries and therefore this could be influencing results. It would be useful to consider these differences more accurately to consider an optimal time to introduce NNS and in what format so that infants can gain maximum benefits from the programme.

4. 3. 6 Other outcomes from the NNS studies

Days in hospital were reported by most studies with the cost implications being identified as important to consider in overall management. Some infants went home after using NNS on average 13.7 days sooner than Control infants who had an average of 17.67 days in hospital (Gaebler & Hanzlik, 1995). Others who received NNS went home between 9 – 21 days compared to their Control

group peers who went home between 11 – 92 days (Harding et al. 2006; Harding, 2009). Significant differences in less time spent in hospital were noted as a benefit of completing a NNS programme in a range of studies (Fucile et al, 2002; Measel & Anderson, 1979; Rocha et al, 2007; Yildiz & Arikan, 2012) although in the 2011 and 2012 studies by Fucile et al, there were no significant differences in hospital stay. In contrast, Harding et al, (2014), found significant differences between the Intervention groups (Group 1, mean = 37.9 days in hospital, range 24 – 64; Group 2, mean = 40.2.days in hospital, range 9 -104) compared to the Control group (mean = 56.2 days in hospital, range 11 – 110). Although it is hard to prove, one suggestion about these differences was that the parents carried out the intervention and were coached by trained therapists and nurses to “read” the infant’s early non verbal communication. It could be that the parents felt more confident in managing their infants through the coaching received and the support to identify and interpret their infant’s various states. In a smaller study focusing on complex feeding needs, infants went home within the same time shown by the two Experimental groups in the 2014 study (Harding et al, 2015).

One outcome measured in some studies has been weight, the rationale being that if NNS can stimulate quicker transition to full oral feeding, then infants will put on weight more quickly. Weight has not been significantly different between infants receiving NNS and those who have been in Control groups in some studies (Fucile et al, 2002; 2005; 2011; 2012; Lyu et al, 2013; Mattes et al, 1996; Measel & Anderson, 1979; Sehgal et al, 1990; Yildiz & Arikan, 2012; Zhang et al, 2014) whereas in only a few other studies it has been significant (Bernbaum et al, 1983; Field et al, 1982; Liu et al, 2013; Standley et al, 2010).

4.4 Reflection on the theoretical philosophy of non-nutritive sucking

Research data discussed earlier in this chapter suggest that oral stimulation can accelerate maturation of sucking, enhance sucking frequency and improve amplitude of suction and expression as well as sucking endurance (Bache et al, 2014; Barlow et al, 2008 ; Boiron et al, 2007; Bingham et al, 2009; Bragelien et al, 2007; Coker-Bolt et al, 2012; Field et al, 1982; Fucile et al, 2002; 2005; 2011; 2012;

Gaebler & Hanzlik, 1995; Harding, 2009; Harding et al, 2006; 2012; 2014; 2015; Hill, 2005; Hwang et al, 2010; Lau & Smith, 2012; Lessen, 2011; Liu et al, 2013; Lyu et al, 2014; Mattes et al, 1996; Measel & Anderson, 1979; Neiva, & Leone, 2007; Poore et al, 2008; Pimenta et al, 2008; Rocha et al, 2007; Rochat et al, 1997; Sehgal et al, 1990; Standley et al, 2010; Yildiz & Arıkan, 2012). From these studies it is not unreasonable to assume that stimulation through use of NNS can provide opportunities to develop mature sucking skills, i.e. NS competence. A variety of methods of implementing NNS programmes have been evolved. Historically, there have been two ideas about why NNS is important. The first is that infants need positive oral experiences through stimulation due to the serious and invasive procedures that they have undergone which could have a negative impact on sensory development, therefore non-nutritive sucking is important as a positive experience with the idea that Vagal nerve activation stimulates secretory motor and endocrine processes that lead to better digestion and metabolism (Bernbaum et al, 1983; Case-Smith, 1987; Ernst et al, 1989; Gaebler & Hanzlik, 1995; Field et al, 1982; Ernst et al, 1989; Widstrom et al, 1988). The second idea is that stimulation of the muscles through NNS (an oral-motor approach) will lead to productive nutritive sucking and possibly impact on later speech development (Case-Smith, 1987; Fucile et al, 2002; 2005; Gaebler & Hanzlik, 1995; Measel & Anderson, 1979). These ideas have influenced outcomes measured in relation to NNS as a therapeutic approach. Various methods of carrying out a NNS programme have evolved and include a combined oral motor and sensory approach (Bache et al, 2014; Boiron et al, 2007; Coker-Bolt et al, 2012; Fucile et al, 2002; 2005; 2011; 2012; Gaebler & Hanzlik, 1995; Hill, 2005; Hwang et al, 2010; Lau & Smith, 2012; Lessen, 2011; Lyu et al, 2014; Pimenta et al, 2008; Rocha et al, 2007), sensory stimulation approach (Barlow et al, 2008; Matthes et al, 1996; Poore et al, 2008; Standley et al, 2010; Yildiz & Arıkan, 2012) or a communication and oral readiness approach (Harding, 2009; Harding et al, 2006; 2012a; 2014; 2015; Shaker, 2013). There is an understanding that oral readiness and recognition of infant behavioural states is crucial to the process of implementing feeding competence and that NNS is a part of this, but interpretation of these

signs is difficult (McGrath & Cooper, 2002; Medoff-Cooper & Ray, 2004; McCain et al, 2001; McCain & Garside, 2002).

Fucile et al (2002) use the argument regarding the intensity of invasive procedures that infants receive, i.e. placing of tubes, suctioning, to justify their intense sensory and oral – motor programme and therefore a positive oral experience by use of NNS is important to prepare infants for oral feeding. They also state that NNS through their method “*strengthened the oral musculature necessary for adequate sucking*” (Fucile et al, 2002 p 235) suggesting that this is primarily an oral-motor programme that stimulates the muscles, but with an additional sensory component. From previous studies where they have developed their approach and understanding of the needs of premature infants the authors do discuss in this paper that improved oral feeding and maturation are dependent on positive oral experiences. It is not clear if these positive experiences refer to interaction and communication, safe and competent feeding, oral motor development, or a combination of all of these. In the discussion, mention is made that perhaps parents and caregivers could carry out a NNS programme, but the reason why this did not happen was because it was felt important that the intervention was completed in the same way each time. The programme is very specific as outlined in Table 4.3, with a vigorous stimulation of an infant’s mouth, both inside and out which has to be dispensed in a specific way. This approach is completed by therapists and excludes parents from completing the intervention. The implications of involving parents has been discussed by Harding (2009) who highlighted the importance of parental participation in the care of their infants, as well as discussing parent involvement in a case study (Harding et al, 2012a). Gaebler & Hanzlik (1990) are the only other researchers who describe the importance in involving parents in implementing NNS from the perspective of developing a positive opportunity to bond with the infant. Although Hill (2005) concludes that pacifier use before a feed is important for infant state organisation and improved feeding performance the concept of enhancing parents’ abilities to interpret and understand early non-verbal communication is not present as a strategy as the

project mainly focuses on feeding outcomes using an oral-motor and sensory approach.

Fucile et al, (2005) discuss that NNS and oral stimulation did help develop feeding development and that ...*"This supports the notion that the development of sucking is not only an inborn conditioned reflex dependent upon neurophysiologic maturation, but that it can be enhanced with practice."* (p162). The implication is that NNS can provide patterning that alters an infant's abilities in relation to nutritive sucking abilities. Although Boiron et al (2007) use a programme based on the Fucile et al (2003; 2005) work, they conclude that ; *"Non-nutritive sucking promotes the coordination of sucking and swallowing, accelerates the maturation of the sucking reflex.... improves the initiation and duration of the first nutritive sucking. "* (p 439). These authors have not been so precise in differentiating which essential component parts of sucking have developed, although they later comment that NNS alone is not enough to enable an infant to obtain full oral feeding because of the tendency for a premature infant to have reduced endurance, immature patterns of development and developing suck – swallow - breathe skills.

The use of NNS to develop functional sucking skills is described as a method of developing NS by Yildiz & Arikan (2012). A description is given of an "absent" suck in the infant with the suggestion that rhythmic stimulation through NNS will help to facilitate productive sucking and enable infants to gain weight. Differences in averages of discharge weights between all three groups was not significant, though the authors write about how pacifier sucking leads to increased functional sucking, yet if, as stated, NNS does improve and develop the sucking reflex and therefore help to increase nutrient suction then this would potentially help infants gain weight more. This is not the case in this study.

In studies by Barlow et al, (2008; 2014) and Poore et al, (2008), a device known as an NTrainer is used to stimulate NNS patterns for premature infants. This is described by the authors as important for stimulating the mechanoreceptor neurons in the infant's lips, tongue and jaw, and therefore provides neuronal stimulation that influences the Trigeminal nerve. Again, the precursor skill of NNS leading to NS is presented in the discussion, and the suggestion is reiterated

regarding brainstem stimulation and its benefits alongside the fact that NNS and feeding abilities are highly correlated. One benefit described by Barlow et al (2008; 2014) and Poore et al (2008) is that the NNS pattern would be presented consistently through use of the NTrainer. They argue that this type of stimulation is of benefit to the developing infant and will ensure that the early critical period for sensory development is not missed (Kolb et al, 2000a; 2000b; Kolb et al, 1993; Urasakai et al, 2002). Providing cortical activation and synaptic modulation will be facilitated through use of the NTrainer (Barlow & Estep, 2006; Barlow et al, 2008; 2014; Poore et al, 2008). However, premature infants have developing nervous systems where neurons and glial cells travel to specific, genetically determined locations during the process of migration and differentiation (Arshowsy et al, 1997; Castro – Alamancos, 2002; Craig & Boudin, 2001; Ishiama et al, 2003; Lo & Erzurumlu, 2011; Ma et al, 2006; Yamanumura et al, 2002; Yao et al, 2001). Once in their location, these cells are activated by neurotropic factor chemicals which ensure that the synapses are used; if synapses do die, then synaptic rearrangement occurs (Ishiama et al, 2003; Ma et al, 2005). From the literature about the NTrainer, it is assumed that synapses will be stimulated or stimulation may support some synaptic rearrangement (Barlow& Estep, 2006; Barlow et al, 2008; 2014; Poore et al, 2008). However, it is difficult to draw conclusions as the genetic determination of cell location is not clear in the arguments about NNS and it is hard to speculate if stimulation could enable cells to alter their function and modulate in some way (Yao et al, 2001). The developing nervous system of an infant with its synaptic flowering and pruning of cells could perhaps present different challenges compared to neurological repair post damage such as in an acquired problem (Han et al, 2005; Hanson & Landmesser, 2003). The argument is further complicated by the different sites of activation in the nervous system for nutritive and non – nutritive skills (Harding & Cockerill, 2014). These complications in the argument suggest that there is still much that is not understood in relation to the links NNS has with other skills in a developing infant.

Gaebler & Hanzlik (1995) use as adapted version of the NOMAS and discuss that it needed adaptations as it did not have enough differentiated criteria

information. Changing the NOMAS to an adapted scale has not been repeated by any other researchers. There are some crude criteria for oral readiness which could partially be replicated from this study, but adapting an already simple schedule has questionable value. The authors' further comment that NNS is not suitable for infants with neurodisability as they are too fragile and suggest that such a programme could cause hemorrhages in the brain, though they do not support this statement with any citations. This is contradicted by the Harding et al (2012) study in which an infant with neurodisability used NNS safely and successfully for physiological organisation, satiation and oral hygiene.

Lessen (2011) states that; "*Few studies have tested the effect of oral stimulation on feeding ability.....and no studies have been located that tested the effects of oral stimulation on feeding progression of infants before reaching 30 weeks PMA*". – P130). This statement is correct in that most studies do not begin to work with infants before 30 weeks gestational age as infants may not be showing signs of oral readiness. (Bosma, 1963a; 1963b; Gewolb et al, 2001). This paper focuses on infants who traditionally would not have intervention carried out at this age. Thirty weeks is considered too young for most infants to commence a programme to develop skills to cope with oral feeding; the development of the coordination of sucking and swallowing is not likely to be complete (Bosma, 1963 a; 1963b). The main focus in this paper is on cost implications for long stay infant-stays post birth. The potential idea is that an earlier intervention where weaker muscle tone, endurance and sucking strength are improved will be beneficial for the infant. The conclusion is that any stimulation at any time will improve muscle tone and it does not take into consideration the importance of maturation, stability and oral readiness. Lessen (2011) does mention that some infants did not complete the intervention; two transferred to another hospital (no reason given); one had wrong calculation of post menstrual age; three infants had to be intubated at 29 weeks; four infants developed bowel problems and had to be nil-by-mouth and one infant died from necrotizing enterocolitis, therefore leading to nine exclusions from the sample of 19 infants. This high number of infants who were unable to complete the study suggests that perhaps they were too immature to benefit from the

intervention at that time. In addition, it perhaps does not fit within the philosophies of care for infants currently referred to. It also promotes oral motor exercises for infants which are still unclear in their benefits. Finally, this author writes about the intervention being continued at home. This is interesting as it suggests that oral motor interventions will still help the infant with ongoing development of oral skills. The oral motor programme used for this study uses the Beckman's principles (1988). Further research is needed to understand how, and if, oral motor exercises are of benefit, as at present, there is insufficient evidence to suggest that they cannot be used (Harding & Cockerill, 2014).

Practitioners who work with infants have used a variety of strategies to promote oral feeding; NNS has dominated the literature, although it is becoming evident that it is not the most effective intervention to promote functional feeding outcomes. Some literature has shown similar outcomes for infants compared to the use of NNS. White-Traut et al (2002) focused on auditory, tactile, visual and vestibular intervention (ATVV) with 22 infants prior to feeding. A female voice was used with the infants with simultaneous massage for 10 minutes followed by 5 minutes rocking. Throughout the 15 minute programme, eye contact was maintained with the infant. This was done prior to their first three oral feedings; ATVV was performed for 15 minutes before the first oral feed, after the second feed and immediately before the next 2 feeds. Intervention was started between 33 – 35 weeks corrected age and behavioural states were used as a marker. Significant differences noted between the distributions of the behavioural states between the 2 groups. Infants who received ATVV were more alert, but data does not specifically refer to changes in oral feeding, therefore it is hard to draw specific conclusions to compare to NNS as a strategy.

McCain (1992) found that NNS, compared with the combined use of NNS and rocking, but not stroking alone helped focus the infant prior to feeding, and had the most beneficial effect. In a later study, McCain (1995) found that NNS did increase an *alert* state significantly with infants, but there were no significant differences in feeding success when comparing two groups. Pickler et al (1993; 1997) supports this view and also found that NNS helped infants to focus and develop that important quiet alert state, and it was this, rather than muscle

stimulation that enabled infants to transition to successful full oral feeding. Although the numbers of studies that explore issues related to feeding and oral readiness are small, the improvements shown by the infants suggest that the interaction that occurs with the infant rather than a sequence of exercises is possibly the factor that has the most powerful impact on development.

4.5 Infants with disabilities and complex feeding

Non-nutritive sucking is sometimes used with infants who have difficulties achieving oral feeding because of congenital difficulties. Few studies have evaluated the benefits for this group. Harding et al (2012a) in their single case study showed that it was possible to have a rhythmic non nutritive suck but a poor nutritive suck. However, the parents felt that using non-nutritive sucking helped them to interpret their child's communication and behaviour skills better. They also felt that they were carrying out something practical that would help her oral skills and preserve good oral hygiene. The short paper in press (Harding et al, 2015) considers nine infants with neurodisability. All showed varying patterns of dysfunctional NNS when assessed, and only two out of the nine developed more consistent sequential sucking patterns and were able to develop nutritive sucking abilities. This short paper suggests that assessment of NNS provides important information about infant oral states, but it also discusses how NNS can be used as one strategy amongst others includes assessment of oral changes and infants states as well as training parents about an infant's state through verbal coaching and establishing an important communication environment during non - oral feeding. Interestingly, despite the high number of infants in this study showing dysfunctional sucking patterns, all infants showed maturational changes with their sucking (Harding et al, 2015). The changes in sucking burst durations and number of sucks per burst due to a maturing suck are noted as being important indicators of changes of feeding function once an infant begins to feed (Bingham et al, 2010; Rochat et al, 1997). Chapter 3 discussed the need to develop further initiatives to improve the range of therapy approaches to support infants and children who have congenital disorders.

4.6 Summary

Premature infants appear to have greater difficulties in showing clearly the typically expected behavioural states (Pickler et al, 1993; 1997; Thoyre et al, 2005; White-Traut et al, 2002). The literature on infants and infant development, particularly premature infants, discusses that infant behavioural state is an important part of routine care giving, assisting the infant through a variety of methods such as NNS can help the infant develop the *quiet-alert* state which is important for effective feeding (Field et al, 1986; McCain, 1992) and for that all important early interaction experience (Harding et al, 2005; Harding, 2009; Harding et al, 2012; 2014; 2015; White-Traut et al, 2002). Non nutritive sucking also has an important role in the development of the infant's ability to interact with the environment (Als et al, 2004; Als, 1986; Colombo, 2001). Premature infants show varying behavioural state patterns in an inconsistent way, and are often uncoordinated in their first feeding attempts (McGrath & Bodea Braescu, 2004; Pinelli & Symington, 2005; Tronik et al, 1990; Vanden Berg, 1990). The ability to feed orally does not just depend on the development of NNS. It is influenced by many factors such as gestational age, behavioural state, physiologic abilities, neurobehavioural organisation, general health, muscle tone and the ability to coordinate the important suck-swallow-breathe cycle (Anderson et al, 1979; Bosma, 1963a; Bosma, 1963b; Conway, 1994; Tronik et al, 1990; Vanden Berg, 1990). Feeding is a challenge as it requires the organisation of both sensory and motor elements of the nervous system (Bosma, 1963a; 1963b).

Non - nutritive sucking seems to help some infants to develop NS by consolidating physiological stability and enhancing infant states for showing oral readiness pre-feeding. The infants who benefit most from NNS as an approach where it seems to help the development of oral feeding are those who seem to have no significant additional medical problems. However, it seems likely that this success is not for the reasons hypothesized by the majority of the studies mentioned in this chapter. It is already known that as a premature infant matures and as gestational age increases, their NS and NNS patterns increase in frequency and there is a decrease in time required for each sucking burst

(Bingham et al, 2010; Medoff-Cooper, 1991; Medoff - Cooper et al, 1993). This is an important point as these studies found that there are always maturational changes with both NS and NNS, so perhaps these changes with sucking would happen without additional stimulation. Harding, (2009); Harding et al, (2006) commented on the maturation of the suck after an infant starts to suck both nutritively and non - nutritively. It has also been stated in this chapter that the neurological activation of NNS is different from NS although the pathways for the output are shared (Clark, 2003; Martin et al, 2001; Robbins et al, 2008). The studies described do not substantially critique the neurological underpinnings of NNS and its role in the development of nutritive sucking. Some studies report that oral stimulation through use of NNS does not enhance sucking ability i.e. the actual amount of milk taken, at the beginning of a feed, but do not explore why this should be the case with reference to neurological development (Bache et al, 2014; Bragelien et al, 2007; Hwang et al, 2010; Lau & Smith, 2012; Mattes et al, 1996).

NNS is important as it links to the infant's sensory-motor development and therefore is acting as a cue to stimulate an *awake* state for feeding (McCain, 2003). Using NNS as a strategy could prompt a parent to learn to interpret their infant's first communication signals, and this is a crucial skill to empower parents with, particularly those caring for vulnerable infants. NNS may also help parents to observe sucking patterns as well as non-verbal communication signs more easily and therefore learn to interpret feeding communication later on. Swaddling, rocking and pacifier use all provide comfort and therefore impact in a positive way on the limbic system. An infant with a congenital disability may be able to suck non-nutritively, but subsequently may still be challenged to suck nutritively as NNS is activated by a different part of the brain compared to NS. Consequently, it is imperative that a more robust rationale that involves infant behavioural and early communication states is devised. It is not NNS alone that can organise an infant's ability to make the transition to full oral feeding; rather, research is beginning to suggest that interpreting the infant's non-verbal communication is the of the most important strategies to implement when working on feeding and development with this vulnerable population.

4.7 Research findings completed by the author

The following papers published by the author focuses specifically on non-nutritive sucking.

1. Harding C. (2008). Issues around non-nutritive sucking. *Developmental Medicine and Child Neurology*, 50(1) 76-80

This is a general commentary in response to the publication of the Boiron et al (2007) study. It comments on the need for further studies that use NNS to begin to explore more specifically the links (if there are any) between NNS and NS. This commentary also refers to the variation in methodologies that studies about NNS use which make generalization of the strategies discussed hard.

2. Harding, C. (2009). An evaluation of the benefits of non-nutritive sucking for premature infants as described in the literature. *Archives of Disease in Childhood*, 94(8), 636-640

This paper discusses in more detail the Harding et al, (2006) study and includes some parent feedback on using NNS as a therapeutic means of developing their infant's skills. It highlights the importance of training and engaging with parents during the early implementation of feeding and discusses many of the themes presented in this chapter overall.

3. Harding C., Frank L., Dungu C., Colton N. (2012). The use of non-nutritive sucking to facilitate oral feeding in a term infant: A single case study. *Journal of Pediatric Nursing*, 27; 700 – 706

The purpose of this paper was two fold. First, it explored the links between NNS and NS. Second, it attempted to examine the process of therapy, and the steps towards full oral feeding with an infant who had complex needs post a traumatic birth history. Much of this paper is about the steps taken with the parents to achieve full oral feeding, with efforts made to cite relevant research to support the rationale.

4. Harding C., Frank L., Van Someren V., Hilari K., Botting N. (2014) How does non-nutritive sucking support infant feeding? *Infant Behavior and Development* 37; 457 – 464

5. Harding C., Frank L., Van Someren V., Hilari K., Botting N. (2015) Assessment and management of infant feeding: *IN PRESS in Infant*.

The aim of these two studies, 4 & 5, was to evaluate NNS as a tool to help parents and carers develop competence in identifying infant pre-feeding and feeding states. The aim of all of these studies in Chapter 4 has been to encourage practitioners to consider how NNS is effective. Few studies included infants who have neurological problems that impact on effective feeding development. However, two of the studies below focus on these infants. One is a single case study (Harding et al, 2012a), and the other a small study of nine infants (Harding et al, 2015). Supporting infants and their parents to make the transition from tube feeding and oral care, through to partial oral feeding alongside non-oral feeding, requires the use of a range of strategies. Use of NNS needs to be clearly explained to parents, especially for those infants where oral feeding will not be an option. If full oral feeding is not going to develop, then reaching a compromise with parents that enables some oral stimulation or small amounts of nutrition with good interaction should be achieved. This article suggests that training parents about an infant's state through verbal coaching, using NNS and establishing an important communication agenda during non-oral feeding can contribute towards improving quality of life. Some oral intake when judged to be safe can have important physiological as well as health benefits for infants. These benefits cannot be underestimated. This article also outlines the most important pre-feeding skills for those infants who are taking time to learn to feed orally, but who can move beyond the need for alternative feeds and progress to full oral feeding at their own pace, with the support of professionals with expertise in the management of infant feeding (Harding et al, 2015).

