

# BMJ Open

## What do parents of children with dysphagia think about their multidisciplinary team? A qualitative study

Journal:	<i>BMJ Open</i>
Manuscript ID:	bmjopen-2014-005934
Article Type:	Research
Date Submitted by the Author:	19-Jun-2014
Complete List of Authors:	Cowpe (nee Jebson), Emma; Royal Free Hospital, Speech and Language Therapy Smith, Christina; University College London, Language & Communication Div of Psychology & Language Sciences Hanson, Ben; University College London, Department of Mechanical Engineering
<b>Primary Subject Heading</b>:	Qualitative research
Secondary Subject Heading:	Paediatrics
Keywords:	QUALITATIVE RESEARCH, Developmental neurology & neurodisability < PAEDIATRICS, Community child health < PAEDIATRICS

SCHOLARONE™  
Manuscripts

1  
2  
3 What do parents of children with dysphagia think about their MDT?  
4 A qualitative study  
5  
6  
7  
8

9 Authors

10 Emma Jebson, Speech and Language Therapy, Royal Free Hospital, London, UK  
11 Ben Hanson, Department of Mechanical Engineering, University College London, UK  
12 Christina H Smith, Language and Communication, Division of Psychology and Language  
13 Sciences, University College London, UK  
14

15  
16  
17  
18 Corresponding Author

19 Christina H Smith  
20

21 Address

22 Division of Psychology & Language Sciences  
23 Chandler House  
24 2 Wakefield Street  
25 London  
26 WC1N 1PF  
27 Email: [christina.smith@ucl.ac.uk](mailto:christina.smith@ucl.ac.uk)  
28 Telephone: +44 20 7679 4233  
29 Fax: +44 20 7679 4238  
30  
31  
32  
33

34 Word Count

35 Main text (excluding title page, abstract, references, quotes, tables): 2094  
36  
37  
38  
39

40 Keywords: parent, multidisciplinary team, paediatric, dysphagia, qualitative  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

## Abstract

### Objectives:

To seek the experiences and perspectives of parents caring for children with dysphagia, with emphasis on their experiences of working within their child's multidisciplinary team (MDT)

### Setting:

This research was completed in community settings, within families' homes across the UK.

### Participants:

Fourteen families were recruited via purposive sampling. Criteria specified that participants must care for a child under the age of 18 and to decrease ambiguity the term 'diagnosis of dysphagia' was defined as the need for modified (thickened) fluids. Exclusion criteria: caring for an adult over the age of 18; diet and fluid modifications for reasons other than dysphagia (e.g. for symptomatic treatment of Gastro-oesophageal reflux disease (GORD)). Participants were interviewed within their homes using a semi-structured questionnaire and data was analysed using a descriptive phenomenological approach through use of thematic coding and constant comparison. Themes and relationships were inductively generated from the data.

### Results

Participants universally expressed a desire to be involved with their child's multidisciplinary team, and a number of facilitators and barriers to collaborative working were identified. Participants responded to the barriers faced in three ways: reacting emotionally, seeking solutions, and making decisions.

### Conclusions:

This study recorded in-depth reports of participants' experiences of working with healthcare providers. Despite efforts towards family-centred collaborative care, parents shared accounts of times when this has not occurred, reporting negative effects on the wellbeing and quality of life of their child and family.

The study protocol and consent procedure were approved by the local institution ethics committee (LC/2011/007).

### Data sharing:

No additional data available

### Strengths and Limitations of this Study

- Evidence of facilitators and barriers to effective parent-professional collaboration
- Provision of parents' own report of experiences with multidisciplinary teams
- Supports literature relating to the need for holistic, patient-centered care and provides skills and attributes required of professionals in multidisciplinary working
- Small-scale study encouraging further research in this area

## Background

Swallowing difficulties (dysphagia) can vary in aetiology, symptomology and severity and affect children with a variety of medical diagnoses. Up to 90% of children with neurodevelopmental disorders such as cerebral palsy and Down syndrome experience signs of dysphagia including coughing, choking, chest infections, poor weight gain and breathlessness[1], often from birth or early infancy. Children with GORD and those born prematurely are also at increased risk of childhood dysphagia[2-4]. Thus dysphagia can be a symptom of different underlying medical conditions and is diagnosed and treated by a variety of medical specialists.

Children with complex and pervasive needs require support in a range of in- and outpatient specialist settings including hospitals, clinics and schools. Children may be in contact with a range of health and care professionals including Paediatricians, GPs, Speech and Language Therapists, Physiotherapists, Dieticians and Social Workers; for these children and their families well-coordinated input is essential for provision of individualised care[5-7]. Multidisciplinary teams (MDTs) are commissioned to provide joined up, patient-centred support and seek to place children and their families at the centre of decision-making processes[8,9,4]. Government initiatives such as the Early Support keyworking scheme[6] and the Common Assessment Framework[10] have been set up throughout the UK to improve care quality by providing a framework for regular MDT discussion; avoiding repetition of information and reducing carer burden; and providing a single point of contact for better coordination of care and support[6].

