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Assessing children's swallowing: parent and professional perceptions

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Abstract:

Purpose: For infants and children who have difficulties with eating, drinking and swallowing, (dysphagia), there are significant health risks that include aspiration (food and fluid entering the lungs) and poor growth. Videofluoroscopy is often the

instrumental method of assessment used to exclude or confirm aspiration. This exploratory review investigated parental and referrer expectations of videofluoroscopy.

Design/methodology/approach: Data were gathered through the use of structured telephone interviews before and after videofluoroscopy.

Findings: Four key themes emerged: 1) The importance of identifying specifically the problems with swallowing; 2) understanding the rationale for videofluoroscopy; 3) preparing a child for videofluoroscopy, and 4) using videofluoroscopy to inform management. Referrers used videofluoroscopy to confirm their concerns about a child's ability to swallow safely.

Practical implications: Parents understood that the videofluoroscopy was to identify specific swallowing difficulties. They reported anxieties with managing the child's positioning during the procedure and if the child would eat. They also had concerns about outcomes from the study. Some of these issues raise questions about the true value and benefits of videofluoroscopy.

Originality /value: This is the first study that considers parent views of an instrumental assessment. For some parents of children with learning disabilities, mealtimes are an important social occasion. Further studies that focus on decision making about children with learning disabilities who find feeding difficult are warranted as parents feel loss and disempowerment when decisions are made about non – oral feeding.

Key words: assessment; dysphagia; neurodevelopmental disorders; learning disabilities; unmet health needs; community

Introduction:

Infants and children who experience eating, drinking and swallowing difficulties (dysphagia) can find mealtimes stressful (Mathisen, 2001). Many cases of dysphagia in a paediatric population are likely to be associated with learning disabilities (Field et al, 2003). In the typically developing population, parent and carer reports suggest that 25 – 45% of infants and toddlers present with some degree of feeding and swallowing difficulty, mostly colic, vomiting, slow feeding and refusal to eat (Bernard – Bonnin, 2006). In contrast, the number of children with learning disabilities and additional eating difficulties can be as high as 80% (Arvedson, 2008; Brackett et al, 2006). Having a combined physical and learning disability increases the risk of dysphagia (Hardwick et al, 1993; Reilly et al, 1992). Children with disabilities such as cerebral palsy are of increased risk of dysphagia with prevalence ranging from about one fifth of children with cerebral palsy of any degree (Fung et al, 2002; Parkes et al ,2010) to 99% in children with severe cerebral palsy and intellectual disability (Calis et al ,2008). Dysphagia is associated with significant health risks, including poor growth and aspiration (food and fluid entering the lungs) (Field et al, 2003; Harding & Wright, 2010).

The impact of managing swallowing difficulties

When oral feeding is considered to be of high risk in relation to aspiration, alternative methods such as being fed by a tube surgically inserted in the stomach (gastrostomy) may need to be considered (Brackett et al, 2006). Stress increases as the level of the child's physical needs and dependence increase and although children

with complex physical and learning needs can be challenging to feed, parents often develop their own strategies to minimize the risks associated with aspiration (Cowpe et al, 2014). Additionally, parents feel that they need to maintain ownership, control and responsibility for their child's feeding (Hoddinott et al, 2000).

Access to information about dysphagia is not always provided in an accessible or timely way, and consultations with healthcare practitioners are not always felt to be supportive in relation to sustaining oral feeding for as long as possible (Hewetson & Singh, 2009; Peterson et al, 2006; Sleigh, 2005). Issues linked to parents' confidence, identity and feelings of loss and disempowerment in managing their own child's nutritional intake are described in the literature following professional intervention (Hewetson & Singh, 2009; Sleigh, 2005).