1. Harding C. (2008). Issues around non-nutritive sucking. *Developmental Medicine and Child Neurology* 50(1) 76-80

attitudes to 'recreational' drugs as fun and harmless, as well as encouraging a healthy lifestyle as a 'cool' life choice. These findings also highlight the need for public debate on community responses to alcohol and tobacco, particularly given the general acceptance of a heavy drinking culture within mainstream society.

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'Issues around non-nutritive sucking'

SIR-In recent years there has been an extensive rise in research within the area of non-nutritive sucking within the preterm infant population. It was, therefore, pleasing to see that another paper has been published that evaluates an aspect of this. However, there were some features of this paper, by Boiron et al.,¹ on which I wish to comment, and I want to raise these issues as discussion points for your readership.

Clinically, speech and language therapists and neonatal nurses are aware of developing positive oral experiences to promote both interaction and to encourage and maximize oral skills.^{2,3} Early oral motor stimulation is encouraged to maintain and develop the sucking reflex. Authors such as Harris⁴ and Wolf and Glass⁵ recommend perioral and intraoral touch-pressure and nipple and finger sucking experiences before bottle or breast-feeding. Bazyk² suggests that non-nutritive interventions for preterm infants who receive tube feeds are justified and can accelerate the transition from tube to oral feeding by allowing the infant to practise using their oral motor musculature. Harding et al.⁶ implemented a speech and language therapy programme based around non-nutritive sucking, parent training, and longer-term outcomes. The infants who received the intervention spent a difference of 5 fewer days in hospital and 3 fewer days to achieve full oral feeding.

Evidence has also highlighted that non-nutritive sucking can assist neurodevelopmental organization, aid neurobehavioral maturation, and optimize ventilation in preterm infants who require nasal non-invasive ventilatory support.^{5,7-14} In addition, these programmes may allow critical aspects of oral motor development to receive stimulation and reduce the impact of other necessary procedures such as nasogastric feeding.⁴ These are important considerations as studies show that feeding difficulties within the neonatal population may prolong discharge home.¹⁵ Delayed introduction to oral stimulation programmes generally and feeding may also lead to longer-term aversions.¹⁶

Studies have evaluated the impact of non-nutritive sucking on oral feeding. However, none have clearly addressed the link between non-nutritive sucking and nutritive sucking, nor have they proposed an intervention strategy for use in a neonatal environment. Measel and Anderson¹² randomly assigned infants aged 28 to 34 weeks' gestation to a treatment group, (use of pacifier during non-oral feeding to provide an association between sucking and satiation), or control group, (no pacifier). Specific details of the treatment protocol are not given, but the treatment group of infants were ready for bottle feeds earlier, had fewer tube feeds, gained more weight, and were discharged earlier. Field et al.⁹ and Seghal and colleagues¹⁷ obtained similar results, but in common with the Measel and Anderson¹² study, they did not specify clearly their rationale for their non-nutritive sucking programme, nor did they specify what it was.

Recent studies such as those by Fucile et al.^{10,11} and Boiron et al.¹ have more precisely described the non-nutritive programme being implemented for the infants. In the Fucile et al.¹¹ 2005 study, the treatment group received a daily 15-minute oral stimulation programme (stroking the peri- and intra-oral structures), for 10 days prior to oral feeding. This is an impressive result given the relatively undemanding treatment programme. The Harding et al. study⁶ is another that specifically highlights a particular programme

with clear rationales for infants before they move onto full oral feeds. The 2007 Boiron et al. study¹ sets out use of an oral stimulation programme as well as oral-motor support despite stating a clear rationale to support why the particular intervention plan was decided upon. However, although the outcomes for support and oral stimulation are positive, the question as to the link between the actual intervention and the beneficial impact on the development of non-nutritive sucking is not clear. None of the studies relate the experience of touch during these non-nutritive interventions that is highly likely to occur to the research linked to skin-to-skin, or Kangaroo Care that undoubtedly contributes to the infant's overall development,^{18,19} and it is felt that the positive outcomes with the support group could be attributed partially to sensory feedback from touch. In addition, the issues around breastfeeding and non-nutritive sucking have yet to be explored in a more rigorous manner.

Review of the literature for the benefits of non-nutritive sucking reveals that despite considerable variability in methodology as well as in outcomes being measured, non-nutritive sucking clearly has benefits in promoting an infant's readiness to begin oral feeding. This paper by Boiron et al.¹ does add the importance of pacing and the suck-swallow-breathe cycle, although I am not sure of the rationales underpinning the interventions described, nor am I sure of the role of the 'therapist' in the intervention (i.e. was this person a speech and language therapist or a nurse?) In addition to the issues around skin-to-skin care and other aspects of developmental care, I was a little concerned to read about the researchers, rather than the parents, carrying out the intervention, and the fact that all the infants were bottle fed, rather than having a mix of breast and/or bottle feeders. I was also unsure of any blinding of the data, or any inter- and intrarater reliability with interpreting data collected within the paper, so I feel that the results need to be interpreted with caution, as should the clinical ramifications of this study.

I would be most interested to know if any other readers raised similar questions.

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'Repeated diffusion-weighted magnetic resonance imaging in infantile non-haemorrhagic, non-accidental brain injury'

SIR-Shaking non-accidental brain injuries (NABI) are major causes of neurodevelopmental disabilities. Diagnosis remains very challenging because of non-specific clinical presentation without external signs of trauma. Magnetic resonance imaging (MRI) is more sensitive than computed tomography for detecting non-haemorrhagic lesions, such as cortical contusion, diffuse axonal injury, oedema, cerebral swelling, and features of hypoxia-ischaemia.^{1,2} Nevertheless, conventional MRI may be insufficiently sensitive in the acute phase, as suggested by a possible discrepancy between the virtual absence of MRI abnormalities and severe neurological outcome.^{3,4} Whereas high T₂ signal of incompletely myelinated white matter may mask signal abnormalities, diffusion-weighted (DW) MRI with apparent diffusion coefficients (ADC) maps is independent of T₁ and T₂ relaxation, allowing discrimination of changes in water diffusion in NABI.^{4–7} However, the contribution of single DW imaging to the understanding of the lesions' dynamics is expected to be limited.

We describe repeated DW studies (1.5 Tesla) in four consecutive infants with shaking NABI with non-haemorrhagic intraxial lesions (Table I). Informed consent was obtained from a parent for each scan. We excluded parenchymal haemorrhage because of the complex appearance of blood in DW images. Our study did not include any case of death or severe neurological outcome related to malignant hyperhaemic cerebral swelling with cerebral herniation, though this is a classical complication of NABI.¹ Ascertainment of non-accidental event was based on a validated algorithm including clinical history, type of injury, and associated findings.⁸ Initial MRI

2. Harding, C. (2009). An evaluation of the benefits of non-nutritive sucking for premature infants as described in the literature. *Archives of Disease in Childhood*, 94(8), 636-640

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Original article

An evaluation of the benefits of non-nutritive sucking for premature infants as described in the literature

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ABSTRACT

Babies have specific needs that assist them in their development and enable them to thrive. Feeding is an important aspect of development. When feeding, there are opportunities for babies to develop a positive interactive bond with parents. This has a long-term impact on the well-being of infants in terms of emotional development, social learning, and health. Infants born prematurely and those born with specific needs making them vulnerable are likely to develop the necessary skills to allow them to mature, interact and thrive.

Many premature infants may need alternative feeding methods until they are ready to develop the skills necessary for oral feeding. A beneficial approach for infants who are showing oral readiness is the use of a non-nutritive sucking programme. This paper explores the research that supports non-nutritive sucking, and considers other variables that need to be included in further research, including those infants who have neurodisability.

Feeding is an essential early routine that is necessary for nutrition and for developing a positive bond between parents and infants. It therefore has a long-term impact on the consolidation of well-being.¹ As well as being a social activity, feeding involves the use of tactile and olfactory senses that are essential in an infant's early development. Management of these skills in a vulnerable infant population requires a sensitive, multidisciplinary approach to maximise each infant's potential.² This short report seeks to explore the use of non-nutritive sucking as a support for premature infants in the development towards a smooth transition towards oral feeding. It will also consider the relevance of the evidence base for effective clinical application. A pilot project will be discussed that seeks to explore some of these issues.

SUCKING BEHAVIOUR IN INFANTS

Sucking in particular is vital in the early development of the infant whether it involves breast- or bottle feeding. It is essential as the means of receiving nutrition, of providing stability in distress and also of exploring the environment. Successful and effective feeding is an energetic activity that is described as being complex, requiring the coordination of a suck-swallow-breathe cycle.^{3,4} Research studies show that a stable swallow rhythm appears to be established earlier than a suck rhythm.⁵ In the high-risk neonatal population, the suck-swallow-breathe sequence is rarely well coordinated before 34 weeks.⁶ Premature infants often require approximately 20 postnatal days to achieve a maximal suck rate and their suck-swallow patterns are immature,

What is already known on this topic

- ▶ Non-nutritive sucking is a beneficial process in helping to stabilise the infant during a range of processes.
- ▶ In particular, non-nutritive sucking has been shown to assist quicker transition from tube- to oral feeding within a premature infant population.

What this study adds

- ▶ Consideration about how future studies need to consider the benefits of non-nutritive sucking and its application to a neurodisability population of premature infants.
- ▶ Evaluation of current research in relation to current practice and how it can be applied to the neonatal environment.

displaying a dysrhythmic pattern, although individual variation is recognised within this population.⁶

Infants use two types of sucking. Nutritive sucking is the process of obtaining nutrition with a rate of one suck per second, and is constant over the course of feeding. It involves intake of fluid due to the alternation of expression and suction. Suction is the negative intraoral pressure which occurs when the tongue and jaw become lower and the soft palate closes the nasopharynx.^{7,8} In contrast, non-nutritive sucking occurs at two sucks per second, in the absence of nutrient flow and may be used to satisfy an infant's basic sucking urge or as a state regulatory mechanism.^{9,9} The two forms also differ in their influence on respiratory rate. Paludetto *et al*¹⁰ and Daniels *et al*⁹ suggest that increases in transcutaneous oxygen levels occur during non-nutritive sucking. They suggest that there is a higher respiratory rate during nutritive sucking pauses whereas in non-nutritive sucking, the respiration occurs during the sucking. Key environmental factors also influence the feeding process. They are the presence/absence of fluid, their viscosity¹¹ and satiation, that is, the presence of milk in the stomach which inhibits nutritive sucking.¹²

THE NEONATAL ENVIRONMENT

The hospital neonatal environment is specifically designed to provide support and to maximise an infant's potential in all areas of development. Most

3. Harding C., Frank L., Dungu C., Colton N. (2012) The use of non-nutritive sucking to facilitate oral feeding in a term infant: A single case study. *Journal of Pediatric Nursing* 27; 700 - 706

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ELSEVIER

The Use of Nonnutritive Sucking to Facilitate Oral Feeding in a Term Infant: A Single Case Study

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Nonnutritive sucking

This individual case study presents an evaluation of and reflection on the use of nonnutritive sucking as a technique to facilitate nutritive sucking with an infant with feeding difficulties. Nonnutritive sucking is used in a variable way with mainly premature or sick infants. However, the rationale underpinning use of such an approach is not clear. The infant participant in this study, Baby H, was born at 37 weeks. This case illustrates the use of nonnutritive sucking as an approach with supported rationales for promoting transition toward oral feeding with infants who have complex needs and who are term infants. The literature focuses on using nonnutritive sucking with premature infants who have no additional difficulties such as hypoxic neonatal encephalopathy, meconium aspiration, sepsis, or severe perinatal asphyxia. The intervention carried out with Baby H demonstrates that nonnutritive sucking can contribute toward the management of an infant's feeding development. Baby H took 23 days to develop a sequential nonnutritive sucking pattern, but her ability to transfer this to nutritive sucking and safe feeding took the first 17 months of this infant's life. This study is unique in that it explored the issues involved with a term infant who had complex needs that impacted on feeding development. It is important because many practitioners use nonnutritive sucking with infants who have complex needs.

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NONNUTRITIVE SUCKING (NNS) has been identified as having many benefits for premature infants. These include assisting neurodevelopmental organization, supporting neurobehavioral maturation, and optimizing ventilation in preterm babies who require nasal noninvasive ventilatory support as well as reducing pain (Boyle et al., 2006; Fucile, Gisel, & Lau, 2002; Fucile, Gisel, & Lau, 2005; Pinelli & Symington, 2005). In addition, NNS may allow critical aspects of oral-motor and feeding development to progress through stimulation and reduce the length of time spent on

nasogastric (NG) tube feeding (Boiron, Da Nobrega, Roux, Nenrot, & Saliba, 2007; Fucile et al., 2002, 2005; Harding, 2009; Harding, Law, & Pring, 2006; Pickler & Reyna, 2004; Pinelli & Symington, 2005; Rocha et al., 2006).

Background

Infants use two types of sucking: nutritive sucking (NS) and NNS. NS is the process of obtaining nutrition with a rate of one suck per second and is constant over the course of feeding. It involves intake of fluid due to the alternation of expression and suction. Suction is the negative intraoral pressure that occurs when the tongue and jaw become lower

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4. Harding C., Frank L., Van Someren V., Hilari K., Botting N. (2014). How does non-nutritive sucking support infant feeding? *Infant Behavior and Development* 37; 457 – 464

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How does non-nutritive sucking support infant feeding?



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ABSTRACT

Fifty nine premature infants participated in a randomized controlled study to determine the effectiveness of non-nutritive sucking (NNS). It was predicted that NNS would not accelerate the development of full oral feeding or early language skills as sometimes perceived in practice. However, it was predicted that using NNS as a strategy to support parents to identify and respond to early communication and oral readiness signs would increase confidence in infant management and enable quicker discharge home. Infants were aged 26–35 weeks gestation. Infants with no significant difficulties were randomly assigned to one of three groups; Group 1, NNS pre-tube feeding ($n = 19$); Group 2, NNS on onset of tube feeding ($n = 20$) and Group 3, Control ($n = 20$). Follow-up occurred at 6 months. There were no significant differences with number of days to full oral feeding between the groups receiving NNS and the Control group, $\chi^2(2, n = 59) = 4.33, p = .115$. A significant difference in number of days in hospital between the Control group and the other two groups was found $\chi^2(2, n = 59) = 7.678, p = .022$. Significant changes were noted with the development of more normal sucking patterns in Groups 1–3. At 6 months there were no significant differences in receptive or expressive language skills between all groups. NNS had no significant impact on the transition to full oral feeding or later language development. There was a significant difference in the number of days in hospital between the Control group and the other two groups which involved parents in identification of early communication signs. Possible reasons for this change and future directions are discussed.

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1. Introduction

This paper considers using non-nutritive sucking (NNS) to support transition to full oral feeding for infants. There are many methods of administering NNS in the literature and these are often a prescribed programme of oral-motor and sensory exercises implemented by a health care professional which do not involve parents (Barlow, Finan, & Lee, 2008; Boiron, Da Nobrega, & Roux, 2007; Fucile, Gisel, & McFarland, 2011; Gaebler & Hanzlik, 1996; Hwang, Vergana, & Lin, 2010; Pimenta, Moreira, & Rocha, 2008; Rocha & Lopes Moreira, 2006). The focus of this study is from a speech and language therapy and nursing perspective and it recognizes the benefits that NNS can have. It is novel as it concentrates on training parents to use NNS in its simplest form as a tool to guide the infant to a state for effective early feeding. Therefore, the main focus of this study is about understanding the importance of an infant's early communication as well as exploring how NNS is effective. This approach fits well within the Developmental Care model of interpreting the infant's needs (Als, 1986). Some

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5. Harding C., Frank L., Botting N., Hilari K. (2015) Assessment and management of infant feeding: *Infant*, 11(3);pp 85 -89

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RESEARCH STUDY

Assessment and management of infant feeding

Some infants have difficulty establishing the consistent suck-swallow-breathe cycle that is important for the development of competent feeding. This article summarises the progress of nine infants with neurodevelopmental disorders to consider the core components necessary for a comprehensive feeding assessment for vulnerable infants. It also highlights the main approaches used to support the development of infant feeding.

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Key points

Harding C., Frank L., Botting N., Hilari K. Assessment and management of infant feeding. *Infant* 2015; 11(3): 85-89.

1. Not all infants will have achieved full oral feeding when they go home from neonatal care.
2. Supporting parents to identify infant states is an important part of oral feeding and oral care development.
3. It is important that practitioners who work with infants understand the rationale underpinning approaches that support infant feeding.

Feeding requires coordination of sucking, swallowing and breathing. Infants demonstrate two types of sucking: nutritive sucking (NS) and non-nutritive sucking (NNS).¹ NS is the intake of fluid that occurs when there is an alternation between expression and suction at one suck per second, whereas NNS does not involve any nutrient flow and is at two sucks per second.¹ NS is coordinated with swallowing and breathing.² Oral readiness, usually demonstrated by waking for feeds, is an essential part of feeding development.³

The feeding problems seen in vulnerable infants are likely to be multifactorial in origin. Difficulties include an ineffective cycle of sucking, swallowing and breathing which can lead to variable oxygenation, irregular breathing sequence and consequently poor digestion.⁴ The lack of ability to develop a suck-swallow-breathe cycle could be due to other factors such as poor motor skills and posture, an immature autonomic nervous system, gastro-oesophageal reflux or fatigue effects from heart difficulties. Underdeveloped or abnormal neurology, eg central nervous system damage or neuromuscular disorders, can also impact on feeding development.⁴

As an infant matures sucking amplitude, rate, pressure, timing of sucking cycles, sucking efficiency and proficiency begin to change and become more consistent over time. These sucking attributes are important in the development of competent feeding. Undeveloped motor skills and abnormal muscle tone can contribute to weak sucking pressure, a decreased sucking cycle, variable pressure throughout the feed, and reduced oral

intake.⁵ Poor general health, particularly respiratory difficulties, may delay the development of competent feeding skills and impact on the establishment of a consistent suck-swallow-breathe cycle.⁶

Few studies discuss the management of infants who struggle to develop competent feeding skills; the vast majority of articles that look at feeding in premature infants focus on NNS and its link to development of oral feeding.⁷ For infants with more complex needs, NNS does not have similar benefits. This is because NS and NNS have different and distinct sites of neurological activation.^{8,9} However, NNS is important in helping parents and carers to learn to focus on the differing states of their infants as well as helping the preparation of an appropriate state to attempt some feeding or oral care. This article summarises the progress of nine infants with neurodevelopmental disorders who used NNS to help focus their parents' attention on the developing infant states. It also summarises the main types of approaches that focus on maximising feeding and oral motor competence.

Assessment of early oral motor and feeding skills

Observation

Observation focuses on the infant's interaction with the environment, in particular parent-infant responsiveness, and can provide important information about developing behavioural states.¹⁰ Infant states are well classified with descriptors that include: deep sleep, quiet alert, active sleep, active alert, drowsiness, crying and indeterminate states.¹⁰ For

4.8 Implications, recommendations and concluding remarks

The randomized controlled trial by the author (Harding et al, 2014) compares favourably with studies focused primarily on using NNS to hasten the time to full oral feeding. Infants took between 8 - 50 days to achieve full oral feeding (Group 1; NNS pre – feed, average = 19.7 days, range = 8 - 41 days; Group 2; NNS on onset of feed, average = 16.5 days, range = 9 – 48 days; Group 3; Control, average = 23.9 days, range = 9 - 50 days). There were no significant differences between the groups, although slight differences are noted here. The averages of 19.7 days, 16.5 days and 23.9 days are above the average time for a premature infant to achieve full oral feeding as stated by Pickler et al, (2006). Other studies show similar times to achieve full oral feeding, with a range of 5 – 38 days to achieve full oral feeding, (Bingham et al, (2010); 38 ± 16 days with NNS (mean and SD) , compared to 47 ± 17 days to achieve full oral feeding in the Control group(mean and SD); 11 – 18 days (Fucile et al, 2002;2005) and 10.10 days with tactile support compared to the Control group which had an average of 20.7 days to achieve full oral feeding. Compared to the presented study, there are differences which could suggest that healthcare practitioners may be more efficient at administering NNS as a strategy compared to parents, and therefore achieve better results in time taken to achieve full oral feeding. This would benefit from further exploration, though it is hard to compare this to the long term impact of the benefits of parents using NNS to help identify infant states pre- and during feeding and which can only facilitate better infant – parent bonding opportunities. In addition, many of the studies discussed in this chapter are not transparent about the gestational age of the infants participating.

There is great variability in these studies in how an infant's age is described. This, potentially, can lead to difficulties in effective interpretation of results for particular groups of infants. Many studies use the term [*gestational age*] to define their group (Barlow et al, 2008; 2014; Boiron et al, 2009; Boyle et al, 2006 ; Bragelien et al, 2007 ; Fucile et al, 2002; 2005; 2011; 2012; Field et al, 1982; Gaebler & Hanzlik, 1995; Harding, 2009; Harding et al, 2006; 2013; Hwang et al,

2010; Lau & Smith , 2012; Mattes et al, 1996 ;Neiva & Leone, 2007; Pimenta et al, 2008 ; Rocha et al, 2007; Rochat et al, 1997; Standley et al, 2010; Yildiz & Arıkan, 2012). Others refer to [*postmenstrual age*], [*menstrual age*], [*corrected age*], [*post-conceptual age*] (Bingham et al, 2009; Hill, 2005; Lessen, 2011; McCain et al, 2002; Poore et al, 2008). Most studies are not clear about differentiating between early and later premature infants and do not always clearly stratify their data to accommodate such differences. The American Academy of Pediatrics (2004) discussed that variable interpretation of age created challenges in interpreting data and suggested that “conceptual age” should be avoided. This document argues that consistent definitions need to be used with premature infants so that more accurate comparisons can be made when examining neurodevelopmental, medical and growth outcomes. It suggests that gestational age should be defined as weeks, and that this time represents the time that has elapsed from the first day of the last menstrual period a woman has had until the first day of life of the infant. If fertilisation methods or reproductive technology was employed, then gestational age involves adding two weeks to the conceptual age. Chronological age is the age of the infant from birth in days, weeks, months or years. Postmenstrual age is the gestational age of the infant plus its chronological age. Corrected age uses the chronological age reduced by the number of weeks born before 40 weeks; it recommends that this should not be used beyond three years of age with ex-premature infants. During hospital stays, the term “postmenstrual age” is recommended, and on discharge, “corrected age” is the preferred term in the USA (APA, 2004) though this has yet to be a consistent method of defining age in the UK. This is an important point to address as this significantly impacts on how results from studies are interpreted.

A clearer and more plausible rationale for NNS needs to be defined as many authors claim that NNS has specific benefits (Table 4.4). Non nutritive sucking appears to be a stimulant that triggers a whole system response with an interaction with the physiological system, social system, sensory system and interactive system of the infant. When NNS is being facilitated, an associative cue between oral activity and satiation as well as the consistent formation of oral

readiness states is being developed as well as the foundation and framework for communicative interactions by caregivers. It is usual that a parent or carer will comment, respond and interact with an infant when carrying out a procedure such as this. Healthcare practitioners may do this also, but are possibly more immediately responsive to infant signs and therefore can adapt use of NNS more competently. The three sequential sucks in the Harding studies (2006; 2009) was preceded by observations of the infant's state, and encouraging the infant to prepare for feeding; strategies used included changing the nappy, undressing, etc, so the infant would focus and move towards the quiet alert state so important for feeding as well as supporting parent confidence with introducing feeding skills (Carr Swift & Scholten, 2009). It could be argued that by doing this, health care professionals are teaching the parents to look for how their infant attempts to organize sucking; in this context you can also encourage parents to look for specific parameters, describe what they see, then transfer their observations when the infant begins NS. The aspect of setting the parameters for early communication interaction is one that has not been discussed in any of the papers except Gaebler & Hanzlik, (1995) and the Harding papers in this chapter. Early communication opportunities are crucial in helping the infant learn, and it also enables the infant to have better emotional stability early on (Bochner & Jones, 2003; Bowerman & Levinson, 2001; McLaughlin, 2006; Tomasello et al, 2007).