Despite its prevalence, the cost of dysphagia upon health services has not been calculated, nor has the burden on child and family health and wellbeing been determined. There has been no specific research to date into the experiences of carers of dysphagic children within the UK although one study has explored the experiences of carers of dysphagic children in the USA[11]. Research has focused on the needs of carers of children with complex needs which may or may not involve dysphagia as a symptom[12-16], or has been confined to specific settings such as schools[9,17,18] or Child Development Centres[19]. Research completed by Craig et al[20,21] has explored the experiences of parents of children requiring gastrostomy feeding; their research outlines a range of pertinent issues for caregivers including the emotional and social impacts of enteral feeding, the impact on child and carer QoL, and the need for good-quality information and support for families of children facing decisions around gastrostomy feeding.

## Method

### Participants

This cross-sectional study involved parents and carers of children with a diagnosis of dysphagia, aged between two and 11 years. Information about the study was distributed through special schools, charities and local and national support groups in the form of letters, online forums and newsletters. Parents self-selected by contacting the researcher based on the information provided, and gave formal consent to participate in the study. Fifteen parents were initially recruited; one interview was discounted from analysis as the individual with dysphagia was 24 years old. Analysis was completed with interviews from 14 parents; the children's characteristics are summarised in table 1.

Table 1: Individual Child Characteristics

Parent ID number	Child age	Medical diagnoses	Age at diagnosis of dysphagia	Nutritional intake	Route to recruitment
1	10	CP epilepsy, GORD	Under 1 year	Oral diet	School
2	5	Lissencephaly	18 months	Oral diet	School
3	3	No diagnosis	8 months	Oral diet	School
4	11	CP, hydrocephalus, epilepsy, VI, HI	Under 1 year	PEG plus oral tastes.	School
5	4	CP, Chronic Lung Disease, GORD	1 year	Oral diet (previously PEG)	School
6	4	Alagille Syndrome	Under 1 year	Half oral, half PEG	School
7	2	DS, CHD	Under 1 year	Oral diet	Charity
8	12	DS, GORD	5 years	Oral diet	Charity
9	6	Congenital cytomegalovirus, GDD	1 year	Oral diet	Family worker
10	3	DS, CHD, GORD, HI	Under 1 year	Oral diet	Charity
11	7	DS	Under 1 year	Oral diet	Charity
12	5	DS	Under 1 year	Oral diet (previously PEG)	School
13	6	DS, GORD, VI, HI	2 ½ years	Oral diet	School
14	3	DS, Hirschprung's Disease, GORD	3 years	Oral diet	Charity

Key: CP: Cerebral Palsy GORD: Gastro Oesophageal Reflux Disease  
 DS: Downs Syndrome GDD: Global Developmental Delay  
 VI: Visual Impairment HI: Hearing Impairment  
 CHD: Congenital Heart Disease

#### Procedure

The local institution research ethics committee approved the study protocol and consent procedure (LC/2011/007). Participants were contacted and interviews were scheduled at their convenience. Thirteen parents were interviewed at the family home and one parent was interviewed at her place of work.

A descriptive, phenomenological approach was used to gather and analyse the data; utilising participants' reports to better understand their experiences of caring for a child with dysphagia. A semi-structured questionnaire formed the basis of interviews: parents were asked questions relating to their child's swallowing history, support received in the initial stages, their ongoing needs and current support. Use of a semi-structured questionnaire gave

1  
2  
3 structure to interviews whilst allowing for flexible questioning and deviation from the  
4 'script', allowing for a more natural conversational (rather than formal) interview  
5 approach[22, 23]. Interviews took approximately one hour and were audio recorded for  
6 transcription.  
7

8  
9 The researcher kept a journal for additional notes throughout the data collection process and  
10 recorded perceptions on the attitude of interviewees (e.g. positivity / negativity) in addition to  
11 themes that began to emerge[23,24].  
12

### 13 Analysis

14 Interviews were transcribed and returned to participants to verify accuracy. Two parents  
15 made minor clarifications to comments within their manuscript; one parent providing further  
16 detail of the chronology of her daughter's medical interventions and another providing the  
17 full name of their child's thickener. The parent's amendments were recorded prior to coding.  
18  
19

20 Following verification the transcripts were analysed by the interviewer using thematic coding  
21 and constant comparison[25]. A transcript was selected at random and manually coded line by  
22 line with short phrases summarising each unit; examples included *negative emotions*, *creative*  
23 *problem solving* and *service flexibility*. Units varied in length; comprising of phrases,  
24 sentences or a number of lines, with one code applied to each unit.  
25  
26