Instrumental assessment of swallowing

Videofluoroscopy (VFSS) is an instrumental procedure used to assess swallowing (Arvedson, 2008). A VFSS provides dynamic imaging which shows the mouth (the oral phase), the back of the throat (pharyngeal phase), and top of the stomach (oesophageal phase) during swallowing and as such is regarded as the gold standard for identifying aspiration (Arvedson, 2008). This radiological procedure provides recorded images (on videotape or digitally) of a client's swallowing when eating foods and liquids mixed with radiopaque material. Although it is regarded as an important assessment in identifying aspiration, inter – rater reliability between professionals such as speech and language therapists (SLTs) and radiologists is variable. The inter - rater reliability is low when interpreting recordings of adults swallowing in relation to the severity of swallow dysfunction (Bryant et al, 2012; Perry & Love, 2001; Stoeckli et al,

2003). Aspiration of solid foods appears to have a higher rater – reliability compared to fluid rater-reliability in adult studies (Kuhlemeier et al, 1998; Scott et al, 1998). In contrast, SLTs rating of swallowing *fluids* safely using VFSS with children has a high rater-reliability, compared to poor rater-reliability with *solids* (de Matteo et al, 2005). There is a possibility that parents and professionals may disagree about the validity of VFSS and whether it reflects children's feeding ability in real life settings. The relationship between aspiration and compromised respiratory health is complex and can sometimes be contested by members of the multi-disciplinary team (Cass et al, 2005).

Expectations when using instrumental assessment

Referring professionals expectations and thoughts on outcome of the VFSS may include stopping oral feeding (in case of unsafe swallowing), or advice about which substances of food are safe to swallow (Brackett et al, 2006). Parents may be more hopeful about the outcome of VFSS in relation to advice on how to maintain oral feeding. Adequate preparation of parents in relation to potential outcomes with opportunities for shared decision making in relation to a child's eating and drinking is a necessary part of the process (Elwyn et al, 2012). There is scant research exploring parental expectations of VFSS and whether their understanding of swallowing problems before and after the procedure changes. The aim of this pilot study was to ; (a) consider parental expectations and concerns, (if any) about the VFSS procedure and the impact it would have on the management of their child's mealtimes; and (b), to consider the referrer expectations and perceptions on how the VFSS would help with children's feeding management.

Method:***Design***

An exploratory study was carried out involving telephone interviews for parents and referring professionals administered before and after a VFSS. The telephone was used as in many cases, parents travelled from outside London to their appointments, and the availability of the researcher to collect data was time limited. These interviews were completed periodically over a ten month period at a Central London hospital. The student speech and language collecting the data was only available for the specified period, therefore this was a time limited study. The study protocol was approved by a Central London NHS ethics committee (NRES Westminster, REC reference 11/LO/0629, IRAS ID = 65253) and the City University London ethics committee. Written parental and referrer consent was obtained prior to data collection.

Participants

Parents of children on the waiting list for VFSS were sent written information about the study. Parents self-selected their participation by contacting the Speech and Language therapy team once they had read the information. Nine parents of children aged between 11 months to 13 years of age (average age = 5 years 6 months) were recruited to take part in this study. All parents who participated were mothers of the

children. Eight of the children referred for a VFSS had neurodevelopmental disorders, and one child had no specific diagnosis (Table 1). Six referrers participated. Three SLTs elected not to participate in the study. No reason was provided for non-participation. All referrers were SLTs working in community settings. Work experience of the SLTs ranged from 4 - 32 years (average = 13 years) post qualification. The referring SLTs had requested a VFSS due to concerns regarding the safety of children's swallowing.

Interview schedules

Two interview schedules were used in this study: one for parents and one for referrers. The parent schedule questions aimed to ascertain parental knowledge of their child's condition and the reason for the VFSS referral. This interview schedule used the typical pre – and post- videofluoroscopy interview questions conducted in the department where the study was carried out. Parents were asked why their child had been referred for a VFSS, what, if any, risks they felt their child experienced during eating and drinking, and what they understood would happen during the procedure. They were also asked their opinions after the VFSS, and if the assessment information changed their management. Referrers were asked basic demographic questions and they were additionally asked questions about what they felt the child's difficulties were before VFSS, and if the outcomes were anticipated or not. Questions also were focused on the VFSS procedure for both parents and referrers and the likely impact of the results on the management of the child's eating and drinking. Questions were either open-ended, or required a rating on a scale (e.g. [a little] ... [a lot]) but with opportunities to expand on the reasons behind the rating.