A meta – analysis on NNS IN 1987 (Schwartz et al, 1987) identified that using NNS did decrease the number of days to achieve full oral feeding and to spend fewer days in hospital. As has been discussed, more recent studies have not been able to draw any cohesive conclusions from the benefits of NNS, but attribute a range of possible reasons as to the main benefits. The most likely benefit is two fold. First, NNS calms or prepares an infant and orientates them towards achieving the quiet alert state so important for feeding (Burroughs et al, 1978; McCain, 1992; 1995; 1997; Pickler & Frankel, 1995; Pickler et al, 1997). This orientation enables the infant to maximize the benefits of this physiological state and thus attempt to successfully feed. Secondly, when preparing infants to feed, and when parents and caregivers are actively involved in this process, an

understanding of the infant's early communication and responsiveness emerges, and it is this response to the infant and the interaction that follows that provides support and development, and therefore enhances feeding competence (Harding, 2009; Harding et al, 2012; Harding, 2014). This fits well with the Als et al (2004) study which evaluated Developmental Care (Als, 1986). Infants who received Developmental Care (Als, 1986) had better neurobehavioral functioning and more developed left frontal, occipital and parietal regions with more robust connections between areas in the brain. It can be hypothesized that people interacting with the infant through Developmental Care (Als, 1986) management made the differences in outcomes through learning to communicate effectively with an infant. The relationship between NNS and NS has been discussed; using NNS to gauge physiological stability by monitoring of oxygenation can be initially a useful clinical indicator of competence (McGrath & Bodea - Braescu, 2004). Some authors claim that measurements of NNS can predict if oral feeding will be successful (Bingham et al, 2009). However, in contradiction to this, an infant can demonstrate NNS skills, but not be able to develop NS skills as a consequence (Harding et al, 2012a; Harding et al, 2015). None of the studies mentioned in this chapter have consistently demonstrated that NNS consistently improves weight gain, heart rate, oxygen saturation, gut transit time of milk or an increase in energy intake, and studies that focus specifically on NNS and oral feeding have a variety of outcomes.

The interactive, social and communicative elements through using NNS are supported by Psychoanalytic Theory (Bowlby, 1969; 1973; Stern, 1977; Winnicott, 1960). The application of a strategy to everyday situations to make them relevant and meaningful relates to Transactional Theory (Sameroff & Fiese, 1990). Premature infants are at high risk of not being able to show clear behaviour signs of hunger to the caregiver, and at risk of poor carer - infant interaction as well as limited awake states to support feeding (Bingham et al, 2009; McCain, 1995; Singer et al, 2003). As the infant matures, there is an increase in neurobehavioural performance due to motor, autonomic, state organisation and interactive responses usually from 32 - 40 weeks post conceptual age (Huppi et al, 1996).

Exercise interventions imply that the problem can be “fixed”. Similarly, there are false notions where parents perceive that gavage feeding will impact on later oral-motor development, and that any oral-motor programme will “fix” the oral musculature and therefore “help” the infant develop eating and drinking and “good” language skills later. The randomized controlled study in this chapter did not show any significant differences in language development at 6 months, although a very simple screen was used to check this (Harding et al, 2014). Programmes which are usually administered by health care professionals and not parents are instrumental in de-skilling care-givers and undermining their abilities to participate in the facilitation of their infant’s development (Carr Swift & Scholten, 2009). The paper by Harding et al, (2014) has shown that there were no significant differences when NNS was used compared to a Control group of infants. This gives some weight to the argument that NNS and NS are quite different and therefore one cannot be or transition to be the other as they are activated by different parts of the brain as well as having other distinct properties such as differing intra-oral pressures. Therefore it is unlikely that NNS will lead to NS in the direct way implied in many of the studies discussed (Bache et al, 2014; Barlow et al, 2008; 2014; Boiron et al, 2007; Bragelien et al, 2007; Coker-Bolt et al, 2012; Field et al, 1982; Fucile et al, 2002; 2005; 2011; 2012; Gaebler & Hanzlik, 1995; Hill, 2005; Lau & Smith, 2012; Lessen, 2011; Liu et al, 2013; Lyu et al, 2014; Mattes et al, 1996; Measel & Anderson, 1979; Neiva & Leone, 2006; 2007; Poore et al, 2008; Pimenta et al, 2008; Rocha et al, 2007; Rochat et al, 1997; Sehgal et al, 1990; Standley et al, 2010; Yildiz & Arıkan, 2012; Zhang et al, 2014). The most significant difference between the groups was the time taken to be discharged home, so infants who had received the interventions went home more quickly. Feedback from parents suggests that this difference may be due to parent confidence in “reading” and understanding their infant’s needs, and this particular aspect would benefit from further exploration.

CHAPTER 5

CONCLUSIONS

CHAPTER 5: Conclusions

This chapter will summarise the studies in this thesis critically with reference to the current evidence. It will also discuss the contribution that these studies make to the literature and evidence base. A number of clinical considerations have been developed throughout this thesis. These include; i) the understanding of clinical populations and the evaluation of current therapy protocols within research; ii) the role of communication as a potential strategy in the management of feeding disorders; iii) the clinical context, in particular the use of carers and staff in delivering therapy and its impact on intervention fidelity, and iv) differences in findings in non-nutritive sucking research and indications of a range of possible mediating/moderating factors. This final chapter evaluates the contribution of this research and makes suggestions for future studies.

5.1 Summary of key themes

One theme pervasive to this thesis is the importance of communication. This means communication in its broadest sense. The importance of the observation of infant states has been discussed as well as the skills of the range of parents, caregivers and staff that SLTs work with. Communication as a tool for reducing risk during feeding has not been fully discussed. However, a number of the papers presented make suggestions for future explorations. The possibility of using communication to enable risk reduction has been suggested, for example, in the discussion of the importance of observing infant states. The papers presented also demonstrate both the opportunity for developing communication skills for children with complex needs within mealtimes, as well as the possibility of using communication in specific ways to reduce risks associated with choking when

eating and drinking (Harding et al, 2010a; 2010b; 2010c). Using communication strategies to support a child's receptive and expressive skills might help them prepare their oral skills to manage liquid and food effectively. This could contribute to risk reduction as well as enhancing the quality of life within the routine context (Harding & Halai, 2009; Harding et al, 2010a; 2010b).

As well as exploring communication in relation to eating and drinking difficulties, non-nutritive sucking (NNS) has also been considered. Speech and language therapists use NNS in their daily practice with neonates. However, there is no clear philosophy to underpin the SLT use of NNS. There is wide variation in outcomes in studies, and the efficacy of this approach from a SLT clinical context has not been reported. Four papers in this thesis considered NNS (Harding, 2009; Harding et al, 2012a; 2014; 2015). Each of these papers evaluated aspects of NNS rarely discussed in the current literature. In summary, the new contributions were: i) replication of a typical SLT method of using NNS (Harding et al, 2012a); ii) using a specific tool to measure infant sucking patterns before and after intervention; iii) consideration of parent and carer administration of a procedure (Harding et al, 2006; 2014; Harding 2009), iv) inclusion of infants who had persistent reflux, respiratory or heart difficulties but with no other additional problems (Harding et al ,2014); v) infants with neuro-disability, who are typically excluded from studies about NNS (Harding et al, 2015), and vi) simple evaluation of infant language development at 6 months of age to investigate further the links between NNS, feeding and speech development (Harding et al, 2014;2015). The outcomes of these studies were that NNS made no significant difference in number of days to full oral feeding (Harding et al, 2014) in contrast to Boiron et al, (2007); Fucile et al, (2002; 2005; 2011); Rocha et al, (2007); Standley et al, (2010) and Yildiz & Arikan (2012). Harding et al, (2014), did

find significant differences between the Intervention groups (Group 1, mean = 37.9 days in hospital, range 24 – 64; Group 2, mean = 40.2 days in hospital, range 9 -104) compared to the Control group (mean = 56.2 days in hospital, range 11 – 110). In the individual case study, it was found that NNS did not automatically lead to NS, and that despite significant early feeding difficulties there seemed to be no early difficulties with language development (Harding et al, 2012a). This study, therefore, is in conflict with the majority of other studies which state that NNS will support the development of NS (Barlow et al, 2008;2014; Boiron et al, 2007; Coker-Bolt et al, 2012; Fucile et al, 2002; 2005; 2011; 2012; Gaebler & Hanzlik, 1995; Hill, 2005; Hwang et al, 2010 ; Lau & Smith, 2012; Lessen, 2011; Lyu et al, 2014; Matthes et al, 1996; Pimenta et al, 2008; Poore et al, 2008; Rocha et al, 2007; Standley et al, 2010; Yildiz & Arikan, 2012).

There were a number of limitations in the studies presented, particularly in relation to carrying out the research protocols within a complex clinical environment. These issues, as well as methods of devising a more robust research protocol are now discussed.

5.2 Methodological issues

5.2.1 Heterogeneity and variability in clinical samples

There were time limitations and lead researcher availability issues with the Harding et al (2014) RCT study. This may have delayed timely identification of the correct post – menstrual age (PMA) alongside oral readiness signs to begin the NNS programme. Therefore, if an infant started the programme either too early or a few days later than when they were displaying oral readiness signs, then this could impact on the time to achieve full oral feeding, in that it may take longer to achieve

full oral feeding if not responded to promptly. This is a complex issue to dissect due to the challenges of identifying infant states in relation to oral readiness. It is not known generally if the infant states of infants of different birth GA vary at the PMA when oral feeding trials are begun. Oral readiness emerges between 32 - 34 weeks PMA regardless of GA. Sometimes an infant is born early, and the GA of the infant may not be correct, and it may appear more immature due to a miscalculation of its conception (AAP, 2004). Infants also develop at different rates even when they are the same GA (AAP, 2004). Part of this is due to the reason why they have been born early, and may also be due to any treatments their mothers may have received. This suggests that premature infants are a variable population, even for those who do not have any obvious identifiable signs of difficulty. The Harding studies, for example, implemented NNS at 31 - 34 weeks PMA (Harding, 2009; Harding et al, 2014). There is wide variation in the literature, i.e. 32.9 – 36.3 weeks PMA (Fucile et al, 2002); 32 weeks PMA (Fucile et al, 2005. 2011; 2012); 32 – 36.3 weeks PMA (Bingham et al, 2009); 32 -34 weeks PMA (Boiron et al, 2007); 34 weeks PMA (Barlow et al, 2008;2014); 29 weeks PMA(Lessen , 2011); 31 -34 weeks PMA (Bache et al, 2014)and as reported in Chapter 4, infants have started programmes to prepare them from full oral feeding from 20 weeks PMA – 36.9 weeks PMA (Table 4.2). This variability makes the results from the various interventions harder to interpret and generalise. There are many different variables to be considered in accounting for the wide variation in outcomes in infant NNS studies.

The Harding et al (2014) study had wide variation in the number of days to full oral feeding: 8 - 50 days, which is considerably greater than the reported studies (Barlow et al, 2008; 2014; Bingham et al, 2009; Boiron et al, 2007; Fucile et al, 2002; 2005; 2011; 2012; Hill, 2005; Lessen, 2011; Liu et al, 2013; Lyu et al, 2013; Mattes et al,

1996; Measel & Anderson, 1979; Neiva et al, 2006; 2007; Poore et al, 2008; Rocha et al, 2007; Sehgal et al, 1990; Standley et al, 2010; Yildiz & Arikan, 2012; Zhang et al, 2014; see also Table 4.2). It could be that these studies had more stringent inclusion criteria, with a higher number of infants excluded with typical difficulties expected such as reflux (Gewolb et al, 2001). However, the researcher wanted to replicate as far as possible a typical range of premature infants. Therefore, unlike the studies quoted above, infants with reflux, mild heart murmurs and respiratory difficulties, but who had no known neurodevelopmental problems or additional significant adverse health difficulties were included in the study. Also, infants with mixed feeding regimes were included, i.e. breast, breast and bottle and bottle feeding only. Breast feeding can be challenging to sustain and to maintain and this could have caused some infants to take longer to achieve full oral feeding in this sample (Nyquist, 2008). In comparison, the Bache et al (2014) was the only other study which included infants who still required oxygen as well as breast and bottle feeders, although they did not include infants with more complex needs. These infants still had quicker outcomes in relation to achieving full oral feeding compared to the Harding et al (2014) study, in that the Intervention group achieved full oral feeding in 13 -38 days, and the Control group achieved full oral feeding in 12.9 – 36.9 days (there were no significant differences between the groups). Bache et al (2014) suggest that infants with additional respiratory needs as well as those who are small for their age require more time to develop full oral feeding competence, and these participants could alter overall outcomes. It would be interesting to compare infants kept in the Harding et al (2014) and Bache et al (2014) studies and to note similarities and differences between the participants.

Another factor in the Harding et al (2014) study could be that the Control group had a higher number of infants with a lower GA compared to the other groups. In a future study, it would be important to stratify infants based on their gestational age ranges (26 – 27; 28 – 29; 30 -31; 32 -33). The randomization process did not account clearly for this, and it is often the case that lower GA infants will take longer. In addition, it may be important to consider how many mothers were first time mothers, as well as maternal age, socio – economic factors and parental early history. These factors could have an impact on outcomes, e.g. the first time mother may feel less confident with beginning oral feeding (Gray et al, 2013; Pinelli, 2000; Singer et al, 2010).

Two important areas would also benefit from further exploration: i) detailed birth history of the infant participants, i.e. were they born early due to maternal or other factors, and ii) follow up of the infants feeding and communication development at 6, 12,18 and 24 months. This would provide important information, alongside the birth history, about early feeding (including weight gain, food preferences, foods that were found difficult to eat, etc.), and communication development. As this thesis has discussed, there are many myths associated with the relationship between feeding and language development (Harding & Cockerill, 2014), however, a further study could begin to unravel the nature of the links between these two distinct areas. In addition, it would be important to gain greater insights into the particular difficulties that infants with more complex needs actually experience when developing early feeding skills, and to consider if there were core clinical features that could enable some preventative intervention to be developed. It would also be important to consider those infants who are non-oral feeders and follow their progress as individual case - studies to focus on understanding the nature

of congenital conditions that impact on feeding competence and interaction. Infants with difficulties beyond what would normally be expected within a premature infant population need to be studied further, as these are the cases that typically receive therapy intervention.

5.2.2 Sample size and recruiting

The RCT completed by Harding et al (2014) was a time limited study and recruitment did not continue once 60 had been co-opted onto the research programme. A future larger scale study with fewer constraints on time would allow for a more confident interpretation of the results (Jones et al, 2003; Robson, 1993). An interesting consideration is that the studies which suggest that NNS does facilitate quicker transition to full oral feeding could be false positive outcomes, i.e., Type I errors because other important variables, such as gestational age, post menstrual age of the infant when starting oral feeding, parents feeding regimes and interaction with their infant and monitoring of neuro-developmental and medical needs have not been adequately controlled for (Barlow et al, 2008; 2014; Bingham et al, 2009; Boiron et al, 2007; Fucile et al, 2002; 2005; 2011; 2012; Hill, 2005; Lessen, 2011; Liu et al, 2013; Lyu et al, 2014; Mattes et al, 1996; Measel & Anderson, 1979; Neiva et al, 2006; 2007; Poore et al, 2008; Rocha et al, 2007; Sehgal et al, 1990; Standley et al, 2010; Yildiz & Arikan, 2012; Zhang et al, 2014). A larger study sample would increase the power and also allow for confounding variables to be controlled for. As a number of strategies would be considered, a randomized controlled trial should be carried out. A sample size calculation would need to aim for an expected development of full oral feeding success rate of 95% (with a confidence interval or p value of 0.05) in the Intervention groups compared to a 70% success rate in the Control group, so the minimal sample size required to identify any detection of

difference between groups would be 37 infants in each group, with a power of 80%, and an alpha level of 5% (Jones et al, 2003). Research procedures are challenging to implement in a clinical setting.

It is not clear from the Harding et al (2014) study how blinding was managed. Staff did know which infants were receiving which intervention, although parents were not informed of the alternative options other infants received. Further consideration needs to be given to achieving appropriate use of blinding so that the risks from bias can be reduced. Because the main researcher was monitoring the project, this may not have enhanced validity. An SLT colleague who worked in another setting completed an interrater reliability of infant states and sucking skills in relation to the stated research protocol. However, due to time constraints, this was only done at one time point. It would be advisable to repeat this more often in future studies.

Having a multi-centre sample, including units outside of an inner city area could ensure a wider, more representative sample of mothers, therefore reducing the risk of having too many maternal variables such as personal deprivation, poverty, etc. Overall, important parent participant characteristics to consider should include the following: *the number of children at home or if it is the first infant; ethnicity; family composition; maternal education; maternal age at delivery; anxiety and depression ratings (Abidin, 1995); ways of coping, e.g. confrontive, distancing, self-controlling, seeking social support, avoidance, problem solving, positive reappraisal (Folkman & Lazarus, 1988).*

The papers that consider communication require further consideration as it could be argued that using communication does not help either to support a child

with complex learning and eating and drinking needs, or reduce risk, especially as very small sample sizes were gained for each of the studies (Harding et al, 2010a; 2010c; 2012c; Harding & Halai, 2009). For example, in the Harding et al (2010c) paper, the parents receiving the hunger provocation intervention used language that was complicated or provided unhelpful prompts for the children involved. They used a high number of verbal reprimands and excessive commenting and coaxing in an attempt to encourage the children to eat. It is acknowledged that this was only based on two children, and in contrast to the other studies in this thesis, the children involved did not have additional significant learning needs. They had language skills within the range expected for typically developing children and had evolved verbal and non-verbal methods of communicating their wish to avoid completing eating a meal. As explained in the paper, the children had difficulties learning to tolerate eating all of their meals orally due to lack of a positive eating experience which impacted on the opportunity to reduce gastrostomy tube feeds. Both the parents' use of language and the children's avoidance strategies through communication could be reasons for not using communication as part of a feeding management programme. This paper did report that "It is difficult to make an assumption about which strategies enabled the children to make progress" (p 274, line 41) as there were many variables involved in this study which a larger sample could explore more effectively (Harding et al, 2010c).

There are many factors which complicate the consideration of using communication as part of a dysphagia management programme. These factors include the level of cognition of the child being supported to eat and drink, the child's ability to feed himself, the child's own abilities to communicate, positioning, previous experiences with eating and drinking, parent anxiety and cultural values

associated with mealtimes (Cass et al, 2005; Field et al, 2003; Hewetson et al, 2009; Peterson et al, 2006; Sleigh 2005). As discussed in Chapter 1, Kerr et al (2003) and Table 1.6, p28, a high number of children with swallowing difficulties have additional learning needs. These children are likely to have reduced communication competence and have to rely on others to interpret their non-verbal or idiosyncratic communication when indicating that they are having difficulties; this is important especially when monitoring risks associated with swallowing difficulties within a vulnerable population (Lace & Ouvry, 1988). In addition to this, it is likely that many of these children may require help and support with eating and drinking (Parkes et al, 2010; Reilly et al, 1992; 1993; 1996). Other studies comment on social isolation for children with complex physical disabilities (Loughlin, 1989; Blockley and Miller, 1971), and the fact that helping a child with complex needs to eat and drink can also be time consuming (Pinnington & Hegarty, 2000; Sullivan et al, 2005).

It would be important to investigate the impact of verbal prompts on the eating and drinking process, both as a means to assist a client, and as a way of thinking about minimizing the risks associated with swallowing problems. One study has identified that people respond differently when asked to eat and drink compared to when they receive no instructions (Bennett et al, 2009). This study reported that people take smaller sips when instructed to drink (6ml vs. 24ml on average / mean) compared to when they spontaneously ate and drank. The responses of these participants in relation to verbal commands would be interesting to explore further. The number of participants in this study was small, 32. There are a number of points that require further consideration. Participants in the Bennett et al (2009) study were healthy, with no progressive or acquired difficulties likely to impact on swallow or cognitive skills. A larger sample that explored participant responses within a typical

paediatric population would be interesting. It could be anticipated that in addition to thinking about the impact of language and cognition skills of each child, there could also be variation in oral – sensory responses, which would influence the outcomes (Mathisen, 2001). However, many of the participants studied in this thesis had developmental and/ or learning difficulties. This makes response to communication as a strategy more challenging to consider. As described in Chapter 1, the language style of carers of children who have complex needs tends to be facilitative and directive (Ferm et al, 2005; Hemsley & Baladin, 2003; Mathisen 2001; Tulviste, 2000; Veness & Reilly, 2007).

5.2.3 Care delivered by other people

When SLTs manage their caseloads, they frequently work with parents and carers to encourage and support use of therapeutic techniques in everyday settings. The papers presented in this thesis replicated as far as possible a typical therapy context. Each study had specific research protocols for carers to follow as well as training about each of the projects. It would have been useful to include the details of the staff training, with a clear description of what the staff were asked to do in the different studies included in this thesis. For example, the NNS protocol devised for the neonatal studies did not factor in a minimum number of times per 24 hours that the NNS programme was to be completed, nor did it consider the competing demands of the nurses' role in terms of balancing priorities (Harding, 2009; Harding et al, 2014; 2015). Nurses may not have had time to carry out NNS on some occasions if the parents were not available to do it. It would have been interesting to gain some before and after measures from staff to get different insights into what they felt the benefits and challenges of using NNS as part of an oral feeding therapy programme were. It would also have been useful to conduct some

more in depth interviews with the parents from both the Intervention and the Control groups to evaluate if there were differences in parent perceptions of general health status between the two groups.

The programme protocols were simple for all participants; two groups received NNS, one before a tube feed, one on initiation of a tube feed with both groups additionally focusing on an infant's state. However, it was hard to monitor whether the research protocols were adhered to by both parents and staff. Training might not have been adequate for parents to ascertain whether they were consistent and confident in their application of the NNS, and if they were accurate in their identification of infant states. A skilled and experienced SLT demonstrating a programme may be hard for others to replicate. The same issues with modelling and training could also apply to staff. What the SLT may define as a state may not be interpreted in the same way by parents and staff. It is possible that parents may not have been consistent in their application of the protocol. It is also possible that due to the staff rota system and differing staff awareness of the project, the intervention may have been carried out and encouraged inconsistently by nursing staff. There is also a risk that some staff could have carried out the intervention with Control group infants as NNS is something that they are used to carrying out in their daily practice. Perhaps the Harding protocol (Harding et al, 2006; Harding, 2009; Harding et al, 2014) was too simple for some staff to feel it was necessary to complete, and maybe a more structured protocol such as that described by Fucile et al (2005) could be perceived to have more tangible procedures to follow. Having a structured protocol as in the Fucile et al (2002; 2005; 2011; 2012) papers has benefits as it can be easily replicated, although the outcomes with studies that have followed the same protocol still vary greatly (See Table 4.2).