27 Additional transcripts were then added to the set and manually coded, with codes being  
28 continually compared within and between scripts and amended where required[26]. As  
29 analysis progressed codes were grouped into broader themes. For reliability of the coding,  
30 25% of the coded transcripts were validated by an independent researcher with experience in  
31 qualitative data analysis.  
32  
33

### 34 Results

35 One overriding theme emerged from the data, present in all 14 interviews: all parents and  
36 carers expressed their desire to be involved in their child's care through close involvement in  
37 the MDT. Three sub-themes emerged relating to factors particularly facilitating or hindering  
38 their ability to be involved within the MDT. A further three sub-themes emerged as parents  
39 described their responses to the barriers they have experienced (figure 1). Participants' quotes  
40 are provided verbatim alongside their identifying number (table 1).  
41  
42  
43

#### 44 Being involved within the MDT

45 Without exception, parents reported a desire to be recognised as a key member of their child's  
46 MDT. Parents valued the specialist knowledge and opinion of healthcare professionals, but  
47 wanted to be identified as the expert about their child.  
48  
49

50 'My son is my number one subject' (14)

51 'I'm the one dealing with it everyday. If you want to ask something it's better to ask me.'  
52 (10)

53 'We know our children better than [professionals] do as individuals; they have to take  
54 our views on board and respect our opinions.' (7)  
55  
56

#### 57 Facilitators and barriers

58  
59  
60

The facilitators and barriers to parents' collaboration with the MDT were categorised into three separate sub-themes: (i) accessing services, (ii) professional knowledge and (iii) professional skillset, as below:

*i) Accessing services*

Parents described three main issues around their ability to access services; time, staffing, and flexibility of service delivery. When asked how satisfied they were with the support they had received for their child's dysphagia, nine parents reported some degree of dissatisfaction with service accessibility and availability,

'They won't come and see him at home, which is a real shame.' (2)

'My daughter was ill for the whole winter. [The community Speech and Language Therapist] came as a favour to check her swallow, but there's a fine line now she's in school, with whose remit it is.' (12)

'They said they didn't have enough staff [in hospital] to give support with her feeding.' (3)

'It was quite a few years before they had a permanent Speech and Language Therapist at school.' (4)

Those who had felt largely satisfied with their support acknowledged the same qualities as important; reporting easier access to help and advice due to flexibility and availability of health and care staff,

'The [respiratory] physios are really good. They come in [if she is unwell] and monitor her sats. It saves going to A&E and they take swabs that can be sent off.' (5)

'When we went for the Videofluoroscopy the Speech and Language Therapist came with us...Every six weeks she comes here to see him.' (7)

'We're lucky that we have had support. They're always at the other end of the phone if we need it' (11)

'We have much more support now.' (10)

*ii) Professional Knowledge*

Parents attributed their health and care professionals with a level of expertise and specialist knowledge; however, some parents felt that this knowledge was poorly demonstrated by professionals at crucial time points when it was needed; particularly in the early stages of seeking support and specialist advice for their child. Five parents received misdiagnoses of their child's dysphagia, which resulted in a wait of up to five years for an accurate diagnosis and to receive specialist intervention,

'I kept showing her feeding to so many different consultants and no one spotted it ...they kept saying 'it's a virus, she's fine'. Thirteen times in her first year she was on antibiotics for chest infections.' (3)

'I'm surprised the paediatrician didn't signpost [specialist assessment] more clearly; she knew what [Lissencephaly] was and its implications.' (2)

'I just couldn't believe it took them so many years to take it seriously; it amazed me.' (8)



Those with positive experiences also highlighted the importance of well-demonstrated expert knowledge. These families reported an increase in their knowledge of their child's condition as a result,

'[The specialist's] advice, which I found useful was that there were three things to look at: if he was getting pneumonias...if he was failing to thrive...or if it as taking a very long time to feed him' (2)

'[The specialist] had lots of questions; over the phone I was talking to her and she said my daughter had reflux and dysphagia, just from the phone call.' (8)

### iii) Professional Skillset

Parents provided a list of qualities they value in healthcare professionals (table 2), placing the greatest importance on communication skills. Parents valued professionals who demonstrated a willingness to listen and who actively sought their opinions.

Table 2: Valued Professional Qualities

ID number	Qualities Listed
1	Accessible; two-way communication; being honest without being too negative.
2	Flexibility in appointments; listening and walk alongside you; treating you as a thinking person; addressing my son at appointments.
3	Interacting with my daughter; working well with other professionals; following through with what they say; talking to who they say they will; when you feel they want to help you and are on your side; making notes and giving you copies; being contactable; being approachable; being honest; not being overworked.
4	Being there; being contactable; liaising with each other; being trustworthy.
5	Being caring, friendly; knowing my child so I don't need to repeat myself; record keeping.
6	Good people skills, sensitive to my child's needs and my concerns; good communication; sympathy; seeing my child as an individual.
7	Listen and take the parents' views seriously; communication with parents; explaining jargon; sharing information.
8	Showing expertise in their field; treating children as individuals; not labelling children
9	Professionals working together; putting my child first; sharing information.
10	Listen to parents; being reliable
11	Approachability; being able to explain things.
12	Honesty; encouragement; new ideas; continuity.
13	Approachability; friendliness; warms; engaging our child; active, unhurried listening; empathy.
14	Asking questions of me; active listening; acting on what we say; not labelling our child.