- Put Table 1 about here -

Procedure

Interview schedules were administered by telephone by an SLT student four weeks before and four weeks after the VFSS. Telephone interviews were conducted as the participants lived a considerable distance from the hospital where the VFSSs took place. The interviews were conducted by the student as she was not directly involved in the child's clinical care.

The schedules took 20 - 30 minutes to administer for both parents and referrers. The post - interview schedules were completed four weeks after the VFSS so that parents and referrers had time to receive a written version of the results and management recommendations from the assessment. Open ended questions were analyzed and responses were viewed as a whole to enable consideration of themes in the data. Parent perceptions were compared with referrer concerns, expectations and recommendations for changes in management. A Grounded Theory approach (Glaser & Strauss, 1967) was used to categorise themes as they emerged from the data.

Results:

Four key themes emerged from the data collected. These themes were; 1) Identification of an eating and drinking problem; 2) Understanding the VFSS procedure; 3) Preparing the child for VFSS, and 4) Using VFSS to inform management.

Identification of an eating and drinking problem

Both parents and referrers appeared to be able to identify that all children referred for VFSS had a learning disability and difficulty with eating and drinking that might put their health at risk. Before the VFSS assessment, six parents said that they were "very concerned" about their child's eating and drinking difficulties. This concern reduced to two parents after the VFSS assessment. Problems with feeding, eating and drinking noticed by parents included coughing with fluids and food (5), vomiting (2) and chest infections, or wet, gurgly breathing (6). All parents were able to describe their child's specific difficulties before VFSS, e.g.

"Swallowing problems; food might be going into the lungs causing chest infections" (ID: 5)

After the VFSS parents described their child's difficulties in relation to aspiration:

"Pooling at front of mouth and in pharynx; disorganised swallow, but no aspiration seen." (ID:1)

"He does aspirate a bit but not harmful; holds food in mouth for a while; sometimes control when going down is reduced." (ID: 9).

Three commented that the difficulties with eating and drinking carried significant health risks for their child. Although five had previously experienced a VFSS with their child, they did not comment on the relationship between dysphagia and poor health.

Referrers who participated in this study had requested a VFSS following clinical assessment where they observed possible signs of aspiration and risk related to swallowing problems. These included hospital admission and respiratory symptoms; reflux related difficulties and a complex medical history ; breathing problems when drinking fluids with non-verbal signs of discomfort and prolonged mealtimes with problems managing some textures . Referrers described additional difficulties with swallowing including coughing during eating and drinking; vomiting; chest infections; breathing difficulties; food refusal, and a range of individual comments including back arching, flushed cheeks, managing flow of a liquid, poor oral skills and distress during mealtimes. Despite the wide range of clinical experience in terms of years (average, 13 years), all referrers identified key features indicative of aspiration risk.

Understanding the VFSS procedure

All participants confirmed that they had received written information about the procedure prior to attending. One participant (ID: 3) reported that the information had been unhelpful, but did not state why. Another participant (ID: 7) admitted that she had not yet read the information, but intended to. From the parent group, seven described an X-ray to observe the swallow:

"Trying different things to see what makes him gag; X-ray to see the swallow; feedback on the day." (ID: 2)

Preparing the child and parent for VFSS

Parents expressed a variety of anxieties about preparing their child for the VFSS procedure. One parent was concerned about managing to negotiate the VFSS suite as their child had dystonic cerebral palsy and required use of a chair (ID: 1). Two others were concerned that the VFSS might not be a productive use of time as their child did not enjoy eating, and that a different and unfamiliar environment for a meal would have a negative impact on their ability to feed at that time. Over half of the sample (6) felt that the child may have difficulties with the assessment either due to lack of understanding or behaviour was likely and that this was stressful to consider before the actual procedure took place. Parents reported that they were very concerned about what VFSS might reveal about their child's dysphagia although no one gave an example of what those concerns might be.