Working with significant others is an integral part of clinical practice. Harding and Halai (2009) explored the effectiveness of a training programme for staff working with children with significant special needs. Six training sessions were provided and included risk issues, identification of risk and using communication during meal times. This paper reported that staff had good knowledge about swallowing problems prior to training but also some gaps in knowledge in relation to texture modification and identification of risk. This highlighted the importance of staff training and monitoring when delivering therapy / intervention plans. It also highlighted the importance of checking with participants carefully that they understand any protocols being used, especially when it is in relation to a therapy programme being delivered by others rather than the SLT. Harding and Halai (2009) reflect on the assumption that ongoing use of appropriate strategies within a functional context has learning benefits. They also discuss the importance of considering a child's nonverbal communication and recommend that the role of communication would benefit from further research.

5.2.4 Parents

Managing an infant or a child with a complex eating and drinking problem is stressful (Holditch – Davis et al, 2003; Mathisen, 2001; Mathisen et al, 2000; Miles et al, 1999; 2007). It is possible that some parents were unable to complete the NNS intervention consistently when they were upset or exhausted. This was evident in the single case study where Baby H's mother had significant anxieties about progressing onto full oral feeding due to a severe aspiration event post birth (Harding et al, 2012a). It could be argued that her mother's feelings about this event prohibited a quicker transition to ceasing tube feeds, and that this anxiety contributed to a longer period of tube feeding than was necessary. It would therefore be important

in future studies to monitor and assess larger groups of infants who are not typical in their presentation and to monitor both oral motor development and tolerance of oral feeding, and the overall progress in relation to parent confidence.

Learning to care for a premature infant is challenging for carers (McGrath & Medoff-Cooper, 2002; Pickler et al, 1993; 1996; 2006; White-Traut et al, 2002). The mental health of parents of very preterm infants (≤ 32 weeks GA) is known to be precarious (Gray et al, 2013; Pinelli, 2000). Mothers of premature infants report increased stress with managing their child's development in the first three years of life (Brummette et al, 2011; Singer et al, 1999). Parents of premature infants find interpreting their infant's signals difficult, particularly around mealtimes, which potentially can impact on the introduction of oral feeding (Harding et al, 2014; 2015; Shaker, 2013; Silberstein et al, 2009). Later, parents of ex-premature infants are at risk of developing reduced interaction and play experiences with their children (Cmic et al, 1983). Given the stresses associated with caring for a premature infant, it would have been useful in the Harding et al (2014) study to evaluate if there were any differences in parent satisfaction and well-being between the Intervention and Control groups. The rationale for using such measures is that parents may have a higher level of satisfaction if they feel supported. The follow up at 6 months post intervention was carried out by telephone interview due to time constraints using the Pre-School Language Scales (Boucher & Lewis, 1997). Parent reporting may not have been accurate, and participants may have misunderstood some of the questions being asked and either over- or under-estimated their child's language development. However, if there were no difficulties with time and resource allocation, a useful measure would have been The Infant Development Inventory (Ireton & Thwing, 1976). This inventory can be used with young children aged 0 – 6

years of age. It is often used in research as a means of reporting on an infant's early health and development, including language. It also has parent questionnaires which parents may find easier to do in their own time, rather than via the telephone.

There are a number of tools that could assist in exploring if there are differences between parents receiving intervention, and those who do not, and if this might be a factor in parents being discharged with their infants sooner. One example is the SF-36 Health Survey (Ware, et al, 1994). This is a multi-purpose measure, comprising 36 questions, that considers both mental and physical health. It produces an eight-scale profile of scores as well as a summary of physical and mental measures. It has been specifically designed to evaluate overall patient well – being post receiving a health care intervention and could be used with parents. The mental health component considers social functioning, emotional state and vitality, all aspects that are likely to be reduced when caring for a premature infant. It would be interesting to see if mothers of infants who stay in hospital longer have lower social functioning, emotional state and vitality ratings compared to parents of infants carrying out one of the interventions. Another reason for selecting the SF-36 is that the content and construct validity of the assessment tool is high, and its validity has been recognised across a wide range of surveys about health distress and family functioning; additionally, it is not disease specific (Dubernard et al, 2006; Ware & Kosinshi, 2001). Other measures with recognised validity which could be used are the Parenting Stress Index (PSI 3rd Edition, Abidin, 1995) and the Ways of Coping Questionnaire (WCQ, Folkman & Lazarus, 1988). The PSI is a standardized self-report tool consisting of 120 items. Parents rate their views about their competence, isolation, attachment with their infant, health, role within the family, depression and their current relationship. The WCQ is a 66 item tool which focuses on coping

strategies such as avoiding, seeking social support, accepting responsibility, problem solving and positive reappraisal. The SF – 36 would be prioritised as it is shorter in comparison with the PSI and WCQ.

The complexity of exploring communication is further complicated by the differing communication style of parents, carers and the children they are supporting as well as the different cultural values attributed to mealtimes socially by contrasting cultural groups. One paper explored typical mealtimes in this thesis: a descriptive paper involving six mother-child dyads of children aged from 8 months to 3.05 years (Harding et al, 2012b). This was a descriptive paper which explored the benefits of research into this area. It outlined the importance of what happens in everyday routines as therapy goals are often functional. The paper also raised the notion of risk management in relation to communication strategies as being a “developing idea” which needed further research. The final part of the paper made some suggestions in relation to children with complex needs. Four key areas would need exploration in an attempt to understand the role of communication during mealtimes: 1) language use during the mealtimes of children with complex eating and drinking needs; 2) what supports the child; 3) a focus on the caregiver’s attention, pace and overall strategy management to assist the eating and drinking skills; 4) an evaluation of a child’s independence and choice during the mealtime. It may also be helpful to explore parents’ values, culture and expectations in regards to feeding and communication within meal times.

However, as indicated above, considering communication as a strategy within dysphagia management is complex. In particular, thinking about using communication for a child with learning disabilities remains an issue that requires further in-depth consideration and evaluation. It would be useful to explore the

benefits and disadvantages of verbal prompting, using AAC during a meal, using language to reassure a child, and integrating functional goals within a mealtime, as well as parent and carer views. Although the papers in this thesis have explored some of these questions, the topic is an important one that needs further investigation in order to manage effectively the needs of infants, children and young people with complex feeding, eating and drinking needs.

5.2.5 Measurement and inter-rater reliability within clinical settings

There is a paucity of reliable tools to measure feeding and communication outcomes. The Harding et al (2012a) study was observational, and it would be helpful in future studies to use a tool that has intra – and inter-rater reliability, and which has been used in other studies, such as the Schedule for Oral Motor Assessment (SOMA) (Reilley et al, 1995; Skuse et al, 2000) for eating and drinking development, and the Infant Developmental Inventory (Ireton & Thwing, 1976) for communication development.

The Neonatal Oral Motor Schedule (NOMAS; Meyer Palmer, 1993) was selected to assess infant sucking skills as this is a tool used frequently by SLTs to assess sucking patterns (da Costa et al, 2008). During the three day NOMAS training course, participants gain an inter-rater agreement percentage score of their rating abilities. No other infant assessment requires the assessor to gain a level for inter-rater reliability (da Costa et al, 2008). However, caution is appropriate as the reliability measures were taken on term infants rather than premature infants (da Costa et al, 2008). The NOMAS is still regarded as the main method of assessing infant sucking patterns (da Costa et al, 2010b). However, given the problems that may impact on its reliability as an assessment tool as discussed in the previous section (da Costa et

al, 2008), it may be necessary to consider using a device such as the NTrainer, devised by Finan and Barlow (1988), and used to stimulate non-nutritive sucking in three of the studies mentioned in this thesis (Barlow et al, 2008; 2014; Poore et al, 2008). This might be a better, and more reliable way of measuring sucking as it stimulates the sucking reflex in the same, rhythmic and consistent way, and provides pressure recordings from the stimulated muscle activity in the oral cavity, which can be used to record signs of maturation (Finan & Barlow, 1988). The pulse initiated by the NTrainer remains static and does not alter in relation to infants' responsiveness to having something in the oral cavity (Finan & Barlow, 1988). As a further study would involve a larger number of participants and SLTs gathering data, using this device would increase the validity of the data being collected about sucking patterns.

5.2.6 Accurate identification of infant states

Infant states have not been described as part of the intervention in any of the studies that explored the use of NNS (Bache et al, 2014; Barlow et al, 2008; 2014; Boiron et al, 2007; Boyle et al, 2006; Bragelien et al, 2007; Coker-Bolt et al, 2012; Field et al, 1982; Fucile et al, 2002; 2005; 2011; 2012; Gaebler & Hanzlik, 1995; Hill, 2005; Hwang et al, 2010; Lau & Smith, 2012; Lessen, 2011; Liu et al, 2013; Lyu et al, 2014; Mattes et al, 1996; Measel & Anderson, 1979; Neiva & Leone, 2006; 2007; Pimenta et al, 2008; Poore et al, 2008; Rocha et al, 2007; Rochat et al, 1997; Sehgal et al, 1990; Standley et al, 2010; Yildiz & Arikan, 2012; Zhang et al, 2014). The Harding et al (2014) study did not measure oral readiness using one of the identified checklists discussed in Chapter 4 of this thesis (McCain, 2003; Thoyre et al, 2005). Oral readiness states were assessed using the Als (1986) terms that described each of the states and relied on the lead researcher to identify and model what the stated terms represented. This was chosen as the neonatal staff participating in the project were familiar with

these terms, and referred to infant states using the same vocabulary in the medical notes when recording feeding progress.

Methods of assessing infant readiness remain a challenge. Consistency when identifying infant signs as well as consistency of interpretation can be difficult because of the range of the gestational birth ages of infants. It would be appropriate to consider using one of the infant feeding readiness instruments to evaluate changes in an infant's state. The checklists and assessments available for infant feeding all provide useful guidance, but have limitations also (Jensen et al, 1994; McCain, 2003; Mizuno et al, 2002; Nyquist et al, 1996; Thoyre et al, 2005). There are a range of possible assessments tools available to evaluate infant states, although a systematic review of instruments to assess infant feeding readiness found that none of the tools described met the systematic review Cochrane data base criteria (Crowe et al, 2012). The New-born Individualized Care and Assessment Program (NIDCAP) (Als, 1986) is another tool that could be considered for assessing infant states. It would require staff, rather than parents to assess the infant, as NIDCAP requires a trained and certified health care professional to implement the Assessment of Premature Infant Behaviour (APIB) tool. This observes 91 neonatal behaviours every 2 minutes for 1 hour. However, a systematic review of NIDCAP studies (Ohlsson & Jacobs, 2013) and another study (Ohlsson, 2009) found no evidence that NIDCAP improved the short term medical or long term neurodevelopmental outcomes. In particular, there were no statistically significant differences between groups receiving the NIDCAP intervention compared to those who received the standard neonatal care. Small trends showing better developmental changes were noted at 9 months only, but not at 4, 12, 18 or 24 months. The only significant finding was that infants who received NIDCAP tended to

go home 6 days sooner. This is in contrast to the Als et al (2004) study which reported significantly better neurobehavioral functioning in the frontal and occipital brain regions in groups of infants who had received NIDCAP at 9 months corrected age. The conflicting evidence as highlighted in these studies make it hard to decide to use the NIDCAP observation assessment and indicate that very careful consideration needs to be given to the training needs of those completing any intervention. A future study should consider establishing intra – and inter- rater reliability with the Als (1986) descriptors. This could involve video recordings of infant states rated by different raters to check reliable interpretation, agreement and direct joint observation on a ward round. In addition, it would be important to further critique and discuss within the wider research community the problems related to the accurate reporting of assessments which rely on observation.

5.2.7 Language and communication

In considering longer term follow up measures in language and communication with the developing infants, The Infant Development Inventory (Ireton & Thwing, 1976) as described earlier, would be suitable for the infants at time points of 6 months, 12 months, 18 months and 24 months. This method of assessment has been described as having a good sensitivity in identifying delay, and a fair sensitivity in identifying normal development (Creighton & Suave, 1988). However, the Infant Development Inventory (Ireton & Thwing, 1976) relies on parent reporting. It is highly likely that an inner city sample would include participants whose first language is not English. This could create difficulties in collecting accurate data, and use of an interpreter may inhibit parent reporting. Moreover, the Infant Development Inventory (Ireton & Thwing, 1976) has not been developed with a

premature infant population; at present, there are no measures that are suitable for developing children who have been born early.

If follow up was to be considered beyond 18 months of age, the Very Early Processing Skills (VEPS) assessment (Chiat & Roy, 2007; 2008; 2013; Roy & Chiat, 2004) could be a suitable assessment to be administered when the child was 24 months of age. The skills measured in the VEPS, include phonological (Bishop et al, 1996; Conti-Ramsden et al, 2001; Gathercole, 2006) and socio-cognitive processing (Baldwin 1995; Carpenter et al, 1998; Charman et al, 2003, 2005; Sigman & Ruskin, 1999; Tomasello 1995; Tomasello et al, 1990; Toth et al, 2006). These skills have been focused on, as they are foundation skills for early language development. VEPS has robust sensitivity in that children are correctly identified as having phonological and socio-cognitive processing difficulties, and a high specificity in that children are correctly identified as being within the average range with their phonological and socio-cognitive processing development. This would be an appropriate assessment to use as children who are born prematurely are often considered at risk of language and learning difficulties later on (Woodward et al, 2006).

5.2.8 Future considerations

In relation to NNS, to summarise, a future study should repeat the Harding 2014 protocol to build the evidence base for SLT practice. It should include information on feeding regimes, birth history, neuro-developmental and other needs, family composition, parent backgrounds, parent well-being, expectations and satisfaction measures. Infant participants should be stratified by gestational age and there should be clear randomization and blinding procedures. A multicentre study is recommended with follow-ups at 2, 12, 18 and 24 months. There would need to be

a clear training programme for staff and SLTs implementing the intervention with a pilot study to investigate training effectiveness. Clear protocols for working with parents would also be needed, with assessment and monitoring of their understanding and ability to recognise infant states. In relation to tools, it would be appropriate to consider the use of the NTrainer and VEPS in addition to the NOMAS (Meyer – Palmer, 1993) and Infant Developmental Inventory. It would also be necessary to establish inter- and intra-rater reliability for the ALs (1986) infant state descriptors.

Within clinical practice, mealtimes are a daily event and communication is considered a central part of the management for children with learning disabilities (Table 3.1, p 101 - 106). What is “risk” in relation to managing eating and drinking difficulties through consideration of communication? Examples include misreading the child’s non – verbal communication during a meal, so that poor pacing inhibits effective bolus management, and therefore creates a poor swallow; misinterpreting or missing aspiration signs; working within a set time framework to complete a meal rather than going at a pace that allows for communication exchange, and therefore simultaneously allows for effective clearance in the pharyngeal tract. The Compensatory and Environmental dysphagia strategies highlighted in Table 3.1 Chapter 3 (pp 101 -106) focus largely on texture modifications, positioning, behavioural strategies, with few mentioning the importance of communication during mealtimes. Independence during mealtimes can enable children with learning disabilities to control the speed and pace of the meal; importantly, by setting the pace themselves, a bolus of food can be more effectively managed before taking the next mouthful (Pinnington & Hegarty, 2000). This study focused on consistency of food presentation through use of a robotic arm. It was hypothesised

that the consistency established as led by the child could help in the maintenance of a stable posture and improved oral motor control. This could help motor learning with the child utilizing oral motor skills they might not use when being supported by an adult. Differences in motor control between Intervention and Control periods were assessed. Oral motor skills were not maintained in Control periods. It would be interesting to see if the children managed to prevent greater numbers of choking episodes by managing their own food bolus sizes. It would also be interesting to compare the same sample of children being supported to eat by familiar carers and to see if verbal prompting made any difference. Non-verbal risk signs such as choking could be evaluated across three settings; independent feeding, being supported to eat with verbal prompts and the usual method of being given food.

Developing communication in meal times is explored further in Harding et al (2011), which looked at the implementation of AAC. One participant (K) achieved significant changes in communication in mealtimes but not in music or free play. Some reflection is given to why K did improved significantly in mealtimes, in particular, the specification of choice. His learning support assistant during the mealtime used photographs to support choice, and because of the tangible nature of food, this is where the best outcome was achieved. In future research it may be useful to examine the environmental contexts for similar children in a cohort study. This could be longitudinal with an emphasis on following the same research protocol with a larger group. An ABA (A = baseline measures/ period of no treatment; B = intervention) design could be considered so that no participants are excluded, but rather all have a period of intervention followed by a non-intervention period. Participants could be assessed using the Functional Communication Profile (Kleiman, 2003), the Checklist of Communication Competencies (Bloomberg et al, 2009), an

assessment of cognitive skills, monitoring of responses to commands across settings and over time, and monitoring of staff strategy use.

5.3 Impact of the range of studies presented in this thesis

The impact of the work presented in this thesis will now be summarised. Although this work covers a wide range of topics, there are some key aspects which link the papers and where the value of this work in relation to its impact can be evaluated. Unlike the majority of studies set out in the evidence Table 3.1, p101 – 106, the studies in this thesis all represent an attempt to examine specific techniques and methods currently used by SLTs. Very few studies examine current SLT practice when working with infants, children and young people with feeding, eating and drinking difficulties.

The studies included in this thesis have contributed to the evidence base in a number of ways including:

- Highlighting the importance of checking the knowledge, skills and training of significant others in delivering therapy strategies, e.g. positioning, texture modification, etc., and making proposals as to how to extend this (Harding & Halai, 2009; Harding & Wright, 2010). In contrast with other studies that focus on the specific detail of therapy programmes (Chadwick et al, 2002; 2003; 2006; Crawford et al, 2007), this study evaluated the understanding that school staff had about dysphagia. It also attempted to gain some insight into staff knowledge about why some therapy strategies were recommended.
- Developing a collaborative therapy plan involving structured and planned use of AAC, deliverable in meaningful contexts to the children

involved (Harding et al, 2010a). This paper also identified the number of sessions needed to assess and implement such a programme. It has contributed to the evidence base by identifying specific components of therapy strategies to implement, the impact of collaborative working and the time required to achieve change.

- Describing observations and analysis of communication during typical mealtimes in a small sample (Harding et al, 2012b), in contrast with the use of more directive and unhelpful language styles which did not support eating and drinking skills (Harding et al, 2010c). This issue is complicated as it involves many factors as explained previously. Some of the papers in this thesis have initiated discussion about communication and mealtimes and highlighted it as an area that requires further understanding and investigation (Harding & Halai, 2009; Harding et al, 2010a; 2010c; 2012b).
- Designing a simple method of evaluating change for children who have progressive disorders: a study using everyday tools such as straws to evaluate and record changes in function over age and gender within a typical group of children has been completed (Harding & Aloysius, 2011). This paper, and the additional supporting material in Chapter 2, discusses the importance of differentiating more clearly between children who have congenital compared to progressive disorders and adapting assessments accordingly. This is part of a wider lifespan project which is exploring the assessment and monitoring of progressive disorders using simple clinical methods (Harding & Aloysius, 2011; Harding et al, 2014).
- Devising a protocol for NNS based on current clinical practice in the UK, and presenting it in a format which can be replicated, and which has a

clear rationale for its use (Harding, 2009; Harding et al, 2006; 2012a; 2014; 2015). The studies by the author include use of the NOMAS (Meyer – Palmer, 1993) to measure sucking skills, which the other NNS papers do not do. This additionally contributes to the evidence base as it discusses data collected from infants with congenital difficulties who are not included in papers published on NNS (Harding et al, 2015). All these works raise further areas of research, in particular, addressing the identification of infant states and oral readiness signs as part of using NNS therapeutically.

Many of the papers published and cited in this work make suggestions for further investigations. The goal is to continue with these investigations to answer more of these questions and therefore contribute to providing a more substantial and evidence based range of strategies to improve the quality of life for infants, children and young people with dysphagia. The title of this thesis is "The unmet needs of infants, children and young people with dysphagia". The work contained here has highlighted that the evidence to support assessment and intervention for this population, particularly those children with congenital neurological disorders is still small, but developing. It is important that congenital neurological disorders are further researched both in terms of neuroplasticity as well as understanding the conditions themselves more clearly so that effective and realistic therapy approaches can be established for children with learning disabilities and additional feeding, eating and drinking needs. Studies that describe and investigate children with these problems are small in number, and the definition of "dysphagia" is varied with studies focusing on only some or all phases of the swallow (Rommel et al, 2003). These differences can make generalization of strategies difficult. A clearer definition

of the paediatric population where the congenital, progressive and acquired needs are considered as separate entities would help improve understanding of which strategies to use with which children. The development of more valid and reliable assessment materials to provide more accurate measures would also be valuable. Better designed studies, such as randomized controlled trials could provide further important information, and a multi – disciplinary approach to research may be a way of linking more of the neurological and physiological aspects discussed in this thesis. Future studies need to investigate strategies that are currently used with the additional development of therapy approaches that are meaningful, useful and easily integrated into daily activities. The environment is a crucial aspect of intervention, and considering everyday adjuncts such as communication as part of mealtime management can only serve to improve the mealtime experience for infants, children and young people with dysphagia.

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APPENDICIES

APPENDIX 1 Gag Assessment Search Results

Results of search for studies re: testing a gag reflex as part of clinical assessment. Terms used: [gag reflex / assessment / dysphagia / oral – motor assessment]

medication, without functional evidence, probably by a lack of collaboration between the physician and the endoscopist who had not swallowing. This case illustrates the importance of knowing the different mechanisms underlying dysphagia in psychiatric patients, a gastroenterologists to establish a precise diagnosis of the disorder, and adapt the therapy. (c) L'Encephale, Paris, 2011.

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Record 3 of 10

Title: Management of foreign bodies in the airway and oesophagus

Author(s): Rodriguez, H (Rodriguez, Hugo); Passali, GC (Passali, Giulio Cesare); Gregori, D (Gregori, Dario); Chinski, A (Chinsk Botto, H (Botto, Hugo); Nieto, M (Nieto, Mary); Zanetta, A (Zanetta, Adrian); Passali, D (Passali, Desiderio); Cuestas, G (Cuestas, Source: INTERNATIONAL JOURNAL OF PEDIATRIC OTORHINOLARYNGOLOGY Volume: 76 Pages: S84-S91 DOI: 10.1186/1875-2875-76-S1-1 Published: MAY 14 2012

Abstract: Background: Ingestion and/or aspiration of foreign bodies (FB) are avoidable incidents. Children between 1 and 3 years a exploration of the environment through the mouth, lack of molars which decreases their ability to properly chew food, lack of cogni and inedible objects, and tendency to distraction and to perform other activities, like playing, whilst eating. Most FBs are expelled sp impacts the upper aerodigestive tract. Approximately 80% of children's choking episodes are evaluated by pediatricians. The sympto simulate different paediatric diseases such as asthma, croup or pneumonia, delaying the correct diagnosis.