'Parents have the answers even if we don't have the terminology.' (12)

'More the medical side than the community side have no respect or value for what the parents have to say...it's quite nice when you find people who actually listen.' (10)

'The interpersonal (skills) are as important as the clinical (skills).'

 (13)

Parents also described the importance of a positive working relationship between healthcare professionals, themselves and their child:

'In the medical profession it'd hurt me when they wouldn't even address my son at appointments; they would talk to me about him, in front of him, without even saying hello.' (2)



1  
2  
3 ' [I value] people that are good at interacting with my daughter...people who work with  
4 her rather than just talking to mum.' (3)  
5 'Every six weeks [our Speech and Language Therapist] comes here to see [my son] ...  
6 he really likes her.' (7)  
7  
8

9 Parents with negative experiences described times when they felt unheard and 'on a different  
10 page' to professionals. Parents raised concerns that too strong a focus was placed on health  
11 and risk, at times to the detriment of their child's emotional wellbeing and QoL.  
12

13  
14 'I felt that [the professionals] were very risk-averse...their first concern was to ensure  
15 the risk was minimized completely and utterly, rather than recognising that there was a  
16 risk but that it wasn't too great yet.' (2)  
17 'We told school that if the children are having any treats, our daughter can have them  
18 too... There was an event where all the children were having hot chocolate with  
19 marshmallows. They wouldn't let our daughter have one and she got upset.' (8)  
20  
21

22 Parents discussed the importance of information sharing, identifying a need for up-to-date,  
23 jargon-free information to maximise their understanding and involvement. Parents reported a  
24 similar need for more effective information sharing between professionals within the MDT.  
25 Parents identified times when poor collaboration had negatively impacted upon the wellbeing  
26 of their child, or upon themselves as caregivers,  
27

28  
29 '[The professionals] don't liaise with each other at all...although they are all in the same  
30 building.' (4)  
31 'I repeat myself all the time...it's hard to keep bringing up the past.' (5)  
32 'In school there is a lack of communication...at one time they had stopped feeding her. I  
33 felt so upset by it.' (6)  
34  
35

### 36 Responses to Barriers

37 Parents' responses to the challenges they have faced were summarised in the following  
38 themes: (i) reacting emotionally, (ii) seeking solutions, and (iii) making decisions.  
39

#### 40 i) *Reacting Emotionally*

41 Parents who had encountered barriers to support reported high levels of anxiety, frustration  
42 and distress and feelings of being unheard. Parents who experienced difficulties at the early  
43 stages of their child's care described associated feelings of guilt and helplessness at their  
44 child's failure to thrive, and frustration in their search for answers. All parents with these  
45 experiences reported a significant impact on their emotional wellbeing.  
46  
47

48  
49 'I struggled with it; it was awful. It made me extremely depressed because I just didn't  
50 know what was going on, and no one seemed to be paying any attention.' (3)

51 'I felt that this was very poorly handled in terms of the emotional impact it can have on  
52 a parent, to say you might not be able to feed your child yourself.' (2)

53 '[The Speech and Language Therapist] was only focussed on communication. She asked  
54 us every time how feeding was going; I dreaded her asking me that...I hated telling her  
55 he just couldn't eat, but she just said to keep trying. It was so demoralising...'  
56 (13)  
57  
58  
59  
60

1  
2  
3 ii) *Seeking Solutions*

4 All parents described times when they had adopted a proactive approach towards seeking and  
5 receiving help: researching into their child's medical conditions, recommended treatment,  
6 medication and available support. Parents report using the knowledge they had gained to  
7 actively request or refuse specific services or interventions,  
8

9  
10 'It's been more parent-driven; no one takes ownership of the problems.' (13)

11 'Things take a long time. I work with children with disabilities and have some  
12 knowledge, but even with knowledge you need to do a lot of pushing.' (10)

13  
14 Parents reported the value of peer support and identified times when they have felt  
15 empowered by the knowledge they have gained from other parents and carers in a similar  
16 situation,  
17

18  
19 'At first I didn't want a PEG but... I spoke to other parents who said they're really good.'  
20 (6)

21 'It's been useful meeting other parents, to talk about things with them and share  
22 experiences.' (11)

23 'I wrote to the GP and asked [for thickener], because somebody else used it and gave me  
24 some sachets.' (1)

25  
26 'Talking to other parents [helps] too, not just professionals' (4)  
27

28  
29 Some parents used the knowledge they had gained to directly challenge professional advice or  
30 seek second opinions; six parents contacted private professionals for second opinions and two  
31 families contacted overseas specialists for advice,  
32