Using VFSS to inform management

All parents received information prior to the VFSS. Three parents were able to appreciate the importance of identifying if aspiration was present or not. One parent felt that the VFSS was important so that the school could understand her child's feeding management needs (ID: 8). Others felt that VFSS would in some way help contribute towards managing better feeding strategies and reducing poor health associated with

aspiration (2), although three said that the VFSS results would not influence how they fed their child.

After the VFSS, all parent participants rated the experience as being helpful in understanding their child's feeding difficulties. Four parents reported that the VFSS had guided them to change the way they fed their child [a lot] compared to two who reported that the VFSS had influenced feeding management [a little bit]. Parents were able to describe management strategies:

"Time spent on meals reduced GREATLY – now 30 minutes, due to changing the texture." (ID: 7)

_Put Table 2 about here

All referrers reported that the VFSS findings were broadly what they expected from their clinical observations and assessments (Table 2). Referrers interviewed stated that the outcome of the VFSS had changed their management strategies. Referrer 1 reported that texture modification would be added to the child's feeding plan, as did referrer 2. However, referrer 2 also recommended a gastrostomy in addition to texture modification. Referrer 3 recommended a "taster" programme of small amounts of puree, although the plan was to have a gastrostomy inserted. One referrer reported that small amounts of oral intake could be given but supplementary nasogastric tube feeding was still needed. For two referrers (7 and 8), they reported that the VFSS had confirmed what they had predicted and advice on management would not change. Table 2 shows outcomes from each of the VFSS completed, compared to parent and

referrer understanding of the reason for a referral for the procedure, and the understanding of the outcome.

Discussion:

The sample size for this pilot study is small, with great variations in age and gender which makes it difficult to draw specific conclusions. However, it does raise some important points that warrant further research, both from the perspective of the parent of a child with complex swallowing problems and also professionals referring for VFSS. All children who received VFSS, (except one, ID: 9) had diagnoses associated with feeding and swallowing difficulties (e.g. cerebral palsy, gastroesophageal reflux, etc.). Parents had opinions about what the VFSS would show and its impact on feeding management, but their views tended to be complex and varied (Table 2). All referrers suspected aspiration (e.g. aspiration alone; aspiration of reflux; increased respiratory effort with fluids; choking) during clinical assessments and were relying on VFSS to confirm this. The referrers were rarely surprised by the results of the VFSS which might lead to questions about the added value of the procedure, particularly as it means exposing children to radiation (Table 2).

The SLTs predicted identification of specific eating, drinking and swallowing difficulties, and their concerns were identified by VFSS. When examining parent descriptions of their child's difficulties post interview it was interesting to note how their accounts incorporated technical language more readily associated with professional discourse , e.g. "pooling" (ID:1); "aspiration" (ID:2); "lots of aspiration and tiring" (ID:3); " no chewing and gagging" (ID:4) ; "some aspiration; problems with oral control of food"

(ID:8); " He does aspirate a bit" (ID:9). For these six cases, there were no significant differences between the parents' report of the problems compared to those of the referrers (Table 2).

Several cases highlighted differences in the perceptions of the referrer compared to the parent. For example, the parent of child (ID: 9) had reported before the VFSS that he "can't swallow lumpy food and chokes a lot. He makes noises when swallowing". The referrer requested a VFSS as there was a history of chest infections, food refusal, choking and holding food in the mouth. Post VFSS, the parent of ID: 9 described her child's aspiration as being something that did happen, but only in small amounts and that it was "not harmful" if textures were modified. In contrast, the referrer commented that the management plan after the VFSS needed to focus on reducing oral intake to smaller amounts with an increase in tube feeding, perhaps indicating that there was some potential harm. Interestingly, three parents reported that VFSS would not influence how they fed their child. Differences in opinions between professionals and parents have been reported in the literature, with parents believing that professionals focused on risk and health rather than quality of life and the emotional needs of the family (Cowpe et al, 2014). From the data collected, it is difficult to determine whether parents' differing perceptions relate to difficulties understanding the concepts discussed, or emotional barriers in accepting changes in feeding management. It was anticipated that parents would bring up the issue of the potential loss of oral feeding as an outcome of the VFSS. Interestingly, parents' primary focus was their concerns about managing their child's behaviour to be able to participate on the day of the test (3); if the child would actually eat anything (2), and the child's mood (5). The idea that the child's behaviour on the day of the VFSS is a management issue for parents could be