Symptoms: There are three clinical phases both in aspiration and in ingestion of FBs: initial stage (first stage or impaction or FB) sh coughing, obstruction of the airway (AW), occurring at the time of aspiration or ingestion. These signs calm down when the FB lodg or asymptomatic phase). Complications occur in the third stage (also defined as complications' phase), when the obstruction, erosio abscess or fever (FB in AW), or dysphagia, mediastinum abscess, perforation or erosion and oesophagus (FB in the oesophagus). Th actually represent a complication of impaction of FB.

Locations and management: Determining the site of obstruction is important in managing the problem. The location of the FB depen position of the person at the time of aspiration. Determining the site of obstruction is important in managing the problem. Larynx an in children under 1 year. They are linked with the most dangerous outcomes, complete obstruction or rupture. Bronchus is the prefer Esophageal FBs are twice more common than bronchial FBs, although most of these migrate to the stomach and do not require endc following the traditional steps, with a particular stress on history and radiological findings as goal standards for the FB retrieval. Th esophageal FBs is endoscopic removal. Endoscopy should be carried out whenever the trained personnel are available, the instrumer been tested. The delay in the removal of FBs is potentially harmful. The communication between the endoscopist and the anaesthetic establish the plan of action; full cooperation is important and improves the outcome of endoscopy.

Conclusions: Ingestion and or aspiration of FB in children are multifactorial in their aetiology, in their broad spectrum of different r response of each patient to the treatment. Prevention remains the best treatment, implying an increased education of parents on age-a strict industry standards regarding the dimensions of toy parts and their secure containers. (C) 2012 Published by Elsevier Ireland Lt

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Record 4 of 10

Title: Safe initiation of oral diets in hospitalized patients based on passing a 3-ounce (90 cc) water swallow challenge protocol

Author(s): Leder, SB (Leder, S. B.); Suiter, DM (Suiter, D. M.); Warner, HL (Warner, H. L.); Acton, LM (Acton, L. M.); Siegel, MD Source: QJM-AN INTERNATIONAL JOURNAL OF MEDICINE Volume: 105 Issue: 3 Pages: 257-263 DOI: 10.1093/qjmed/

Abstract: Objective: To determine the short-term success of recommending specific oral diets, including drinking thin liquids, to ac dysphagia based on passing a 3-ounce water swallow challenge protocol.

Design: Prospective single group consecutively referred case series.

Setting: Large, urban, tertiary care, teaching hospital.

Participants: 1000 hospitalized patients.

Intervention: 3-ounce (90 cc) water swallow challenge protocol.

Measurements: Specific diet recommendations and volume (in cc) of liquid ingested at the next day's meal 12-24 h after passing a 3-electronically from oral intake information entered on each participant's daily care logs. Eating and drinking success, clinically evide ordering the recommended diet were recorded. Care providers were blinded to the study's purpose.

Results: Of 1000 patients, 907 met the inclusion criteria of stable medical, surgical or neurological conditions 12-24 h after passing protocol. All 907 were both eating and drinking thin liquids successfully and without overt signs of dysphagia. Median volume of li (IQR), 240-460]. Specific diet recommendations were followed with 100% accuracy.

Conclusions: A 3-ounce water swallow challenge protocol successfully identified patients who can be safely advanced to an oral die signs of aspiration within 12-24 h of testing. Importantly, when a clinical 3-ounce challenge protocol administered by a trained prov recommendations, including drinking thin liquids, can be made safely and without the need for additional instrumental dysphagia tes

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Record 5 of 10

Title: Clinical Experience Using the Mann Assessment of Swallowing Ability for Identification of Patients at Risk for Aspiration in
Author(s): Gonzalez-Fernandez, M (Gonzalez-Fernandez, Marlis); Sein, MT (Sein, Michael T.); Palmer, JB (Palmer, Jeffrey B.)
Source: AMERICAN JOURNAL OF SPEECH-LANGUAGE PATHOLOGY **Volume:** 20 **Issue:** 4 **Pages:** 331-336 **DOI:** 10.1016/j.jfls.2011.07.001
 NOV 1 2011

Abstract: Purpose: To determine the clinical performance characteristics of the Mann Assessment of Swallowing Ability (MASA) in a videofluoroscopic swallowing study [VFSS] in a mixed population.

Method: We selected 133 cases clinically evaluated using MASA and VFSS from January through June 2007. Ordinal risk rating (ORR) was evaluated as predictors of aspiration on VFSS. To account for missing items, the maximum possible score was determined and a weighted ORR was calculated. We used receiver operating characteristic (ROC) analysis to compare the sensitivity and specificity of ORR and TNS for predicting aspiration. Results: VFSS identified 51 (38.4%) aspirators, while ORR identified 54 (40.6%) as probable or definite aspiration and TNS 19 (14.3%). ROC analysis demonstrated an area under the curve of 0.74, 95% CI [0.66, 0.82], for ORR and 0.51, 95% CI [0.41, 0.61], for TNS. ORR is better at predicting aspiration on VFSS than the numeric score.

Conclusion: In this sample, the subjective ORR had good predictive ability, while the percentage TNS failed to predict aspiration on VFSS. ORR is a better predictor for a patient's aspiration risk in this population.

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PubMed ID: 21813822

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Record 6 of 10

Title: Oral sensorimotor function for feeding in patients with tetanus

Author(s): Mangilli, LD (Mangilli, Laura Davison); Sassi, FC (Sassi, Fernanda Chiarion); Dos Santos, SD (Dos Santos, Sigrid De Souza Andrade, Claudia Regina)

Source: ACTA TROPICA **Volume:** 111 **Issue:** 3 **Pages:** 316-320 **DOI:** 10.1016/j.actatropica.2009.05.015 **Published:** SEP 2009

Abstract: Tetanus still remains a significant health problem in developing countries; it is a serious disease with a high mortality rate. The purpose of this study was to characterize the oral sensorimotor function for feeding in patients with tetanus. Thirteen patients clinically diagnosed with tetanus at December of 2005 and May of 2007 underwent a screening test for dysphagia, involving the assessment of clinical features and 2 sensorimotor function for feeding in these patients is severely compromised, with the exception for the clinical feature of palate elevation and swallowing test. The factor analysis indicated that the evaluation of tongue movement change in the oromotor examination is important in the water swallowing test, thus suggesting that oral feeding might be unsafe. When looking at developing countries, the prolonged stay in hospital by many patients with tetanus places extra demands on an already stretched healthcare budget. Intervention by a speech pathologist can reduce as well as the number of re-admissions due to complications. (C) 2009 Elsevier B.V. All rights reserved.

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PubMed ID: 19481999

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ISSN: 0001-706X

Record 7 of 10

Title: State of the art in aspiration assessment and the idea of a new non invasive predictive test for the risk of aspiration in stroke

Author(s): Kolb, G (Kolb, G.); Broker, M (Broeker, M.)

Source: JOURNAL OF NUTRITION HEALTH & AGING **Volume:** 13 **Issue:** 5 **Pages:** 429-433 **DOI:** 10.1007/s12603-009-009-0

Abstract: Dysphagia is a common but severe complication in acute stroke. New bedside tests are necessary to assess the risk of aspiration but they must be completed by evaluated instruments.

We evaluated the prognostic validity of the recognition of forms (rf) test related to the assessment by speech and language therapists. Double blinded screening tests.

Geriatric department of general hospital.

50 patients with acute stroke admitted consecutively.

All patients were assessed by SLT, mini mental status test, short test for assessing deficits of memory and attention and abilities of daily living twice with a two-week interval.

Assessment by SLT demonstrated aspiration in 29 of 50 patients. 18 patients failed the rf-test, giving a specificity of 90% (positive predictive value 59%). 5 of 7 patients with aspiration pneumonia failed the test. Test-retest-correlation was 0,827. Performance to results of the activities of daily living-test.

Bedside tests to exclude aspiration in patients with acute stroke are necessary. No test so far combines high sensitivity with acceptable specificity. The rf-test has a high specificity while sensitivity is low. On behalf of good predictivity rf-test may be an interesting supplement to be a candidate for more extended studies.

Accession Number: WOS:000266038100005

PubMed ID: 19390749

ISSN: 1279-7707

Record 8 of 10

Title: Bedside screening tests vs. videofluoroscopy or fibreoptic endoscopic evaluation of swallowing to detect dysphagia in patient review

Author(s): Bours, GJ (Bours, Gerrie J. J. W.); Speyer, R (Speyer, Renee); Lemmens, J (Lemmens, Jessie); Limburg, M (Limburg, Ma

Source: JOURNAL OF ADVANCED NURSING **Volume:** 65 **Issue:** 3 **Pages:** 477-493 **DOI:** 10.1111/j.1365-2648.2008.0491:

Abstract: Bedside screening tests vs. videofluoroscopy or fibreoptic endoscopic evaluation of swallowing to detect dysphagia in patient review.

This paper is a report of a systematic review conducted to determine the effectiveness and feasibility of bedside screening methods for neurological disorders.

Dysphagia affects 22-65% of patients with neurological conditions. Although there is a large variety of bedside tests to detect dysphagia, their psychometric properties and are feasible for nurses to use.

An electronic database search was carried out using Medline (PubMed), Embase, CINAHL, and PsychLit, including all hits up to July 2008. Sensitivity, specificity, diagnosis, and screening. The methodological quality of included studies was assessed.

Thirty-five out of 407 studies were included in the review. Eleven studies with sufficient methodological quality revealed that trial swallow tests with different viscosities led to sensitivities ranging from 27% and 85% and specificities between 63% and 88%. Trial swallow tests with different viscosities led to sensitivities ranging from 57% to 82%. Combining water tests with oxygen desaturation led to sensitivities between 73% and 98% and specificities between 63% and 88%. As abnormal gag, generally had low sensitivity and specificity.

A water test combined with pulse oximetry using coughing, choking and voice alteration as endpoints is currently the best method to detect dysphagia. Further research is needed to establish the most effective standardized administration procedure for such a water test, in addition to a trial swallow to detect silent aspiration.

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PubMed ID: 19222645

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ISSN: 0309-2402

Record 9 of 10

Title: Embolic internal auditory artery infarction from vertebral artery dissection

Author(s): Choi, KD (Choi, Kwang-Dong); Chun, JU (Chun, Jong-Un); Han, MG (Han, Moon Gu); Park, SH (Park, Seong-Ho); Kim, YJ (Kim, Young-Joon); Lee, JH (Lee, Jong-Ho); Park, SH (Park, Seong-Ho); Ki

Source: JOURNAL OF THE NEUROLOGICAL SCIENCES **Volume:** 246 **Issue:** 1-2 **Pages:** 169-172 **DOI:** 10.1016/j.jns.2006.07.010

Abstract: A 51-year-old man developed sudden vertigo, right hearing loss and dysphagia. Examination revealed right Horner syndrome, right nystagmus, right central type facial palsy, dysarthria, reduced soft palate elevation without gag reflex, left hypesthesia, right dysmetria, and right caloric tests documented right sensorineural hearing loss and canal paresis. Brain MRI and cerebral angiography documented right lateral vertebral artery dissection, without involvement of other parts of the brainstem supplied by the anterior inferior cerebellar artery (AICA). This study suggests a possible mechanism of isolated vertigo or hearing loss from labyrinthine infarction. (c) 2006 Elsevier B.V. All rights reserved.

Accession Number: WOS:000238625800026

PubMed ID: 16580695

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ISSN: 0022-510X

Record 10 of 10

Title: Identification of a simple screening tool for dysphagia in patients with stroke using factor analysis of multiple dysphagia variables

Author(s): Nishiwaki, K (Nishiwaki, K); Tsuji, T (Tsuji, T); Liu, MG (Liu, MG); Hase, K (Hase, K); Tanaka, N (Tanaka, N); Fujiwara, M (Fujiwara, M);

Source: JOURNAL OF REHABILITATION MEDICINE **Volume:** 37 **Issue:** 4 **Pages:** 247-251 **DOI:** 10.1080/1650197051002561111

Abstract: Objective: To identify a most useful and simple clinical screening tool to predict videofluoroscopic aspiration in patients with stroke. Design: Factor analysis of multiple dysphagia variables and sensitivity and specificity testing with chi-square test.

Patients: Sixty-one consecutive stroke patients with symptoms suggestive of dysphagia admitted to a university hospital and its affiliated hospital. Methods: Factors were extracted from 6 oromotor examinations (lip closure, tongue movement, palatal elevation, gag reflex, voice, and swallow screen tests (saliva swallowing test and our modified water swallowing test using 30 ml of water) and 4 parameters evaluated.

Sensitivity and specificity of each dysphagia-related variable was determined against aspiration in a videofluoroscopic swallow study. Results: Factor analysis revealed that cough/voice change in the water swallowing test and aspiration on videofluoroscopic swallow study were the most important variables. Chi-square analysis showed that cough/voice change in the water swallowing test was the only variable that was significantly associated with aspiration in a videofluoroscopic swallow study, with a sensitivity of 72% (95% CI: 61-83%) and a specificity of 67% (CI: 55-79%) as a predictor of aspiration (p<0.001).

Conclusion: We recommend our modified 30 ml water-swallowing test as a useful single task-screening tool to detect aspiration.

Accession Number: WOS:000230597100009

PubMed ID: 16024482

ISSN: 1650-1977

PubMed ID: 9270438**ISSN:** 0003-4894**Record 5 of 6****Title:** Palatal and pharyngeal reflexes in health and in motor neuron disease**Author(s):** Hughes, TAT (Hughes, TAT); Wiles, CM (Wiles, CM)**Source:** JOURNAL OF NEUROLOGY NEUROSURGERY AND PSYCHIATRY **Volume:** 61 **Issue:** 1 **Pages:** 96-98 **DOI:** 10.1136/jnnp-2008-018002

Abstract: Palatal and pharyngeal sensation and motor responses, and volitional palatal movement, were tested in 171 healthy adults. In healthy adults palatal and pharyngeal sensation and volitional palatal elevation were present in all; the palatal and pharyngeal motor responses were more easily elicited in older subjects (1.1%) and seven (4.1%) subjects respectively. Pharyngeal motor responses were more easily elicited in older subjects than in younger subjects. Eye watering and retching were the most common accompanying features. In 57 normal subjects tested on five occasions the stimulus required to elicit the motor responses within subjects: in none of four subjects (7%) who initially had absent pharyngeal motor responses were more easily elicited in patients with motor neuron disease than in matched normal subjects; within motor responses elicited by tongue depression were associated with the symptom of food or drink ((going down the wrong way)" > 10 ml per swallow (ml) and swallowing capacity (ml/s). Volitional palatal elevation was absent in five patients (11.6%). In six of eight patients repeatedly (on between two and seven occasions) the palatal and pharyngeal responses were elicited with the same stimulus on each occasion. Pharyngeal sensation and motor responses should be present although considerable variation occurs in the stimulus required. In patients with impaired swallowing are associated with a brisk rather than a depressed pharyngeal response.

Accession Number: WOS:A1996UW07200022**PubMed ID:** 8676170**ISSN:** 0022-3050**Record 6 of 6****Title:** THE GAG REFLEX AND ASPIRATION - A RETROSPECTIVE ANALYSIS OF 120 PATIENTS ASSESSED BY VIDEOFLUOROSCOPY**Author(s):** BLEACH, NR (BLEACH, NR)**Source:** CLINICAL OTOLARYNGOLOGY **Volume:** 18 **Issue:** 4 **Pages:** 303-307 **DOI:** 10.1111/j.1365-2273.1993.tb00853.x

Abstract: An absent gag reflex is often employed clinically as an indicator of aspiration risk. Dysphagia clinic records of 120 neurologically impaired patients, followed by videofluoroscopy, were retrospectively analysed to ascertain if any link between an absent gag reflex and aspiration or laryngeal overspill was demonstrated. No association between an absent gag reflex and aspiration or laryngeal overspill was found (Mann-Whitney U-test: 2-tailed, p = 0.12). Laryngeal overspill was seen in 34/120 patients (28%), and these were more closely related to aspiration risk (Mann-Whitney U-test: 2-tailed, p = 0.001). An absent gag reflex is not a useful predictor of aspiration, and assessment of the gag reflex should not be relied upon to predict airway safety. However, indirect speech therapy assessment of the dysphagic patient.

Accession Number: WOS:A1993LW62400014**PubMed ID:** 8877191**ISSN:** 0307-7772Web of Science™
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**APPENDIX 2 Glossary (Table 4.1) for Chapter 4, Table 4.2,(Studies that use non
- nutritive sucking to support oral readiness and feeding with infants
mentioned in this chapter 4)**

Table 4.1 – Terminology used in Table 4.2

CLD = Chronic lung disease

d/c = discharge

FOF = full oral feeding

GA = gestational age

Gp = group

IOF = introduction of oral feeding

NG = Nasogastric tube feeds

NICU = neonatal intensive care unit

NNS = nonnutritive sucking

NOMAS = Neonatal oral motor assessment schedule

OS = Oral stimulation

PIOMI = Premature Infant Oral Motor Intervention

PMA = post menstrual age

RCT = randomized controlled trial

RDS = Respiratory distress syndrome

SD = standard deviation

Stim = stimulation

T/K = tactile / kinaesthetic

Usual exclusion criteria = infants cannot participate if they have chronic medical problems , congenital abnormalities or chronic medical issues such as Intraventricular haemorrhages III or IV, periventricular leukomalacia or necrotizing enterocolitis

wk = week

Table 4.2 Studies that use non – nutritive sucking to support oral readiness and feeding with infants mentioned in this chapter

Study	Participants (and setting)	Design of study	NNS programme	Aims	Outcomes used	Findings
Bache et al, (2014)	86 preterm infants born between 26 and 33 weeks GA. Usual exclusion criteria. Study carried out in a neonatal setting.	Random allocation to Experimental – NNS or Control Group.	Fucile et al programme (Table 4.2) x 1 daily, 10 days before introduction of FOF at 34 weeks.	To evaluate the benefits of oral stimulation in relation to days to FOF, length of hospital stay and the impact on breastfeeding skills.	1. Days to FOF. 2. Length of hospital stay. 3. Development of breastfeeding.	1. There were no significant differences between the groups with days to FOF. 2. There were no significant differences between the groups with length of hospital stay. 3. The infants who received the NNS programme had a significantly higher rate of successful breast feeding.
Barlow et al, (2008)	31 premature infants, mean GA for Control gp (n = 11) = 29.24±3.10 days, Experimental gp (n = 20) = 29.11±2.32 days. All enrolled at 34 weeks GA. Usual exclusions for poor health, but included in the study if	Prospective cohort study. Control group compared to an Experimental group.	NNS provided to the Experimental group via use of an NTrainer which provided orocutaneous stimulation for 3 minutes for 3 - 4 x daily at 34 weeks for 10 days (@12-24 minutes stimulation per day), or	To evaluate the effects of the NTrainer on NNS patterns for infants slow to develop early oral pre-feeding skills.	1. Total oral compressions per minute. 2. Development of NNS bursts. 3. Development of NNS cycles. 4. Suck cycles per burst. 5. Ratiometric measure % of total mouthing events.	1. Significant difference with higher number of total oral compressions/minute in the Experimental group (149.5% increase compared to the Control = 26.2%). 2. Significantly higher number of NNS bursts in the Experimental group (175.6% increase, compared to the Control = 38.7%). 3. Significantly higher number of NNS cycles in the Experimental group (120.4% compared to the Control group = 15.2%). 4. Significantly higher number

Study	Participants (and setting)	Design of study	NNS programme	Aims	Outcomes used	Findings
	not able to demonstrate a consistent NNS pattern. Study carried out in a neonatal setting.		until the infant achieved FOF. Infants received the intervention when they started to show oral readiness signs @ 34 -38 PMA in both groups, and received the intervention for around 7 -10 days.			of cycles per burst in the Experimental group (120.6% compared to Control = 8.2%). 5. Infants in the Experimental group showed a significantly higher % of mouthing actions at 120.4 % (Control, 15.2%). *Days to FOF not recorded, as main emphasis on changes in NNS bursts and cycles. However, infants started the programme 34 – 38 weeks GA in the Experimental group, and 34 – 38 weeks GA in the Control group, and time recorded to achieve FOF with all infants was 7 -10 days.
Barlow et al. (2014)	160 premature infants born between 23 – 36 weeks GA, including healthy premature infants (N = 48), 23 Experimental, 25 Control Group, RDS infants (N = 38), 18 Experimental group, 20 Control	Random allocation to Experimental – NNS or Control Group within each subgroup of healthy premature infants, RDS and CLD infants.	NNS provided to the Experimental group via use of an NTrainer which provided orocutaneous stimulation for 3 minutes for 3 - 4 x daily at 34 weeks for 10 days (@12-24 minutes stimulation per day), or until the	To evaluate the effects of the NTrainer on NNS patterns for infants who are typical premature infants compared to those with RDS and CLD who are slow to develop early oral pre-feeding skills.	1. Development of NNS patterns. 2. Length of hospital stay.	1. All infants, i.e. healthy premature infants, RDS and CLD infants who received the intervention had significantly more mature NNS patterns compared to the Controls in each group. RDS and CLD infants showed the most significant gains in NNS performance. 2. Healthy premature infants went home more quickly than the other 2, but CLD infants went home significantly sooner (by 2.5 days) compared to the RDS infants. *Days to FOF not recorded, as main emphasis on changes in

Study	Participants (and setting)	Design of study	NNS programme	Aims	Outcomes used	Findings
	group) and CLD infants (N = 74) Experimental group, 74, and Control group 42. Usual exclusions for poor health, but included CLD and RDS infants. Study carried out in a neonatal setting.		infant achieved FOF. Infants received the intervention from @ 33 -35 weeks PMA, i.e. when they started to show signs of oral readiness, and received the intervention between 7 - 10 days.			NNS bursts and cycles. However, infants started the programme 34 – 38 weeks GA in the three Experimental groups, and 34 – 38 weeks GA in all three Control groups, and time recorded to achieve FOF with all infants was 7 -10 days.
Bernbaum et al, (1983)	30 premature infants with appropriate weight for gestational age with a birth weight < 1.5kg. 15 infants in an Experimental group receiving NNS, and 15 infants in a Control group. Usual	Randomized – matched pairs design. Experimental group received a pacifier during tube feeds only and the Control group received no pacifier stimulation during tube feeds.	Pacifier given to Experimental group infants when showing signs of oral readiness (Experimental group, 31.5±1.3 GA) until FOF achieved. No details given for how many sucks were expected, or	To determine if NNS by means of a pacifier influences sucking behaviour. To determine if NNS influences gastrointestinal functions such as transit time, time for oral feedings and weight gain (NNS might stimulate lingual lipase and	1. Weight, length, head circumference growth 2. Gastrointestinal transit time. 3. Sucking pressures. 4. Days for transition to oral feeds 5. Length of hospital stay.	1. Significant difference in weight gain, but not caloric intake. No significant differences noted in length or head circumference. 2. Significant difference in transit time, with Experimental group infants opening their bowels more quickly (p <0.05). 3. Sucking pressures significantly greater from 34 to 38 weeks in the Experimental Group. Experimental group infants developed a more organized pattern of sucking with more sucks per burst. 4. Experimental group infants