33 'I see a private person because I'm unhappy with the support I get.' (3)

34 'I discovered a Speech and Language Therapist in Brazil... she said my daughter has  
35 [dysphagia]... I was shocked; she'd had problems all that time and we had been told it  
36 was nothing.' (8)  
37  
38

39 iii) *Making decisions*

40 Parents described times when they had taken matters 'into their own hands' in the day-to-day  
41 management of their child's difficulties. Parents reported developing their own strategies  
42 based on a 'trial and error' approach with their child; employing a range of techniques to  
43 maximise their child's swallowing safety. Techniques included postural adaptations, changes  
44 to mealtime utensils and environmental strategies.  
45

46  
47 'We had been spoon-feeding him water... he was alright with spoonfuls; any more and he  
48 coughs' (5)

49 'She would have rice pudding and I would give her a dummy after to help her  
50 swallow... when we put the dummy in then she would initiate the swallowing action.' (6)

51 'I take her drink away for a second [between sips] to give her a chance to breathe before  
52 carrying on.' (10)  
53  
54

55  
56 A similar approach was used to manage difficulties encountered with fluid thickeners. Parents  
57 reported a range of difficulties using thickeners on an everyday basis including lumpiness;  
58 problems maintaining fluid consistency over time; managing liquid medications and  
59  
60

1  
2  
3 modifying their child's diet or fluid consistency when unwell or tired. Parents described a  
4 number of techniques that they developed using their knowledge and experience of their  
5 child, in order to avoid such difficulties.  
6

7 'We use a lower dose [of thickener] in milk, it's just enough to slow it down. In his juice  
8 we use slightly more because the cups have bigger holes in.' (7)

9 'We recognise when it needs to be thicker, like when she's poorly.' (13)

10 'We do thicken some of his medication...we give medication in a syringe too so we can  
11 control how he has it.' (11)  
12  
13

## 14 Discussion

15  
16 This study proceeded with explorative aims to seek parents' experiences of their involvement  
17 with their MDT. As a qualitative study this does not seek to generalise findings to the wider  
18 population; as such the qualitative methodologies employed were deemed appropriate for a  
19 study of its size and nature[25,26]. Reliability and validity were established during analysis  
20 through inter-rater agreement and participant validation.  
21  
22

23  
24 Participants expressed their need for healthcare professionals to work proactively, particularly  
25 in the early stages of seeking and receiving a diagnosis of dysphagia. Previous work has  
26 shown that professionals who work holistically and proactively are better able to anticipate a  
27 child's needs, referring for specialist intervention before a critical need arises[27]. Parents  
28 acknowledged the importance of communicative and interpersonal skills in facilitating a  
29 trusting relationship between family members and professionals, particularly when balancing  
30 considerations around risk and QoL. This issue was particularly pertinent for parents caring  
31 for children considered for PEG feeding; an issue requiring great sensitivity and discussed  
32 elsewhere in the literature[20,21,28]. Effective communication was also seen to reduce the  
33 burden on parents to repeat their child's medical information to different members of the  
34 MDT[29]. Keyworking schemes such as Early Support[5,6] and shared documentation may  
35 be one step towards this end, although with current financial and structural changes to the  
36 health and social care system such resources may be limited.  
37  
38

39  
40 The emotional, financial and physical burdens of caring for a child with a disability are well  
41 reported[12-14]. Parents reported a significant impact on the emotional and physical  
42 wellbeing of themselves and their children, acknowledging a need for proactivity on the part  
43 of the MDT, particularly in the early stages of receiving diagnoses and requesting specialist  
44 support. Parents utilised a range of creative approaches in managing the everyday difficulties  
45 of using thickening agents[30] and drew upon the experiences of themselves and others to  
46 develop solutions that worked for them.  
47  
48

49  
50 Limitations: Purposive sampling was the most effective means of recruitment for this study;  
51 however it is acknowledged to create sampling bias[31]. The response rate could not be  
52 calculated as participants were recruited via schools or charities, with administrative staff  
53 responsible for collating participant information and sharing details with the researcher.  
54 Social demographics were not taken for this study; further research exploring the experiences  
55 of socially isolated families would be beneficial.  
56  
57  
58  
59  
60

Acknowledgements: The authors acknowledge all parents who participated and the schools and organisations that provided information to appropriate parents. The authors also acknowledge the help of J. Wood for advice regarding qualitative analysis, and A. Dixon-Dewfall as an independent coder during data analysis.

#### Contributorship statement:

A brief description of each author and their contribution towards the manuscript are detailed below. E Jebson and C Smith accessed the data for the study in its entirety prior to and during write-up; B Hanson had access to any data required whilst revising and approving draft and final copies of the manuscript.