an important psychosocial concept that requires further consideration. In addition, further research on how parents might respond to and manage being told that their child has experienced aspiration post VFSS and might be unable to feed orally would be useful.

The anxieties expressed by the parents in the preparation of the child for the VFSS (e.g. problems with getting the child into the right position for the VFSS due to “dystonia and positioning the wheelchair” (ID:1); managing behaviour, “getting X to eat something” (ID: 4) ,and “ depends on his mood on the day” (ID: 8)), shows the need to prepare parents more thoroughly given the VFSS could indicate the child's need for tube feeding, a decision which could be emotionally charged.

Three parents did identify that the VFSS would help guide the team involved in the development of appropriate goals for their children, and others mentioned that the VFSS was needed to see if aspiration was present (3). One parent (ID: 2) wished that the VFSS could be repeated as the referrer commented that the parent found the recommendation of an increase in tube feeding with reduced oral feeding difficult. Parents may require significant support when dealing with the complex issues surrounding management following interpretation of VFSS results. A professional relationship is important so that information can be shared and parents are supported to express their feelings and views during the decision making process (Elwyn et al, 2012). From the study of Hoddinott et al (2000) it became clear that it is important for parents to maintain some level of ownership for their child's feeding. Conversely, anecdotal evidence suggests that clinicians feel VFSS has value in supporting parents to visualise the complexities and risks of swallow dysfunction, although this did not emerge as a theme among referrers in this pilot study. Given the majority of parents reported

that VFSS had resulted in changes in the way they fed their child, this may be the result of the involving them in the evaluation of swallowing safety by viewing the video images. Although five parents had previously experienced a VFSS with their child, they did not comment on the relationship between dysphagia and poor health.

There are limitations with this study which make it difficult to draw specific conclusions. As noted, the sample size is small with variations in age and gender. In addition, parent participants were self-selecting in this pilot study, so the opinions raised by them are likely not to be reflective of all parents referred for VFSS. Gaining this data using the telephone was another limitation as participants might not have been able to express their views in as much depth as perhaps they would have wished. Using semi – structured interviews with some focus groups in further studies may enable greater consideration of the themes discussed in this study, and consequently allow greater understanding of the emotional and cultural aspects of decision making about managing complex eating and drinking problems for both professionals and parents of children who have complex needs. Only SLTs were referrers in this study. A larger sample in a future study might include a wider range of professionals, in particular community nurses who may be actively involved in supporting families of children with learning disabilities on a regular basis. This could potentially identify more specific information about healthcare practitioner reasons for referral and knowledge about swallowing disorders and associated health risks for children with swallowing problems and learning disabilities.

Finally, the VFSS is only a snapshot of a child's eating skills and does not replicate a typical mealtime experience. Consequently, this may compromise the test's sensitivity and specificity. Future studies could explore referrer confidence in clinical history and

assessment, as compared to VFSS, and what type of impact they feel the procedure might have on parent/carer understanding and behaviour over and above the sharing of clinical assessment results.

In summary, this pilot study highlights several important areas related to parent and referrer perceptions of the value of VFSS. It is clear that further in - depth studies should aim to provide more information to support healthcare practitioner and parent understanding and management of children with complex dysphagia and learning disabilities. Calis et al (2008) stated that clinicians should not wait for parental concern on feeding problems and safety. However, from this study, there is a tentative suggestion that shared decision making in performing a VFSS and the potential emotional need to consider oral versus non-oral feeding is essential for parents and carers of children with learning disabilities who have dysphagia. A wider, multi-centre study would potentially yield a wider range of professional referrers, and comparing reasons for referral with perception of risk in relation to feeding difficulties would highlight areas for future research and professional education.