Study	Participants (and setting)	Design of study	NNS programme	Aims	Outcomes used	Findings
	exclusion criteria. Study carried out in a neonatal setting.		if the pacifier had to be used in a specific way.	augment fat absorption and therefore help energy balance).		took their feeds significantly more rapidly and took 6 days less to achieve FOF (p < .001). 5. NNS infants spent 7 days less in hospital. Significant p < .05.
Bingham et al, (2010)	51 premature infants without additional disabilities aged 25 -34 weeks PMA. One NNU. Usual exclusion criteria.	Prospective observation study.	Pacifiers are used with a transducer to measure suck compressions 10 minutes before a tube feed when infants show oral readiness signs. The pacifier does not have to be moved by a practitioner in a specific way.	Evaluation of using NNS as a predictor of oral feeding performance.	1. PMA at implementation of oral feeding. 2. PMA at FOF. 3. Transition time from IOF to FOF.	1. Investigation began when infants were 34.5 weeks \pm 1.1 weeks (range 32.9 – 38.1 weeks). 2. FOF median PMA 35.3 weeks. 3. Transition time = 15.8 \pm 6.6 days (range 5.0 - 38.0). * Higher NNS sequences predicted quicker transition to FOF.
Boiron et al, (2007)	43 pre term infants, 29 - 34 weeks GA. Started programme aged 32 – 34 weeks GA. Usual exclusion criteria.	Random allocation to one of four groups: 1) oral stim + support; 2) oral stim only; 3) support; 4) control.	NNS programme = 12 minutes oral stimulation as on the Fucile programme (Table 4.2) but only the	Comparison of the efficacy of oral stim and oral support, either in combination or not in relation to the development of NNS and	1. Mean maximum NNS pressure in mmHg. 2. Mean sucking activity (% time in sucking). 3. Time to full oral feeding.	1. Significant difference in NNS sucking pressures with higher mean NNS pressures for the Oral stim + oral support group and the Oral stim group compared to the other 2 groups. 2. Mean sucking activity significantly higher in the Oral stim + oral support group and

Study	Participants (and setting)	Design of study	NNS programme	Aims	Outcomes used	Findings
	Study carried out in a neonatal setting.		first 12 minutes. Administered x 1 daily, 30 minutes before a tube feed 10 -14 days pre cessation of tube feeds.	transition to FOF.		the Oral stim group compared to the other 2 groups 3. Transition to FOF was achieved as follows: a) Oral stim + oral support = 5.6 days (start of oral feeding 33.3 weeks PMA; FOF = 36.6 PMA). b) Oral support = 6.5 days (start of oral feeding 33.3 weeks PMA; FOF = 36.7 PMA). c) Oral stim = 7.8 days (start of oral feeding 33.4 weeks PMA; FOF = 37.2 PMA). d) Control = 11.2 days (start of oral feeding 33.1 weeks PMA; FOF = 36.7 PMA). Both oral stim and oral support enhance transition to FOF in the shortest time.
Bragelien et al, (2007)	36 premature infants, mean GA Group 1 = 32.2 weeks (SD 2.4); Group 2 = 31.4 weeks (SD 2.3). PMA at study entry Group 1 = 35.1 weeks (SD 0.8) versus Group 2 = 34.4 weeks (SD 0.9)	Random allocation to Oral stimulation or Control Group.	Based on Vojta's technique oral motor programme and whole body massage, 15 minutes x 1 daily; infants under 36 weeks GA and showing oral readiness signs.	To study the effect of stimulation of sucking and swallowing on weaning from nasogastric (NG) feeding and length of hospital stay in premature infants.	1. Discontinuation of NG feeds. 2. Days taken to discharge home.	1. The stimulation programme did not result in earlier weaning from NG feeding (Group 1 = 36.8 weeks (SD 0.9), Group 2 = 36.3 (SD 0.9). PMA of Experimental group infants at start of study = 36.8 weeks, and FOF achieved at 37.8 weeks PMA; PMA of Control group infants at start of study = 37.8 weeks PMA, and FOF achieved at 36.3 weeks PMA. 2. The Experimental group were not discharged earlier compared to the Control

Study	Participants (and setting)	Design of study	NNS programme	Aims	Outcomes used	Findings
	Usual exclusion criteria. Study carried out in a neonatal setting.					group (Group 1 = 37.8 weeks (SD 0.9), Group 2 = 37.7 weeks (SD 1.3).
Coker-Bolt et al. (2012)	28 infants born with uni-ventricle anatomy who require surgery shortly after birth, thus experiencing delays in the initiation of oral feeding. All infants were term and were aged between 37 - 40 weeks GA. Study carried out in a neonatal setting.	Quasi-experimental group design to compare two groups of infants, Group 1 = Oral stim; Group 2 = Control.	NNS programme as in Table 4.2 administered x 1 only before surgery, then immediately post surgery, 6 days a week, x 1 day. Unclear when in the feeding regime the NNS programme occurs.	To determine the effects of oral motor stimulation on infants born with complex uni-ventricle anatomy who required surgery shortly after birth.	1. Length of time to reach full bottle-feeds. 2. Length of hospital stay.	1. Infants in the Oral stim treatment group bottle fed 2 days earlier than the Control group. Experimental group infants took 8.3 days (mean, SD = 3.9) to achieve FOF; Control group infants took 6.3 days (mean, SD = 4.5), but this difference was not significant. 2. Infants in the Experimental group were hospitalized for a mean of 28.6 days and infants in the comparison Control group for a mean of 35.3 days. This was a significant difference.
Di Pietro et al. (1994)	36 pre term infants, 29 -34 weeks GA. Usual exclusion	Cross over random allocation to pacifier use or no pacifier	When an infant showed OR signs, a pacifier was	To assess the effects of NNS on behavioral and physiological	1. Changes in infant state 2. Defensive behaviors during NGT. 3. Physiologic data.	1. Changes in infant state – affected significantly by use of a pacifier. 2. Defensive behaviors during NGT significantly less with a

Study	Participants (and setting)	Design of study	NNS programme	Aims	Outcomes used	Findings
	criteria. Study carried out in a neonatal setting.	use Over a period of 2 days once infants showed oral readiness signs.	placed in the infant's mouth 15 minutes before and 15 minutes after a tube feed. Sucking was encouraged by an adult rubbing the infant's tongue to assist sucking movements.	states during tube feeding.		pacifier. 3. Physiologic data, NNS has no significant impact on physiologic states.
Field et al (1982)	57 premature infants, Gestational age < 35 weeks Birth weight < 1.8kg. Experimental group, infants aged 32 ± 2.2 GA; Control group, infants aged 32 ± 1.18 GA. Usual exclusion criteria. Study carried out in a neonatal	Randomized, stratified. Experimental group (N = 30): Pacifier during all tube feeds Control group (N = 27): No pacifier during tube feeds Both groups: Pacifier offered between feeds.	Pacifier given for all tube feeds. No set specific protocol for administering . Pacifier provided when infants started to show OR signs.	1. Assess the clinical benefits of NNS on reducing NG feeds. 2. To assess later bottle feeding skills of both groups using the Brazelton Neonatal Behavior Assessment Scale.	1. Days of tube feeding 2. Number of tube feeds 3. Daily weight gain 4. Length of hospital stay	1. Infants using pacifiers took 27 less tube feeds; Experimental group had 26 ± 21 days of tube feeds, and the Control group had 29 ± 18 days of tube feeding. This was a significant difference. 2. Experimental group infants received 219 ± 191 tube feeds, and Control group infants received 246 ± 171 tube feeds. This was a significant difference. 3. Experimental group infants started bottle feeding 3 days earlier and averaged greater weight gain per day. This was a significant difference. 4. Experimental group infants

Study	Participants (and setting)	Design of study	NNS programme	Aims	Outcomes used	Findings
						were discharged home 8 days sooner. This was a significant difference.
Fucile et al, (2002)	32 premature infants, born 26-29 weeks GA. Usual exclusion criteria. Study carried out in a neonatal setting.	Randomized to Control group (no oral stimulation) vs. an Experimental group of peri-oral stimulation and pacifier use. Infants started the programme when showing signs of oral readiness at around 34 weeks PMA.	NNS programme as in Table 4.2 administered x 2 daily for 10 days, 30 minutes before scheduled tube feed.	To assess if an oral stimulation programme, before oral feeding starts improves the feeding skills of infants born between 26-29 weeks GA.	1. Days to FOF. 2. Overall intake & rate of milk transfer. 3. Length of hospital stay.	1. Days to FOF p = Oral feeding achieved significantly earlier in Experimental group 11 ± 4 days, $p < .005$ 2. Overall intake significantly higher in the Experimental group = $p < .0002$; rate of milk transfer significantly higher in Experimental group = $p < .046$ 3. Length of hospital stay, no significant difference between the two groups.
Fucile et al, (2005)	32 premature infants, born 26-29 GA. Usual exclusion criteria. Study carried out in a neonatal setting.	RCT; Group 1, NNS and peri-oral stimulation, Group 2, Control. Infants started the programme when	NNS programme as in Table 4.2 administered x 2 daily for 10 days, 30 minutes before scheduled tube feed.	To improve maturation of sucking patterns; to enhance sucking frequency; to improve amplitudes of suction and	1. Days to achieve FOF. 2. Sucking rate, frequency and amplitude at 1, 2, 6 and 8 oral feeds per day.	1. Experimental group = FOF 7 days sooner than the Control group; this was significant $p=0.005$. The Experimental group infants took 11 days (mean, SD = 4) to achieve FOF. The Control group infants took 18 days (mean, SD = 7) to achieve FOF. 2. Significant differences in

Study	Participants (and setting)	Design of study	NNS programme	Aims	Outcomes used	Findings
		showing signs of oral readiness at around 34 weeks PMA.		expression and increase endurance.		sucking rate, frequency and amplitude between the two groups only at 1-2 feeds a day. After this stage, there were no differences between the groups.
Fucile et al, (2011)	75 preterm gestational age 29 weeks (SD =0.3); mean birth weight 1340.3g; (SD = 52.5g); 49 males and 26 females. Usual exclusion criteria. Study carried out in a neonatal setting.	Randomly assigned to one of three intervention groups or a control group. The oral group received sensorimotor input to the oral structures, the Tactile /Kinetic (T/K) group received sensorimotor input to the trunk and limbs, and the combined group received both.	NNS programme as in Table 4.2 administered x2 daily for 10 days, 30 minutes before scheduled tube feed.	The aim of this study was to determine whether oral, tactile/kinesthetic (T/K), or combined (oral + T/K) interventions enhance oral feeding performance and whether combined interventions have an additive/synergistic effect.	1. Time from introduction of oral feeding to independent oral feeding 2. Feeding proficiency (intake in the first 5min, %), volume transfer (%), rate of transfer (mL/min) and volume loss (%), 3. Length of hospital stay.	1. Infants in the three intervention groups achieved independent oral feeding 9-10 days earlier than those in the control group ($p < 0.001$; effect size 1.9-2.1). In the Oral group, infants started the programme at 33.8 weeks (SD =3.8) and were on FOF at 44.7 weeks (SD =3.7); the T/K group infants started the programme at 36.6 weeks (SD =5.2) and were on FOF at 46.75 weeks (SD =5.1); the Oral + T/K infants started the programme at 30.4 weeks (SD =3.2) and were on FOF at 40.1 weeks (SD =3.0); the Control group infants started the programme at 30.4 weeks (SD =3.7) and were on FOF at 49.3 weeks (SD = 4.8). Proficiency was highest and most significant in the T/K group. 3. Length of hospital stay was not significantly different between groups ($p = 0.792$).

Study	Participants (and setting)	Design of study	NNS programme	Aims	Outcomes used	Findings
Fucile et al, (2012)	75 preterm infants (mean gestational age 29 weeks (SD =0.3); mean birth weight 1340.3g; (SD = 52.5g); 49 males and 26 females. Usual exclusion criteria. Study carried out in a neonatal setting.	Randomly assigned to one of three intervention groups or a control group. The oral group received sensorimotor input to the oral structures, the T/K group received sensorimotor input to the trunk and limbs, and the combined group received both.	NNS programme as in Table 4.2 administered x2 daily for 10 days, 30 minutes before scheduled tube feed.	To further explore the effects of an oral (O), tactile/kinesithetic (T/K), and combined (O+T/K) sensorimotor intervention on preterm infants' nutritive sucking, swallowing and their coordination with respiration.	1. Suction & expression amplitude. 2. Suck-swallow ratio. 3. Pause –swallow-pause pattern differences between the groups.	1. Greater suction & expression amplitude in Sensorimotor group p<0.035 2. Suck-swallow ratio did not differ significantly between groups. 3. Pause –swallow-pause pattern differences between the groups; the T/K and the sensorimotor plus T/K groups had significantly higher numbers of swallows bracketed by respiration p<0.03. * In the Oral group, infants started the programme at 33.8 weeks (SD =3.8) and were on FOF at 44.7 weeks (SD =3.7); the T/K group infants started the programme at 36.6 weeks (SD =5.2) and were on FOF at 46.75 weeks (SD =5.1); the Oral + T/K infants started the programme at 30.4 weeks (SD =3.2) and were on FOF at 40.1 weeks (SD =3.0); the Control group infants started the programme at 30.4 weeks (SD =3.7) and were on FOF at 49.3 weeks (SD = 4.8)
Gaebler & Hanzlik, (1995)	Two groups of nine randomly assigned, medically	Randomly assigned to one of two groups;	NNS programme consists of the first 12	This study examined the effects of stroking and a	1. Number of days in hospital. 2. % amount taken in first 5 minutes during bottle feeds. 3. NNS normal patterns.	1. The Experimental group went home more quickly (13.78 days, SD 2.72) than the Control group (17.67 days, SD 4.03).

Study	Participants (and setting)	Design of study	NNS programme	Aims	Outcomes used	Findings
Gill et al, (1992)	stable preterm infants, born between 30 weeks and 34 weeks gestation, were selected for the study. Usual exclusion criteria. Study carried out in a neonatal setting.	1) Control = 5 minutes whole body stroking protocol and no NNS. 2) Intervention = 5 minutes whole body stroking protocol plus oral stim programme.	minutes of the Fucile NNS programme (Table 4.2) x 3 times daily, 5 days a week until FOF.	perioral and intraoral pre feeding stimulation programme on healthy, growing, preterm infants in a Level II special care NNU.	4. Liquid intake in first 5 minutes of initial feed.	2. A higher % of feeds overall was taken by the Experimental group in the first 24 hours. 3. On the 3 rd day of oral feeding, the Experimental group had a higher number of normal suck patterns (U = 25, p = .08) compared to the Control group, but this evened out. 4. There were no differences in amount of milk taken in the first 5 minutes of a feed. * Infants began the intervention at around 34 weeks depending on their oral readiness signs, but days to FOF not clear.
	42 infants, gestational age < 34 weeks Birth weight < 2.0kg Usual exclusion criteria. Study carried out in a neonatal setting.	Randomized. Experimental group: Pacifier before bottle feed x 5 minutes Control group: No pacifier	No specific NNS oral motor programme, but sucking on pacifier for 5 mins pre tube feed.	To determine the effect of NNS on behavioural state, i.e. optimal state preparation for feeds.	1. Differences in optimal states for feeding. 2. Number of sleep states.	1. Differences in optimal states for feeding significantly more alert inactivity, quiet awake and active awake states. 2. Number of sleep states greater in Experimental group, with fewer restless states. * Days to FOF not specifically recorded as this study was more focused on infant states.
Harding et al, (2006);	27 – 35 weeks gestation.	Matched pairs design.	Parents /staff providing	To assess if NNS can lead to	1. Oral motor skills using the NOMAS.	1. Significant difference in normal patterns of sucking

Study	Participants (and setting)	Design of study	NNS programme	Aims	Outcomes used	Findings
Harding, (2009)	Correct birthweight for dates. Usual exclusion criteria. Study carried out in a neonatal setting.	Randomized to Treatment or Control group.	NNS through use of pacifier up to 10 minutes on onset of tube feed up to 3 x daily. Main rationale = use of pacifier to enable sequential sucking pattern and to encourage parent observations of infant non verbal signs.	quicker transition to FOF.	2. Days to FOF. 3. Days in hospital.	between the groups ($p = 0.034$). 2. No significant differences in days to FOF, but a trend noted; Experimental infants took 9 -21 days to achieve FOF, and Control infants took 11 -25 days to achieve FOF. 3. Intervention group went home 3 days sooner (not significant $p=0.082$) and spent 5 fewer days in hospital (not significant $p=0.277$).
Harding et al. (2012)	One 37 week old infant with neurodisability. The study involved early care on a NNU through to discharge home. Study carried out in a neonatal setting.	Individual case study.	Use of NNS to stimulate rooting reflex and therefore oral readiness pre tube feed and to encourage observations of infant non verbal signs.	To evaluate and assess the steps taken when using NNS as a strategy in relation to the development of oral feeding.	1. Sucking patterns using the NOMAS. 2. Number of days to achieve FOF.	1. Decreased number of dysfunctional sucking patterns and an increased number of normal sucking patterns. 2. FOF achieved at 17 months of age

Study	Participants (and setting)	Design of study	NNS programme	Aims	Outcomes used	Findings
Harding et al, (2014)	59 infants 26-35 weeks GA. Usual exclusion criteria. Study carried out in a neonatal setting.	Randomized non blinded study to one of three groups; 1) NNS pre tube feed; 2) NNS on onset of tube feed; 3) Control group, i.e. usual Developmental Care approach provided by the NNU.	Parents /staff providing NNS through use of pacifier up to 10 minutes on onset of tube feed, or 30 minutes before tube feed up to 3x daily. Main rationale = use of pacifier to enable sequential sucking pattern and to encourage observations of infant non verbal signs.	To evaluate if NNS has any impact on transition to FOF, or if it improves early communication outcomes.	1. Days to FOF. 2. Days in hospital. 3. Sucking patterns using the NOMAS. 4. Receptive and expressive language outcomes at 6 months.	1. No significant differences between the groups with FOF, $p = .115$. Days to FOF ranged from 8-50 days. Group 1, NNS pre tube feeds = 19.7 days average to FOF; Group 2, NNS on onset of NG feeds = 16.5 days average to achieve FOF; Group 3, Control = 23.9 days to achieve FOF. 2. A significant difference between the Control and the 2 intervention groups, $p = .022$ with days in hospital. 3. Significant increase in normal sucking patterns for all infants, $p < 0.05$. 4. No significant differences in communication development between the 3 groups.
Harding et al, (2015)	9 infants with complex needs, GA 30-42 weeks. No exclusion criteria. Infants were recruited who had complex feeding difficulties.	Case based prospective study where infants' progress with their feeding was monitored.	Infants received a variety of interventions according to their difficulties. Some received NNS as described in the	To consider how NNS can be used to enable parents to read their infants better when managing complex feeding difficulties.	1. Days in hospital. 2. Days to FOF.	1. Days in hospital ranged from 7-92 days depending on the infants' needs. 2. Only three infants were able to achieve FOF; Infant 2 took 14 days, Infant 3 took 7 days and Infant 8 took 112 days. NNS did not enable infants with complex needs to achieve NS, but it did enable parents to interpret their

Study	Participants (and setting)	Design of study	NNS programme	Aims	Outcomes used	Findings
			Harding et al (2014) study.	To consider how NNS can be used as part of an oral care programme for infants who will not be able to take all of their feed orally.		infants' non verbal signs more consistently
Hill, (2005)	156 premature infants, 32 – 34 weeks gestational age. Usual exclusion criteria. Study carried out in a neonatal setting.	three-group repeated-observation control group design	7 days for each scheduled tube feed pre introduction of oral feeding, jaw support, cheek support and pacifier use for 5 minutes at beginning of scheduled feed.	The purpose of this study is to describe the influence of oral support and nonnutritive sucking (NNS) across time on the feeding efficiency of preterm infants, i.e. effective completion of a whole feed rather than days to FOF.	1. Amount of formula taken in first 5 minutes of a feed. 2. Length of feeding time. 3. Changes in sucking bursts.	1. Oral support took significantly more formula in first 5 minutes of a feed compared to NNS & Control groups ($p = .01$). 2. Oral control and NNS groups significantly quicker to feed than the Control group ($p = .01$). 3. Decreased number of suck bursts and pauses and increased sucking sequences in Oral control and NNS groups after 1 week compared to the Control group.
Hwang et al, (2010)	Nineteen preterm infants, defined as "inefficient feeders" aged 24.6 –	Nineteen preterm infants served as their own controls in a cross over	Modified version of the Fucile (Table 4.2) NNS programme, with 3 minutes of	To investigate the effects of an oral stimulation programme, both peri-oral and intra-oral)	1. Feeding duration in minutes. 2. Oral intake during feeds 3. % leakage during feeds 4. Sucking, physiological and alertness variables	1. No differences in feeding duration. 2. Oral intake during feeds – a trend for greater intake during the first 5 minutes during intervention. 3. % leakage during feeds

Study	Participants (and setting)	Design of study	NNS programme	Aims	Outcomes used	Findings
	34.1 weeks GA. Usual exclusion criteria. Study carried out in a neonatal setting.	design. Each infant received either intervention (feeding with oral support) or control (feeding without oral support) for 2 consecutive feedings per day on 2 consecutive days.	peri-oral and intra-oral stimulation (12 minutes in the Fucile programme) with 2 minutes pacifier use. This was carried out for 2 consecutive days x 2 daily pre implementation of oral trials.	plus cheek and jaw support on the feeding ability of inefficient feeders born prematurely.		smaller in the intervention phase. 4. Sucking, physiological and alertness variables – no significant difference between the two conditions. * Days to FOF not specifically recorded as this study was more focused on infant sucking efficiency in relation to stamina.
Lau & Smith, (2012)	87 Pre term infants 24 – 33 weeks GA. Usual exclusion criteria. Study carried out in a neonatal setting.	Randomized into three groups, Control, Sucking Therapy group & NNS group. Infants were recruited when showing oral readiness signs at a mean age of 34 weeks PMA.	NNS programme involved sucking on a pacifier 30 minutes prior to tube feeds, 15 minutes a day, 5 days a week.	To show that swallowing therapy, rather than oral motor work accelerates infant feeding development.	1. Days to FOF. 2. Overall transfer of milk.	1. Days to FOF Swallow Therapy group (14.6 ± 1.6 days) significantly higher than the other two groups. No significant differences between the Control (20.8 ± 1.9 days to FOF) and the NNS group (18.9 ± 0.5 days to FOF). 2. Overall transfer of milk, significantly more mature at 3-5 feeds per day for the Swallow therapy group, but this evens out.