- i.) E Jebson: Responsible for participant recruitment, data collection and analysis, write-up of manuscript. Had access to all data
- ii.) B Hanson: Critical revision of draft versions of manuscript and approval of final version
- iii.) C Smith: Contributions towards research design; provided advice and supervision on research processes and data write-up. Critically revised and approved the manuscript (draft and final versions).

Additional contributors, J. Wood and A. Dixon-Dewfall, were involved in the study during data analysis and interpretation. Both are acknowledged in the 'acknowledgements' section at the end of the paper.

#### Competing interests:

No competing interests

#### Funding:

This research received no specific grant from any funding agency in the public, commercial or not-for-profit sectors.

#### Data sharing:

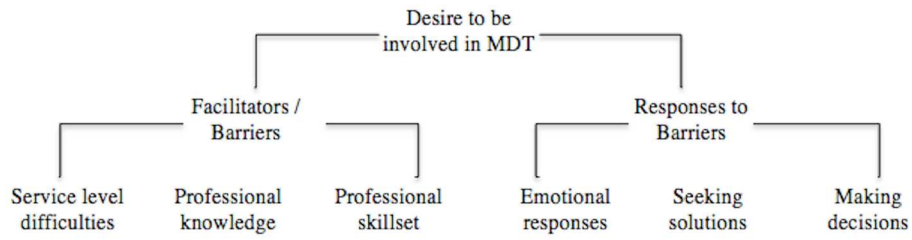
No additional data available

#### References

- 1 Schwarz M. Feeding Disorders in Children with Developmental Disabilities. *Infants and Young Children* 2003;16:317-330.
- 2 Wolf L, Glass R. Feeding and Swallowing Disorders in Infancy: Assessment and Management. San Antonia: Therapy Skills Builders; 1992.
- 3 Vohr B et al. Neurodevelopmental Outcomes of Extremely Low Birth Weight Infants <32 Weeks' Gestation between 1993 and 1998. *Pediatrics* 2005;116(3):635-643.
- 4 Bell H, Sheckman Alper B. Assessment and Intervention for Dysphagia in Infants and Children: Beyond the Neonatal Intensive Care Unit. *Semin Speech Lang* 2007;28:213-222.

- 1  
2  
3 5 Department for Education and Skills, Department of Health. National Service Framework  
4 for Children, Young People and Maternity Services: Disabled Children and Young People  
5 and those with Complex Health Needs. 2004.  
6  
7 6 Department for Education and Skills. Aiming High for Disabled Children: better support for  
8 families. 2007.  
9  
10 7 Department of Health. Better Care, Better Lives: Improving outcomes for children, young  
11 people and their families living with life limiting and life threatening conditions. 2008.  
12  
13 8 Reeves S et al. Interprofessional Education: effects on professional practice and healthcare  
14 outcomes. *Cochrane Database Syst Rev* 2013;3:CD002213.  
15  
16 9 Angell M, Bailey R, Stoner J. Family Perceptions of Facilitators and Inhibitors of Effective  
17 School-Based Dysphagia Management. *Lang Speech Hear Serv Sch* 2008;39:214-226.  
18  
19 10 Department for Education and Skills. Every Child Matters. 2003.  
20  
21 11 Stoner J, Bailey R, Angell M. Perspectives of Parents/Guardians of Children with  
22 Feeding/Swallowing Problems. *Journal of Developmental and Physical Disabilities*  
23 2006:333-353  
24  
25 12 Raina P et al. The Health and Well-being of Caregivers of Children with Cerebral Palsy.  
26 *Pediatrics* 2005;115:626-636.  
27  
28 13 Roberts K, Lawton D. Acknowledging the Extra Care Parents Give their Disabled  
29 Children. *Child Care Health Dev* 2001;27(4):307-319.  
30  
31 14 Fisher H. The Needs of Parents with Chronically Sick Children: a literature review. *J Adv*  
32 *Nurs* 2001;36(4):600-607.  
33  
34 15 Meester-Delver A et al. Predicting Additional Care in Young Children with  
35 Neurodevelopmental Disability: a systematic review. *J Adv Nurs* 2001;36:600-607.  
36  
37 16 Cass H et al. Supporting Children with Multiple Disabilities. *Child Care Health Dev*  
38 1999;25(3):191-211.  
39  
40 17 Arvedson J, Homer E. Managing Dysphagia in the Schools. *The ASHA Leader*  
41 2006;11(13):8-30.  
42  
43 18 Harding C, Halai V. Providing Dysphagia Training for Carers of Children who have  
44 Profound and Multiple Learning Disabilities. *British Journal of Developmental Disability*  
45 2009;55(108):33-47.  
46  
47 19 Burland L. Feeding Issues in Children with Neurodevelopmental Difficulties:  
48 implementation of nutritional care and dysphagia guidelines at St James University Hospital  
49 Child Development Centre. *Dev Med Child Neurol* 2011;53(S3):44-45.  
50  
51 20 Craig G, Scambler G, Spitz L. Why Parents of Children with Neurodevelopmental  
52 Disabilities Requiring Gastrostomy Feeding Need More Support. *Dev Med Child Neurol*  
53 2003;45(3):183-188.  
54  
55 21 Craig G. Psychosocial Aspects of Feeding Children with Neurodisability. *Eur J Clin Nutr*  
56 2013;67:S17-20.  
57  
58  
59  
60