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Table 1: Participants' children's characteristics

Participant	Age	Sex	Diagnosis	Previous VFSS
1	7years 6months	F	Quadriplegic dystonic CP	No
2	11 months	M	Global developmental delay; chromosomal abnormality; GORD	No
3	13 years	F	Quadriplegic spastic CP	Yes
4	2 years 6 months	M	Non-specific congenital disorder. Has a malformed larynx. Gastrostomy tube for weight only	No
5	10 years	M	Non-specific congenital disorder	Yes
6	12 months	M	Non-specific congenital disorder	Yes
7	5 years	M	Dystonic CP	Yes
8	7 years	M	Quadriplegic spastic CP	Yes

9	12 months	M	No known congenital disorder – large tonsils impacting on swallowing	No

CP - Cerebral palsy

GORD – Gastroesophageal reflux disease

Table 2: Comparison of parent perception of reason for referral for VFSS, referrer reason for referral and actual outcome

Parent perception of why the child has been referred for VFSS	Referrer reason for recommending VFSS	Parent report of VFSS assessment & outcomes	Referrer report of VFSS assessment & outcomes
1. No gag or swallow reflex	1. The child had been an in-patient with swallowing difficulties and needed follow up /chest infections /food refusal /limited oral skills	1.Pooling (of food) at front of mouth and in pharynx ; disorganised swallow, but no aspiration seen	1. Oral skills v poor which impacts on the swallow. Outcome: Texture modification – thickeners
2. Poor weight gain & gagging	2. Complex medical history ; chronic reflux; clinical indicators of aspiration noted	2. At risk of aspiration, both liquids and solids. He needs tube feeds	2. Aspiration. Outcome: Some small amounts of thickened textures with tube feeding
3. Trouble with chewing & chest infections	3. History of chest infections & poor health ;school has concerns about feeding the child	3.Lots of aspiration and tiring – gastrostomy fitted / nil by mouth – gastrostomy, but child healthier and happier	3. Child was aspirating. Outcome: Tube feeding needed, with some tastes of puree only. Gastrostomy tube being considered
4.Malformed larynx – poor oral feeding (has a gastrostomy for weight)	4. Changes in voice quality during feeding	4. No aspiration	4. No response to follow up

5. Swallowing problems –food might be going into the lungs	5. Risk features of aspiration seen clinically	5. Everything fine; delayed swallow – holds food in mouth, but can still eat orally	5. No response to follow up
6. Unable to drink milk ; not happy with local service, so VFSS a second opinion	6. Slow to feed	6. No aspiration; a bit of build-up of food in the mouth, but can still feed him	6. No response to follow up
7. No chewing; gagging; takes 1.5 hours to eat meal; tongue often "up"/	7. Long time to feed the child. Child deteriorates on some textures	7. Delayed swallowing ; chewing problems, so need to change texture; thicken fluids as hard to manage	7. Thin fluids a risk. Outcome: no major change to intervention - thicken fluids, and have soft mash for solids
8. Coughing and distressed when eating. Has gastrostomy for night feeds. Eats orally in the day	8. Aspiration signs noted with fluids such as breathing problems and facial expression changes	8. Some aspiration and food holding in his mouth; problems with oral control of food /coordination	8. At risk of aspiration. Outcome: No major change to intervention - Making sure textures are manageable (not too hard to chew), and making sure the oral cavity is clear between mouthfuls
9. He can't swallow lumpy food and chokes a lot; makes noises when swallowing	9. Clinical signs of chest problems ; food refusal ; coughing and choking; holding food in mouth	9. He does aspirate a bit (but not harmful); holds food in mouth for a while; sometimes control when going down is reduced	9. Silent aspiration seen. Outcome: Reduced oral intake /small amounts. Intake mainly via nasogastric tube feeding