Study	Participants (and setting)	Design of study	NNS programme	Aims	Outcomes used	Findings
Lessen, (2011)	19 infants from a neonatal unit born between 26 and 29 weeks PMA. Usual exclusion criteria. Study carried out in a neonatal setting.	A randomized, blinded, clinical trial was conducted to examine outcomes related to the newly developed PLOMI. 10 infants assigned to the Experimental group and 9 in the Control group	Use of the PLOMI, a 5 minute NNS programme which uses Beckman principles (1988) for 7 days, x 1 a day when the infant is 29 weeks PMA.	The purpose of this research was to test the newly developed Premature Infant Oral Motor Intervention (PIOMI) beginning at 29 weeks postmenstrual age (PMA), before oral feedings were introduced, to determine whether the pre feeding intervention would result in a shorter transition from gavage to total oral feedings and a shorter length of hospital stay [LOS].	1. Time taken to achieve FOF 2. Number of days in hospital.	1. Infants who received the once-daily PIOMI transitioned from their first oral feeding to total oral feedings 5 days sooner than controls ($P = .043$); Experimental group infants took 18.1 days \pm 3.7, and Control infants took 23.4 days \pm 5.8. 2. Infants in the Experimental Group were discharged 2.6 days sooner than the Control group.
Liu et al, (2013)	68 premature infants aged between 30 .2 \pm 3.0 weeks	Case matched control study; method of	NNS programme = using a pacifier to	To evaluate the effectiveness of oral motor management	1. Body weight 2. Length of hospital stay 3. Rate of milk per day 4. Milk amount taken per feed	1. Significant differences in body weight with the Experimental group 2003g \pm 191g s. Control group, 1916g \pm

Study	Participants (and setting)	Design of study	NNS programme	Aims	Outcomes used	Findings
	GA. Usual exclusion criteria. Study carried out in a neonatal setting.	randomly assigning infants to groups not clear.	stimulate 5 consecutive sucking movements and PT intervention (not specified what this was or how often).	on the feeding development of premature infants.	on discharge	1.56g ;p <0.002. 2. Significant differences between both groups, with the Experimental group (46.4 days \pm 25.3 in hospital compared to the Control group, 54.7 days \pm 23.5 going home sooner ;p <0.003. 3. There were no significant differences in rate of milk per day between the two groups. 4. There were no significant differences in the amount of milk taken between the two groups on discharge. *Experimental group, start of oral feeding = 35.2 GA; \pm 1.9 VS. Control group, start of oral feeding = 35.6 \pm 2.16. FOF achieved in the Experimental group at 36.5 GA \pm 2.16, and in the Control group FOF achieved 37.7 GA \pm 2.6.
Lyu et al, (2014)	72 premature infants, 29 -34 weeks GA. Enrolled at 33 weeks. Usual exclusion criteria. Study carried out in a neonatal setting.	RCT where Experimental group received the NNS programme and the Control group received the usual care provided in	Fucile et al programme (Table 4.2) x 1 daily, 10 days before introduction of FOF at 34 weeks.	To evaluate the effectiveness of an oral stimulation programme on preterm infant feeding development.	1. Time taken to achieve FOF. 2. Length of hospital stay. 3. Weight gain.	1. Time taken to achieve FOF – significantly shorter in the Experimental group, p<0.05, (9.56 \pm 4.43 days, compared to Control group, 13.19 \pm 6.18). 2. Length of hospital stay, no significant differences (Experimental group 39.97 \pm 14.81 days, compared to the Control group = 41.25 \pm 16.15 days). 3. Weight gain, no significant

Study	Participants (and setting)	Design of study	NNS programme	Aims	Outcomes used	Findings
Mattes et al, (1996)	Gestational age < 34weeks Birth weight > 1.25kg Sample size = 42 Number randomized to each group=14. Usual exclusion criteria. Study carried out in a neonatal setting.	Randomized, Experimental group 1: Sweet edible pacifier during tube feeds Experimental group 2: Latex pacifier during tube feeds Control group: No pacifier but maternal heart beat played during tube feeds	NNS programme involved sucking on a pacifier (with the pacifier teat being rubbed to elicit three sucks), either sweetened or not, depending on group allocation for 4 minutes with a rest period of 1 minute x 1 daily before a tube feed. This was introduced when oral readiness signs were first noted until FOF achieved.	To evaluate the effect of sweet taste stimulation in augmenting the reported growth-enhancing effects of non-nutritive sucking in preterm infants who are gavage-fed	1. Days to FOF 2. Sucking measures, i.e. sucks per minute 3. Weight gain	differences, (Experimental group = 2086.56g±115.24g; Control group = 2178.39±210.02g). 1. Days to FOF: no significant differences between the groups; Group 1 = 19.1 ± 8.9 days; Group 2 = 16.8 ± 10.2 days; Group 3 = 19.2 ± 8.7 days 2. Sucks per minute; no significant differences between the three groups. 3. Weight gain; no significant differences in weight between the three groups.
Measel &	Gestational	Alternate	Use of a	To use oral	1. Weight gain	1. Weight gain – Experimental

Study	Participants (and setting)	Design of study	NNS programme	Aims	Outcomes used	Findings
Anderson, (1979)	age 28 - 34 weeks Birth weight > 1.0kg Sample size = 59 (30 in Control and 29 in Exp groups). Usual exclusion criteria. Study carried out in a neonatal setting.	sequential series and matching. Experimental group: Pacifier during tube feed and 5 minutes after feed Control group: No pacifier during feed or 5 minutes after feed Both groups: Pacifier between feeds PRN	pacifier to stimulate NNS every tube feed. Treatment started when infants started to show signs of oral readiness. Infants entered the study at 33 weeks GA \pm .38 in the Experimental group, and at 33 weeks GA \pm .24 for the Control group.	stimulation via a pacifier to shorten time taken to develop full oral feeding.	2. Readiness for bottle feeds 3. Feeding performance during first bottle feed 4. Differences in time spent in hospital.	group infants = gained 2.6 gm/day more than the Control group. This was not significant. 2. Readiness for bottle feeds – readiness for bottle feeds 3.4 days sooner than the Control group and had 27 fewer tube feeds. The differences between the groups was significant ($p < .05$). FOF took between 5 -40 days across the 2 samples. 3. Feeding performance during first bottle feed 3.4 earlier in the Experimental group. This was significant ($p < .05$). 4. Infants in the Experimental group were discharged home 4 days sooner. This was significant ($p < .05$).
McCain et al, (1995)	20 premature infants, mean gestational age - 31.6 weeks and mean birth weight - 1.649kg Usual exclusion criteria. Study carried out in a neonatal	Randomized, crossover Experimental group: Pacifier before bottle feeds x 10 minutes Control group: No pacifier	Pacifier given before bottle feeds for 10 minutes x 1 per 8 hour shift from signs of oral readiness up to FOF.	Use of a pacifier will increase time taken to FOF As it will prepare an infant's state before a feed.	1. Behaviour 2. Heart rate 3. Length of feeding time/oral intake	1. Significantly fewer behavioral state changes after use of NNS. 2. No changes in mean heart rates between both conditions. 3. No significant difference in length of feeding time / oral intake, although a trend post NNS was noted.

Study	Participants (and setting)	Design of study	NNS programme	Aims	Outcomes used	Findings
Neiva et al, (2007)	95 preterm infants, 30.5 weeks \pm 1.57 SD GA. Usual exclusion criteria. Study carried out in a neonatal setting.	Random allocation to 3 groups; Control, NNS with pacifier and NNS with gloved finger.	Method of implementing NNS not clear, but NNS stimulation carried out everyday during tube feeds, once a day for 10 minutes from first signs of OR to FOF.	To describe the development of the sucking pattern and the effects of NNS To analyze the development of the sucking rhythm, in non-nutritive and nutritive sucking in preterm newborns, as a consequence of non-nutritive sucking stimulation and in terms of corrected gestational age	1. Burst – pause pattern 2. NNS patterns in terms of maturation.	1. Number of sucking bursts and pauses per minute increase, but no significant differences between the groups. 2. NNS patterns remain constant as NS develops – no significant differences between the groups. * Days to FOF not specifically recorded as this study was more focused on infant sucking efficiency in relation to stamina.
Pickler (1996)	Mean gestational age - 29.5 weeks Mean birth weight - 1.3577kg Sample size = 13. Usual exclusion criteria. Study	Randomized, crossover. Experimental group: Pacifier pre-bottle feed x 2 minutes prior to 2 feeds Control group: No pacifier.	NNS programme involved use of a pacifier for 2 minutes x 2 day pre-bottle feeds. No description of how the NNS would be stimulated by	To see if NNS helped the infant prepare for oral feeding by improving their state. It was also hypothesized that NNS might help with oxygen saturation.	1. Behaviour 2. Feeding performance 3. Heart rate 4. Oxygen saturation	1. NNS had a significant effect on infant behavioral state. 2. Feeding performance was significantly better post NNS. 3. Heart rate did not differ between the two conditions. 4. Oxygen saturation was significantly increased post NNS. * Days to FOF not specifically recorded as this study was more focused on infant

Study	Participants (and setting)	Design of study	NNS programme	Aims	Outcomes used	Findings
	carried out in a neonatal setting.		the pacifier given.	heart rate and feeding performance (i.e. amount taken).		behavioural states pre-feeding.
Pickler (2004)	Gestational age <32 weeks No known cognitive, neurological, cardio-vascular, gastro-intestinal or craniofacial disorder Sample size = 13 (data collection completed on 10). Usual exclusion criteria.	Randomized, crossover Blinding of randomization. Experimental group: Pacifier pre-bottle feed x 2 minutes prior to 1 feed Control group: No pacifier for 1 feed	NNS administered by use of a pacifier in a non-specific way 2 minutes before bottle feeding (rest of feed completed by tube).	The purpose of this study was to examine the effect of pre-feeding non-nutritive sucking (NNS) on breathing, nutritive sucking (NS), and behavioral characteristics of bottle feeding.	1. Characteristics of NS (number of suck bursts, sucks/burst, suck burst length) and breathing (number of breath bursts, breaths/burst, breath burst length). 2. Behavior state during bottle feedings. 3. Feeding efficiency (percent of prescribed formula consumed, formula consumed/minute of feeding).	1. NS waves were smoother and more regular than NNS waves. Time to onset and duration of the first non-nutritive suck burst were positively correlated with time to onset for the first nutritive suck burst. 2. Pre-feeding NNS had no statistically significant effect on characteristics of breathing or NS. Behavioral state during feedings and feeding efficiency were not affected by pre-feeding NNS. 3. Use of pre-feeding NNS did not affect feeding efficiency. * Days to FOF not specifically recorded as this study was more focused on infant states to prepare them for feeding.
Pimenta et al. (2008)	98 infants 26 weeks and 32 weeks birth weight < 1,500g. Usual exclusion	Infants were randomized into experimental and control groups. Double	NNS programme as in Table 4.2 administered x 2 daily for 10 days, 30 minutes	To determine the influence of non-nutritive sucking and oral stimulation programmes on breast feeding	1. % of sample breastfeeding on discharge. 2. % of sample breastfeeding at 3 months. 3. % of sample breastfeeding at 6 months. 4. Number of days in hospital.	1. 61.3% breast feeding on discharge from hospital, significantly more in the Experimental group. 2. 32.3% breast feeding at 3 months post discharge from hospital significantly more in

Study	Participants (and setting)	Design of study	NNS programme	Aims	Outcomes used	Findings
	criteria. Study carried out in a neonatal setting.	blinded. Infants were recruited when they started to show oral readiness signs which were 32.0 weeks GA (28.6 – 35.5) in the Experimental group, and 32.4 weeks GA, (27.5 – 34.4) in the Control group.	before scheduled tube feed.	rates at discharge, at 3 and at 6 months of corrected age in preterm infants with very low birth weight.		the Experimental group. 3. 18.75% breast feeding at 6 months post discharge from hospital significantly more in the Experimental group. 4. Infants who had the intervention went home 10.8 days sooner than the Control group. This was a significant difference (Experimental group stayed in hospital 41.81 days \pm 17.7, vs. Control group, 52.37 days \pm 19.51). * Days to FOF not specifically recorded as this study was more focused on breastfeeding rates.
Poore et al, (2008)	Thirty-one preterm infants (mean gestational age 29.3 weeks) GA mean 29.3 weeks, SD = 2.57), each enrolled at 32 weeks PMA. Usual exclusion criteria. Study carried out in	Infants were assigned to groups in a block design—21 infants were assigned to the NTrainer treatment group and 10 were assigned to the no-treatment control	NNS provided to the Experimental group via use of an NTrainer which provided orocutaneous stimulation for 3 minutes for 3 - 4 x daily at 34 weeks for 10 days, or until the infant achieved	To determine whether NTrainer patterned orocutaneous therapy affects preterm infants' non-nutritive suck and/or oral feeding success	1. Non-Nutritive Suck Spatiotemporal Index scores for infants in both groups. 2. Oral feeding intake. 3. spatiotemporal stability of non-nutritive suck pressure trajectories and oral feeding success	1. Non-Nutritive Suck Spatiotemporal Index scores – no significant differences. 2. Significant increase in % oral feeding amounts taken between the two groups. 3. Spatiotemporal stability of non-nutritive suck pressure trajectories and oral feeding success are significantly related.

Study	Participants (and setting)	Design of study	NNS programme	Aims	Outcomes used	Findings
Rocha et al. (2007)	Very low birth weight infants	group Infants assigned to the NTrainer treatment group received 3-min epochs of patterned orocutaneous stimulation during daily gavage feeds using the NTrainer C ₂ device. Infants were recruited when they started to show oral readiness signs at around 35 weeks GA; Experimental group mean GA = 35.68 weeks; Control group mean GA = 35.55.	FOF.	To assess if sensory-motor-	1. Length of hospital stay. 2. Time taken to achieve FOF.	1. Length of hospital stay significantly lower in the

Study	Participants (and setting)	Design of study	NNS programme	Aims	Outcomes used	Findings
	<p>(n=98) 26 and 32 weeks of gestational age. Usual exclusion criteria. Study carried out in a neonatal setting.</p>	<p>infants (n=98) were randomized into a Experimental and Control group. Preterm infants in the experimental group received sensory-motor-oral stimulation and non-nutritive sucking and infants in the control group received a sham stimulation programme. Both were administered from when they reached enteral diet (100 kcal/kg/day) until the beginning of oral diet</p>	<p>(Table 4.2) x 1 daily, 10 days before introduction of FOF at 34 weeks.</p>	<p>oral stimulation and non-nutritive sucking gavage feeding enhances the oral feeding performance of preterm infants born between 26 and 32 weeks of gestational age.</p>		<p>Experimental group= 38 ±16 days of life. 2. Significant difference in the number of days taken to FOF = 52.3±19 days.</p>

Study	Participants (and setting)	Design of study	NNS programme	Aims	Outcomes used	Findings
Rochat et al, (1997)	11 infants born at 32 weeks GA or less; mean PCA = 32 (± 2.0 SD) for the continuous NGT group, and mean PCA = 35 (± 2.3 SD) for the intermittent NGT group. Usual exclusion criteria. Study carried out in a neonatal setting.	Study design not clearly specified. Appears to be a matched pairs design. Group 1 = Continuous NGT feeds Group 2 = Intermittent NGT feeds Both groups received a pacifier at 5 minutes before, 5 minutes on onset and 5 minutes post NGT.	Pacifier given to the infant 5 minutes before and at the end of tube feeds, also for 5 minutes. No specific details given about how to use the pacifier.	To ascertain if NNS has benefits for infant sucking during tube feeds, either intermittent or continuous.	1. Mean duration of sucking burst 2. mean number of sucks per burst 3. mean duration of individual sucks within a burst	1. Increased sucking bursts for IMG during gavage feeding, inc in average sucking duration -significant $p < .05$. 2. Increase in mean number of sucks in IMG group during NGT, significant trend only $p < .051$. 3. Significant increase in mean duration of individual sucks within a burst in the IMG group. = $< .05$.
Sehgal et al, (1990)	40 infants born between 30 weeks and 34 weeks gestation. Usual exclusion criteria. Study carried out in a neonatal setting.	Randomized controlled trial with allocation to an Experimental (NNS) group compared to a Control (no NNS) group.	Pacifier given for the first three minutes of a feed. No specific details given about how to use the pacifier.	To ascertain if NNS has benefits for weight, length and head circumference.	1. Days to FOF. 2. Weight gain. 3. Length. 4. Head circumference.	1. Infants in the NNS group fed orally three days sooner. This was significant, $p < .001$. 2. No significant differences between the groups for weight gain. 3. No significant differences between the groups for length. 4. No significant differences between the groups for head circumference.

Study	Participants (and setting)	Design of study	NNS programme	Aims	Outcomes used	Findings
Standley et al. (2010)	32-36 GA. Usual exclusion criteria. Study carried out in a neonatal setting.	randomized, controlled multi-site study 3x3-block design contrasting number of repetitions of PAL (pacifier-activated-lullaby system) trials by gestational age at the beginning of the trial	Use of NNS via a pacifier to activate music outside of a feed context. Offered for 15 minutes x 1 daily.	ascertain the effect of the pacifier-activated lullaby system (PAL) on cessation of gavage feeding of premature infants due to oral feeding achievement.	1. Time taken to FOF. 2. Impact of gender on FOF skills. 3. Impact of age at onset of intervention, i.e. 32, 34, 36 weeks impacts on outcomes. 4. Time in hospital.	1. Significant difference in time to FOF at 34 weeks. 2. Females nipple fed significantly longer than males. 3) Infants aged 36 weeks took longer to develop FOF but not significantly so. 4. Infants who received the PAL went home sooner than the Control infants, but this was not significant.
Yildiz & Arıkan, (2012)	90 infants were at 32 (\pm 2) gestation weeks. Usual exclusion criteria. Study carried out in a neonatal setting.	Quasi-experimental and prospective study premature infants allocated to each of pacifier, lullaby and control groups	NNS programme was a pacifier given to the infant to suck X 3 daily during tube feeds from OR signs to FOF.	This research aimed to assess the effect of giving pacifiers to premature infants and making them listen to lullabies on the transition period to total oral feeding, their sucking success and their vital signs.	1. Peak heart rate 2. respiration rate 3. Oxygen saturation 4. Time to FOF 5. Time spent in hospital	1. Significant differences in peak heart rate between the two experimental groups VS the Control group. 2. Significant differences in oxygen saturation between the two experimental groups vs. the Control group noted. 3. Significant difference to develop FOF between the pacifier group vs. the Lullaby and Control groups. For the Experimental group, the time to FOF was 9.40 days (SD = 2.84), and for the Control group, it was 12.33 days (SD = 8.13).

Study	Participants (and setting)	Design of study	NNS programme	Aims	Outcomes used	Findings
Zhang (2014)	112 infants were at 32 (± 2) gestation weeks. Usual exclusion criteria. Study carried out in a neonatal setting.	Randomized controlled trial. Infants were allocated to an Experimental 1 group, NNS; Experimental 2 group, OS; Experimental 3 group, NNS + OS; Control group.	Adapted Fucile et al programme (Table 4.2) x 1 daily, 10 days before introduction of FOF at 34 weeks. OS programme = first 12 minutes of Fucile programme, and NNS = 3 minutes on a pacifier.	To evaluate the effectiveness of NNS, OS, and NNS + OS and to consider impact on transition to FOF.	1. Number of days to FOF. 2. Rate of milk transfer and proficiency and volume transfer. 3. Weight. 4. Length of hospital stay.	4. Significant difference in time taken to FOF, with the pacifier group the quickest, followed by the lullaby, and finally the Control group. 5. No significant differences in time spent in hospital. 1. Significant differences between all 3 Experimental groups vs. Control group in days to FOF. 2. Rate of milk transfer, proficiency, volume transfer significantly greater in NNS + OS group compared to all other groups. 3. No significant differences in weight gain between the groups. 4. No significant differences in length of hospital stay between all four groups.

APPENDIX 3 Walshe & Harding presentation for the 2014 ESSD Conference

Walshe M. & Harding C., 2014. Rehabilitating dysphagia in children: Current evidence and directions for research. Presentation given at The Fourth Congress European Society for Swallowing Disorders, Dysphagia Across the Ages, Brussels, 2014



Rehabilitating Dysphagia in Children: Current evidence and directions for research

Margaret Walshe & Celia Harding

Prevalence of Feeding and Swallowing Disorders in Children

- The prevalence of feeding and swallowing disorders in children is increasing due in part to improved survival of premature infants
- The frequency of paediatric feeding, eating, drinking and swallowing difficulties is hard to quantify due partly to poor differentiation between congenital and acquired disorders

(Arvedson et al, 2008; Bernard-Bonnin, 2006; Brachet et al, 2006; Field et al, 2003; Lefton-Grief, 2008; Rommel et al, 2003)

Rehabilitation

Interventions include:

- **positioning** *e.g.* (Clark et al, 2007; Macie & Arvedson, 1993; Mootoosamy & Dietrich, 2002 ; Morton et al, 1996 ; Okada et al, 2007)
- **environmental changes** *e.g.* (Harding et al, 2006; Harding, 2009; Harding et al, 2012; 2014; Hill, 2005; Mathisen, 2001; McGrath & Medoff-Cooper, 2002; Pickler et al, 2006; White-Traut et al, 2002)
- **sensory and behavioural management** *e.g.* (Barikroo & Lam, 2011; Bartostruck et al, 2003; Blumenfeld et al, 2006; Burmucic et al, 2006; Byars et al, 2003; Davies et al, 2009; Christiaanse et al, 2011; Duffy, 2007; Kindermann et al, 2008; Regan et al, 2010; Sciortino et al, 2003)

Rehabilitation

- **texture modification** *e.g.* (Adeleye & Rachal, 2007; Finestone et al, 2001; Khoshoo et al, 2000; Lotong et al, 2003; Muaary et al, 2013; Stuart & Motz, 2009; Vivanti et al, 2009; Whelan, 2001)
- **oral motor exercises** *e.g.* (Barlow et al, 2008; Beckman, 2001; Boiron et al, 2007; De Kun et al, 2005; Fucile et al, 2002; 2005; 2011; 2012; Gaebler & Hanzlik, 1995; Hwang et al, 2012; Poore et al, 2008; Pimenta et al, 2008; Rocha et al, 2007; Rosenfeld-Johnson, 1999).
- **compensatory strategies** *e.g.* (Adeleye & Rachal, 2007; Clark et al, 2007; Finestone et al, 2001; Khoshoo et al, 2000; Lotong et al, 2003; Macie & Arvedson, 1993; Mootoosamy & Dietrich, 2002 ; Morton et al, 1996 ; Okada et al, 2007 Stuart & Motz, 2009; Vivanti et al, 2009; Whelan, 2001)
- **equipment** *e.g.* (Harding & Aloysius, 2011; Harding, Fitzpatrick, Morris & Aloysius, 2014; Lau & Schandler, 2000; Mathew, 1990; 1998)

Research Aims & Methodology

- (1) To examine the efficacy and effectiveness of interventions to prevent aspiration in children with known oropharyngeal dysphagia
- (2) To examine the efficacy and effectiveness of interventions to improve functional eating and drinking

Evidence based systematic review

Methods

Children: defined as 0-18 years, male and female.

Interventions: Any intervention delivered by trained professional that aimed to decrease incidence of aspiration and improve functional eating and drinking

Outcomes:

Primary Outcomes:

Change in aspiration as determined by Instrumental assessment (VFS/FEES).