- 1  
2  
3 22 Denzin N, Lincoln Y. *Collecting and Interpreting Qualitative Materials*. London: Sage; 1998.  
4  
5  
6 23 Walliman N. *Research Methods: The Basics*. London: Routledge; 2011.  
7  
8 24 Meloy J. *Writing the Qualitative Dissertation*. New Jersey: Lawrence Elbaum; 1994.  
9  
10 25 Sandelowski M. Whatever Happened to Qualitative Description? *Res Nurs Health*  
11 2000;23:334-340.  
12  
13 26 Silverman D. *Doing Qualitative Research (2nd ed)* London: Sage; 2005.  
14  
15 27 Arvedson J. Assessment of Pediatric Dysphagia and Feeding Disorders: Clinical and  
16 Instrumental Approaches. *Dev Dis Res Rev* 2008;14:118-127.  
17  
18 28 Petersen M et al. Eating and Feeding are not the same: caregivers' perceptions of  
19 gastrostomy feeding for children with cerebral palsy. *Dev Med Child Neurol* 2006;48(9):713-  
20 717.  
21  
22 29 Dick J. 'Dysphagia Severity Score' System: Clinical Outcomes in Paediatric Dysphagia.  
23 *International Journal of Language and Communication Disorders* 1998;33(S1):268-272.  
24  
25 30 Smith C, Jebson E, Hanson B. Thickened Fluids: Investigation of users' experiences and  
26 perceptions. *Clin Nutr* 2014;33(1):171-174.  
27  
28 31 Polgar E, Thomas S. *Introduction to Research in the Healthcare Sciences (4th ed)*.  
29 London: Elsevier; 2000.  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60



235x67mm (300 x 300 DPI)

peer review only

1  
2  
3  
4  
5  
6  
7  
8  
9  
10  
11  
12  
13  
14  
15  
16  
17  
18  
19  
20  
21  
22  
23  
24  
25  
26  
27  
28  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60



## COREQ Guidelines

**Research team / reflexivity**

Interviewer/facilitator: Which author/s conducted the interview or focus group?  
All interviews were conducted by researcher and author (Emma Jebson)

Credentials: What were the researcher's credentials? E.g. PhD, MD  
MSc

Occupation: What was their occupation at the time of the study?  
Full time practicing SLT

Gender: Was the researcher male or female?  
Female

Experience and training: What experience or training did the researcher have?  
The researcher is a trained Speech and Language Therapist with 10 years experience working in the field of Learning Disability, Autism Spectrum Disorder and Profound and Multiple Learning Disability. Five years experience working with adults and children with Mental Health difficulties and two years experience working as an Early Support Keyworker prior to training as an SLT. Within her Keyworker role the researcher supported families of children with complex needs, coordinating their care and acting as a single point of contact between families and the MDT. As an SLT the researcher has received training and gained experience in eliciting information from case histories, managing challenging conversations and adapting her communication style, taking into consideration the cultural and linguistic needs of the listener.

**Relationship with participants**

Relationship established: Was a relationship established prior to study commencement?  
Brief telephone conversation with interested parents to share information about study, aims and to allow participants to ask questions.

What did the participants know about the researcher? e.g. personal goals, reasons for doing the Research?  
Participants knew that the research was seeking the lived experiences of families caring for children with dysphagia, with a view to publishing the study once completed, to add to the evidence base.

Interviewer characteristics What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic?  
The author shared information about current working role as an SLT; previous research that had been carried out during completion of MSc; professional interests in swallowing and family support.

**Study design: Theoretical framework**

Methodological orientation and theory: What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis?  
Phenomenology and content analysis.

**Participant selection**

Sampling How were participants selected? e.g. purposive, convenience, consecutive, snowball  
Purposive sampling used.

Method of approach. How were participants approached? e.g. face-to-face, telephone, mail, email  
A variety of methods were used in order to reach as many families as possible:

- internet forums
- letters via schools and family workers
- email distribution lists of charities

## COREQ Guidelines

Sample size How many participants were in the study?

Fourteen

Non-participation How many people refused to participate or dropped out? Reasons?

Unable to ascertain response rate: participants were recruited via schools/charities, who did not share how many families had received the letters/information compared to how many had replied. Initially 15 participants were recruited; however data from one participant was later excluded from the study as the participant was caring for an adult child.

**Setting**Setting of data collection Where was the data collected? e.g. home, clinic, workplace

Family homes. One interview was participated at school where parent worked, in a quiet room.