Weight gain

Improved nutritional status

Decreased respiratory infections

Secondary Outcomes:

Positive change to quality of life

Compliance with intervention

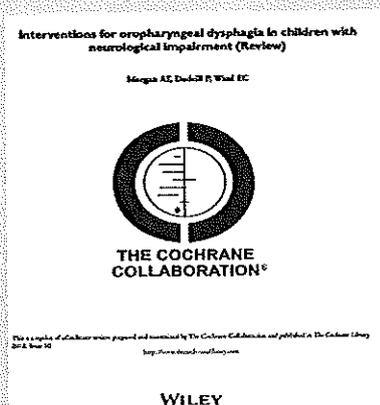
Methods

- All **prospective** randomised controlled trials and quasi experimental studies on interventions for paediatric dysphagia were sought
- A range of electronic databases were searched from inception to June 2014. Studies in all languages were sought
- Methodological quality of studies was rated using the Cochrane Risk of Bias tool. Sub group analysis was carried out on individual interventions and specific paediatric populations

Results

Three systematic reviews

- ARVEDSON J.C., CLARK H., LAZARUS C., SCHOOLING T., FRYMARK T., 2010a. The effects of **oral-motor exercises** on swallowing in children: an evidence-based systematic review. *Developmental Medicine and Child Neurology* 52, (11), 1000-1013
- ARVEDSON J.C., CLARK H., LAZARUS C., SCHOOLING T., FRYMARK T., 2010b. Evidence-based systematic review of **oral motor interventions** on feeding and swallowing in preterm infants. *American Journal of Speech-Language Pathology*, Vol 19, pp 321-340
- MORGAN A.T., DODRILL P., WARD E.C., 2012. **Interventions** for oropharyngeal dysphagia in children with neurological impairment. *Cochrane Database of Systematic Reviews* 2012, Issue 10. Art. No.: CD009456. DOI: 10.1002/14651858.CD009456.pub2



Oromotor Intervention for Oropharyngeal Dysphagia in Children: 4 studies

Gisel (1996)

Population: Children with CP age 4 years 3 months – 13 years

Intervention: Sensorimotor programme:

- Tongue lateralisation,

- Lip control;

- Chewing

5-7 mins per day 5 days per week for 20 weeks

Results:

No statistically significant differences between experimental and control groups on eating time, clearing time, and duration of meals

Sigan et al. (2013)

Population: 81 children with CP age 18 months – 3.5 years

Intervention: Oromotor therapy for 6 months

- Modification to food texture

- Parental training

- Oral stimulation

1hr per week – 12 sessions in total

Results:

Statistically significant differences between experimental and control groups on spoon feeding, biting, chewing, drooling, swallowing, independent eating and drinking, aspiration and choking. No follow up data available

9

Oromotor Intervention for Oropharyngeal Dysphagia in Children

Ottenbacher et al. (1989)

Population: Children and adults with CP; age 5-21.6 years

Oromotor programme: 9 Weeks

- Inhibition of abnormal oral and postural reflexes

- Facilitation of normal tone

- Desensitization of oral region

- 30-40 mins per day 5 days per week.

Results: No statistically significant change in oral motor function and no statistically significant change in weight for experimental and control groups

Sjogreen et al (2010)

Population: Children and adults with myotonic dystrophy; age 7 – 19 years

Lip strengthening programme: 16 weeks

Use of oral screen programme:

- Lip closure force and endurance

- Lip mobility

- Eating skills and saliva control

- 16 mins per day 5 days per week

Results: Difficult to interpret. Bias and incomplete data reporting

10

Results: Risk of Bias

	Sjogreen 2010	Sigan 2013	Orensbaek 1989	Cisak 1996	
Random sequence generation (selection bias)	●	●	●	●	
Allocation concealment (selection bias)	●	●	●	●	
Blinding of participants and personnel (performance bias)	●	?	●	●	
Blinding of outcome assessment (detection bias)	●	?	●	●	
Incomplete outcome data (attrition bias)	●	●	●	●	
Selective reporting (reporting bias)	●	●	●	●	
Other bias	●	?	●	●	

GRADE Quality of Evidence: Low (Balshem et al. 2011)

Conclusions

- The evidence to support interventions for paediatric dysphagia is limited
- *There are no clear valid outcome measures and many measures do not relate to pulmonary health and swallowing outcomes*
- There are no overall specific protocols & not many rater-reliable assessments
- *Research does not differentiate clearly between sensory, behavioural, oral phase and pharyngeal phase disorders or the populations studied*

References

- Gisel EG. Effect of oral sensorimotor treatment on measures of growth and efficiency of eating in the moderately eating-impaired child with cerebral palsy. *Dysphagia*. 1996;11:48-58
- Ottenbacher K, Soggins A, Wayland J. The effectiveness of a program of oral sensory-motor therapy with the severely and profoundly developmentally disabled. *The Occupational Therapy Journal of Research*. 1989;1(2):147-160
- Sigan SN, Uzunhan T, Aydini N, Eraslan I, Ekici B, Caliskan M. Effects of oral therapy in children with cerebral palsy. *Annals of Indian Academy of Neurology*. 2013;16(3):342-346
- Sjogreen L, Tullinius M, Kiliaridis S, Lohmander A. The effect of lip strengthening exercises in children and adolescents with myotonic dystrophy type 1. *International Journal of Paediatric Otorhinolaryngology*. 2010;74:1126-1134

Criteria for judging risk of bias in the 'Risk of bias' assessment tool

SEQUENCE GENERATION	
Was the allocation sequence adequately generated? [Short form: <i>Adequate sequence generation?</i>]	
<p>Criteria for a judgement of 'YES' (i.e. low risk of bias).</p>	<p>The investigators describe a random component in the sequence generation process such as:</p> <ul style="list-style-type: none"> ▪ Referring to a random number table; Using a computer random number generator; Coin tossing; Shuffling cards or envelopes; Throwing dice; Drawing of lots; Minimization*. <p>*Minimization may be implemented without a random element, and this is considered to be equivalent to being random.</p>
<p>Criteria for the judgement of 'NO' (i.e. high risk of bias).</p>	<p>The investigators describe a non-random component in the sequence generation process. Usually, the description would involve some systematic, non-random approach, for example:</p> <ul style="list-style-type: none"> ▪ Sequence generated by odd or even date of birth; ▪ Sequence generated by some rule based on date (or day) of admission; ▪ Sequence generated by some rule based on hospital or clinic record number. <p>Other non-random approaches happen much less frequently than the systematic approaches mentioned above and tend to be obvious. They usually involve judgement or some method of non-random categorization of participants, for example:</p> <ul style="list-style-type: none"> ▪ Allocation by judgement of the clinician; ▪ Allocation by preference of the participant; ▪ Allocation based on the results of a laboratory test or a series of tests; ▪ Allocation by availability of the intervention.
<p>Criteria for the judgement of 'UNCLEAR' (uncertain risk of bias).</p>	<p>Insufficient information about the sequence generation process to permit judgement of 'Yes' or 'No'.</p>
ALLOCATION CONCEALMENT	
Was allocation adequately concealed? [Short form: <i>Allocation concealment?</i>]	
<p>Criteria for a judgement of 'YES' (i.e. low risk of bias).</p>	<p>Participants and investigators enrolling participants could not foresee assignment because one of the following, or an equivalent method, was used to conceal allocation:</p> <ul style="list-style-type: none"> ▪ Central allocation (including telephone, web-based, and pharmacy-controlled, randomization); ▪ Sequentially numbered drug containers of identical appearance; ▪ Sequentially numbered, opaque, sealed envelopes.
<p>Criteria for the judgement of 'NO' (i.e. high risk of bias).</p>	<p>Participants or investigators enrolling participants could possibly foresee assignments and thus introduce selection bias, such as allocation based on:</p> <ul style="list-style-type: none"> ▪ Using an open random allocation schedule (e.g. a list of random numbers); ▪ Assignment envelopes were used without appropriate safeguards (e.g. if envelopes were unsealed or non-opaque or not sequentially numbered); ▪ Alternation or rotation; ▪ Date of birth; ▪ Case record number; ▪ Any other explicitly unsealed procedure.

<p>Criteria for the judgement of 'UNCLEAR' (uncertain risk of bias).</p>	<p>Insufficient information to permit judgement of 'Yes' or 'No'. This is usually the case if the method of concealment is not described or not described in sufficient detail to allow a definite judgement -- for example if the use of assignment envelopes is described, but it remains unclear whether envelopes were sequentially numbered, opaque and sealed.</p>
<p>BLINDING OF PARTICIPANTS, PERSONNEL AND OUTCOME ASSESSORS Was knowledge of the allocated interventions adequately prevented during the study? [Short form: <i>Blinding?</i>]</p>	
<p>Criteria for a judgement of 'YES' (i.e. low risk of bias).</p>	<p>Any one of the following:</p> <ul style="list-style-type: none"> ▪ No blinding, but the review authors judge that the outcome and the outcome measurement are not likely to be influenced by lack of blinding; ▪ Blinding of participants and key study personnel ensured, and unlikely that the blinding could have been broken; ▪ Either participants or some key study personnel were not blinded, but outcome assessment was blinded and the non-blinding of others unlikely to introduce bias.
<p>Criteria for the judgement of 'NO' (i.e. high risk of bias).</p>	<p>Any one of the following:</p> <ul style="list-style-type: none"> ▪ No blinding or incomplete blinding, and the outcome or outcome measurement is likely to be influenced by lack of blinding; ▪ Blinding of key study participants and personnel attempted, but likely that the blinding could have been broken; ▪ Either participants or some key study personnel were not blinded, and the non-blinding of others likely to introduce bias.
<p>Criteria for the judgement of 'UNCLEAR' (uncertain risk of bias).</p>	<p>Any one of the following:</p> <ul style="list-style-type: none"> ▪ Insufficient information to permit judgement of 'Yes' or 'No'; ▪ The study did not address this outcome.
<p>INCOMPLETE OUTCOME DATA Were incomplete outcome data adequately addressed? [Short form: <i>Incomplete outcome data addressed?</i>]</p>	
<p>Criteria for a judgement of 'YES' (i.e. low risk of bias).</p>	<p>Any one of the following:</p> <ul style="list-style-type: none"> ▪ No missing outcome data; ▪ Reasons for missing outcome data unlikely to be related to true outcome (for survival data, censoring unlikely to be introducing bias); ▪ Missing outcome data balanced in numbers across intervention groups, with similar reasons for missing data across groups; ▪ For dichotomous outcome data, the proportion of missing outcomes compared with observed event risk not enough to have a clinically relevant impact on the intervention effect estimate; ▪ For continuous outcome data, plausible effect size (difference in means or standardized difference in means) among missing outcomes not enough to have a clinically relevant impact on observed effect size; ▪ Missing data have been imputed using appropriate methods.
<p>Criteria for the judgement of 'NO' (i.e. high risk of bias).</p>	<p>Any one of the following:</p> <ul style="list-style-type: none"> ▪ Reason for missing outcome data likely to be related to true outcome, with either imbalance in numbers or reasons for missing data across intervention groups; ▪ For dichotomous outcome data, the proportion of missing outcomes compared with observed event risk enough to induce clinically relevant bias in intervention effect estimate; ▪ For continuous outcome data, plausible effect size (difference in means or standardized difference in means) among missing outcomes enough to induce clinically relevant bias in observed effect size; ▪ 'As-treated' analysis done with substantial departure of the intervention received from that assigned at randomization; ▪ Potentially inappropriate application of simple imputation.

<p>Criteria for the judgement of 'UNCLEAR' (uncertain risk of bias).</p>	<p>Any one of the following:</p> <ul style="list-style-type: none"> ▪ Insufficient reporting of attrition/exclusions to permit judgement of 'Yes' or 'No' (e.g. number randomized not stated, no reasons for missing data provided); ▪ The study did not address this outcome.
<p>SELECTIVE OUTCOME REPORTING Are reports of the study free of suggestion of selective outcome reporting? [Short form: <i>Free of selective reporting?</i>]</p>	
<p>Criteria for a judgement of 'YES' (i.e. low risk of bias).</p>	<p>Any of the following:</p> <ul style="list-style-type: none"> ▪ The study protocol is available and all of the study's pre-specified (primary and secondary) outcomes that are of interest in the review have been reported in the pre-specified way; ▪ The study protocol is not available but it is clear that the published reports include all expected outcomes, including those that were pre-specified (convincing text of this nature may be uncommon).
<p>Criteria for the judgement of 'NO' (i.e. high risk of bias).</p>	<p>Any one of the following:</p> <ul style="list-style-type: none"> ▪ Not all of the study's pre-specified primary outcomes have been reported; ▪ One or more primary outcomes is reported using measurements, analysis methods or subsets of the data (e.g. subscales) that were not pre-specified; ▪ One or more reported primary outcomes were not pre-specified (unless clear justification for their reporting is provided, such as an unexpected adverse effect); ▪ One or more outcomes of interest in the review are reported incompletely so that they cannot be entered in a meta-analysis; ▪ The study report fails to include results for a key outcome that would be expected to have been reported for such a study. <p>Insufficient information to permit judgement of 'Yes' or 'No'. It is likely that the majority of studies will fall into this category.</p>
<p>OTHER POTENTIAL THREATS TO VALIDITY Was the study apparently free of other problems that could put it at a risk of bias? [Short form: <i>Free of other bias?</i>]</p>	
<p>Criteria for a judgement of 'YES' (i.e. low risk of bias).</p>	<p>The study appears to be free of other sources of bias.</p>
<p>Criteria for the judgement of 'NO' (i.e. high risk of bias).</p>	<p>There is at least one important risk of bias. For example, the study:</p> <ul style="list-style-type: none"> ▪ Had a potential source of bias related to the specific study design used; or ▪ Stopped early due to some data-dependent process (including a formal-stopping rule); or ▪ Had extreme baseline imbalance; or ▪ Has been claimed to have been fraudulent; or ▪ Had some other problem.
<p>Criteria for the judgement of 'UNCLEAR' (uncertain risk of bias).</p>	<p>There may be a risk of bias, but there is either:</p> <ul style="list-style-type: none"> ▪ Insufficient information to assess whether an important risk of bias exists; or ▪ Insufficient rationale or evidence that an identified problem will introduce bias.

GRADE guidelines: 3. Rating the quality of evidence

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Accepted 30 July 2010

Abstract

This article introduces the approach of GRADE to rating quality of evidence. GRADE specifies four categories—high, moderate, low, and very low—that are applied to a body of evidence, not to individual studies. In the context of a systematic review, quality reflects our confidence that the estimates of the effect are correct. In the context of recommendations, quality reflects our confidence that the effect estimates are adequate to support a particular recommendation. Randomized trials begin as high-quality evidence, observational studies as low quality. “Quality” as used in GRADE means more than risk of bias and so may also be compromised by imprecision, inconsistency, indirectness of study results, and publication bias. In addition, several factors can increase our confidence in an estimate of effect. GRADE provides a systematic approach for considering and reporting each of these factors. GRADE separates the process of assessing quality of evidence from the process of making recommendations. Judgments about the strength of a recommendation depend on more than just the quality of evidence. © 2011 Elsevier Inc. All rights reserved.

Keywords: Quality assessment; Body of evidence; Imprecision; Indirectness; Inconsistency; Publication bias

1. Introduction

In the two previous articles in this series, we introduced GRADE; provided an overview of the GRADE process for developing recommendations and the final outputs of that process, the evidence profile, and Summary of Findings table; and described the process for framing questions and identifying outcomes [1,2]. In this third article, we will introduce GRADE’s approach to rating the quality of evidence. The goal is to provide a conceptual overview of

the approach. A more detailed description, accompanied by examples, will follow in articles dealing with factors that may lead to rating down or rating up the quality of evidence [3–7].

2. What we do not mean by quality of evidence

In discussions of quality of evidence, confusion often arises between evidence and opinion and between quality of evidence and strength of recommendations. We, therefore, begin by explaining what we do not mean by quality of evidence.

3. Opinion is not evidence

In the absence of high-quality evidence, clinicians must look to lower quality evidence to guide their decisions.

The GRADE system has been developed by the GRADE Working Group. The named authors drafted and revised this article. A complete list of contributors to this series can be found on the *Journal of Clinical Epidemiology* Web site.

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APPENDIX 4 NHS Research Ethics Service Letters for NHS Studies



National Research Ethics Service

Local Research Ethics Committee

Telephone: [REDACTED]

Facsimile: [REDACTED]

05 June 2007

Ms Celia M Harding
Lecturer and Speech & Language Therapist.
City University.
Dept of Language And Communication Science,
Northampton Square.
London,
EC1V OHB

Dear Ms. Harding,

Full title of study: Use of an eating and drinking (dysphagia) training programme for staff in a specialist education provision for children with learning disabilities enhances the management of the students they care for at mealtimes.

REC reference number: 07/Q0509/42

The Research Ethics Committee reviewed the above application at the meeting held on 29 May 2007. Thank you for attending the meeting.

Documents reviewed

The documents reviewed at the meeting were:

Document	Version	Date
Application	1	01 May 2007
Investigator CV		
Protocol		
Covering Letter		
Questionnaire		
Participant Information Sheet	1	
Participant Consent Form	1	
summary of proposal		

Provisional opinion

The Committee would be content to give a favourable ethical opinion of the research, subject to receiving a complete response to the request for further information set out below.

Authority to consider your response and to confirm the Committee's final opinion has been delegated to the Chair.

Further information or clarification required

1. The committee were not clear what benefit would be gained from giving the questionnaire to another group of helpers at a different school. No details were provided about how this data would be used. It was recommended that the study should not be extended to another school and the before and after questionnaire should be given to one group of helpers from the same school only.
2. Clarification was sought about the meaning of 'blinding of data' (Question A10-1)
3. What method will be used to score the questionnaire?
4. Before finalizing the questionnaire, advice should be sought from a statistician
5. A consent form would not be necessary as completion of the questionnaire implied consent

When submitting your response to the Committee, please send revised documentation where appropriate underlining or otherwise highlighting the changes you have made and giving revised version numbers and dates.

The Committee will confirm the final ethical opinion within a maximum of 60 days from the date of initial receipt of the application, excluding the time taken by you to respond fully to the above points. A response should be submitted by no later than 03 October 2007.

Ethical review of research sites

The Committee agreed that all sites in this study should be exempt from site-specific assessment (SSA). There is no need to submit the Site-Specific Information Form to any Research Ethics Committee. However, all researchers and local research collaborators who intend to participate in this study at NHS sites should seek approval from the R&D office for the relevant care organisation.

Membership of the Committee

The members of the Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

07/Q0509/42

Please quote this number on all correspondence

Yours sincerely


Chair

Email

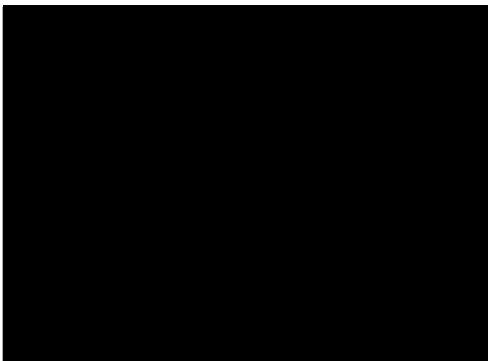


Enclosures: ... List of names and professions of members who were present at the meeting and those who submitted written comments.

*Copy to: Prof. Jane Marshall, Department of Language and Communication Science, City University, EC1V 0HB.
[R&D Department for NHS care organisation at lead site]*

 Local Research Ethics Committee

Attendance at Committee meeting on 29 May 2007



- Consultant Paediatrician
- GP
- Lay Member
- Consultant in Old Age Psychiatry
- Clinical Psychologist
- Consultant in Respiratory Medicine
- Lay Member
- Clinical Pharmacist
- Clinical Pharmacist
- Midwife



National Research Ethics Service
Outer West London REC

Telephone: 020 8869 3928
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15 September 2009

Ms Celia Harding
Speech and Language Therapist / Lecturer.
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Department of LCS,
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EC1V 0HB

Dear MS HARDING

Study Title: An evaluation of an intensive desensitisation, oral tolerance therapy and hunger provocation programme for infants and children who have had prolonged periods of tube feeds.

REC reference number: 09/H0709/48

Protocol number: 1 - July 2009

Thank you for your letter of 21st August and subsequent correspondence by e-mail responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>. *Where the only involvement of the NHS organisation is as a Participant Identification Centre, management permission for research is not required but the R&D office should be notified of the study. Guidance should be sought from the R&D office where necessary.*

Sponsors are not required to notify the Committee of approvals from host organisations.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Participant Information Sheet: for parents	2	
Participant Information Sheet: for 6 year olds	3	
Participant Consent Form: for parents and participants	2	
Assent for for 6 year olds	2	
Response to Request for Further Information		
Paediatrician's Comments	01/05/2009	
Participant Consent Form: Intensive Approach	1 - July 2009	
Participant Consent Form: Feeding Clinic	1 - July 2009	
Participant Information Sheet: Intensive Approach	1 - July 2009	
Participant Information Sheet: Feeding Clinic	1 - July 2009	
Compensation Arrangements		23 April 2009
Covering Letter	1- July 2009	
Protocol	1 - July 2009	
Investigator CV	1 - July 2009	
REC application	1	26 June 2009

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

09/H0709/48

Please quote this number on all correspondence

Yours sincerely


Chair

Email: 

Enclosures: "After ethical review – guidance for researchers"

Copy to: Ms. Nicola Botting, City University
[R&D office for NHS care organisation at lead site]



National Research Ethics Service

Central London REC 1

Telephone: [REDACTED]

Facsimile: [REDACTED]

30 November 2010

Ms Celia Harding
City University London
Dept. of Lang. & Communication Science
Northampton Square
London
EC1V 0HB

Dear Ms Harding

Study Title: Does the use of a parent-lead non-nutritive speech and language therapy / nursing programme promote functional sucking skills, positive weaning outcomes and promote positive interaction opportunities during mealtimes with babies born prematurely?

REC reference number: 10/H0718/57

Thank you for your letter of 12 October 2010, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered in correspondence by a sub-committee of the REC at a meeting held on 26th November 2010. A list of the sub-committee members is attached.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

The Committee has not yet been notified of the outcome of any site-specific assessment (SSA) for the non-NHS research site(s) taking part in this study. The favourable opinion does not therefore apply to any non-NHS site at present. I will write to you again as soon as one Research Ethics Committee has notified the outcome of a SSA. In the meantime no study procedures should be initiated at non-NHS sites.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where the only involvement of the NHS organisation is as a Participant Identification Centre (PIC), management permission for research is not required but the R&D office should be notified of the study and agree to the organisation's involvement. Guidance on procedures for PICs is available in IRAS. Further advice should be sought from the R&D office where necessary.

Sponsors are not required to notify the Committee of approvals from host organisations.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Protocol		08 July 2010
Covering Letter		01 July 2010
GP/Consultant Information Sheets		12 October 2010
Response to Request for Further Information		12 October 2010
REC application		08 July 2010
Evidence of insurance or indemnity		
Referees or other scientific critique report		
Summary/Synopsis		
Investigator CV		18 May 2010
Participant Information Sheet	2	12 October 2010
Participant Consent Form	2	12 October 2010

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
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- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

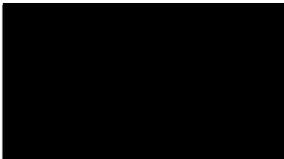
We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

10/H0718/57

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely



Chair

Email:



Enclosures:

*List of names and professions of members who were present at the meeting and those who submitted written comments
"After ethical review – guidance for researchers"*

Central London REC 1

Attendance at Sub-Committee of the REC meeting on 26 November 2010

Committee Members:

<i>Name</i>	<i>Profession</i>	<i>Present</i>	<i>Notes</i>
[REDACTED]	General Practitioner	Yes	

Written comments received from:

<i>Name</i>	<i>Position</i>
[REDACTED]	Pharmacologist
[REDACTED]	Nurse Consultant

APPENDIX 5 Statements of Co - Authors of Publications