Presence of non-participants Was anyone else present besides the participants and researchers?

No

Description of sample What are the important characteristics of the sample? e.g. demographic data, data

Numerical labels were assigned to participants to anonymised data.

Demographics: geographical location; medical diagnoses; time since onset of dysphagia, nutritional intake.

**Data collection**Interview guide Were questions, prompts, guides provided by the authors?

Semi structured interviews were delivered; questions were asked but not always in the order written on questionnaires (to allow for a more 'normal' conversation rather than overtly formal interview). Where information given was ambiguous or unclear the researcher asked for clarification.

Repeat interviews Were repeat interviews carried out? If yes, how many?

No repeat interviews were completed.

Audio/visual recording Did the research use audio or visual recording to collect the data?

Interviews were audio recorded. Consent was gained from all participants.

Field notes Were field notes made during and/or after the interview or focus group?

Annotations were made on questionnaires during the interview; the researcher also kept a journal to record subjective notes such as main themes that seemed to emerge and to capture the general 'feel' of interviews.

Duration: What was the duration of the interviews or focus group?

Each interview lasted between 30 and 70 minutes

Data saturation Was data saturation discussed?

Although qualitative techniques were used the researcher was not employing a Grounded Theory approach and as such data saturation was not considered essential.

Transcripts returned Were transcripts returned to participants for comment and/or correction?

Transcripts were returned to each participant for comment. Two parents made minor clarifications, both transcripts were amended accordingly.

**Data analysis**Number of data coders How many data coders coded the data?

One primary coder. 25% of the transcripts were then coded separately by an independent researcher to

## COREQ Guidelines

maximise reliability.

Description of the coding tree Did authors provide a description of the coding tree?

Not provided within body of article, in line with presentation of similar articles within the journal.

Derivation of themes Were themes identified in advance or derived from the data?

Themes were derived from the data.

Software What software, if applicable, was used to manage the data?

No software required for coding considering small sample size.

Participant checking Did participants provide feedback on the findings?

See Q23.

**Reporting**

Quotations presented Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. participant number

Verbatim quotes were inserted to illustrate the findings. Participant numbers were used to identify quotes.

Data and findings consistent Was there consistency between the data presented and the findings?

Data and findings were consistent

Clarity of major themes Were major themes clearly presented in the findings?

Findings were reported by explicit description of the major themes.

Clarity of minor themes Is there a description of diverse cases or discussion of minor themes?

Key themes were described within discussion of the major themes. Not all minor themes (i.e. themes relating to fewer than 3 participants) were presented, due to word count limitations.

# BMJ Open

## What do parents of children with dysphagia think about their MDT? A qualitative study

Journal:	<i>BMJ Open</i>
Manuscript ID:	bmjopen-2014-005934.R1
Article Type:	Research
Date Submitted by the Author:	10-Sep-2014
Complete List of Authors:	Cowpe (nee Jebson), Emma; Royal Free Hospital, Speech and Language Therapy Hanson, Ben; University College London, Department of Mechanical Engineering Smith, Christina; University College London, Language & Communication Div of Psychology & Language Sciences
<b>Primary Subject Heading</b>:	Qualitative research
Secondary Subject Heading:	Paediatrics
Keywords:	QUALITATIVE RESEARCH, Developmental neurology & neurodisability < PAEDIATRICS, Community child health < PAEDIATRICS

SCHOLARONE™  
Manuscripts

1  
2  
3 What do parents of children with dysphagia think about their MDT?  
4 A qualitative study  
5  
6  
7  
8

9 Authors

10 Emma Jebson, Speech and Language Therapy, Royal Free Hospital, London, UK  
11 Ben Hanson, Department of Mechanical Engineering, University College London, UK  
12 Christina H Smith, Language and Communication, Division of Psychology and Language  
13 Sciences, University College London, UK  
14

15  
16  
17  
18 Corresponding Author

19 Christina H Smith  
20

21 Address

22 Division of Psychology & Language Sciences  
23 Chandler House  
24 2 Wakefield Street  
25 London  
26 WC1N 1PF  
27 Email: [christina.smith@ucl.ac.uk](mailto:christina.smith@ucl.ac.uk)  
28 Telephone: +44 20 7679 4233  
29 Fax: +44 20 7679 4238  
30  
31  
32  
33

34 Word Count

35 Main text (excluding title page, abstract, references, quotes, tables): 2858  
36  
37  
38  
39

40 Keywords: parent, multidisciplinary team, paediatric, dysphagia, qualitative  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

## Abstract

### Objectives:

To seek the experiences and perspectives of parents caring for children with dysphagia, with emphasis on their experiences of working within their child's multidisciplinary team (MDT)

### Setting:

This research was completed in community settings, within families' homes across the UK.

### Participants:

Fourteen families self-selected to participate in the study. Criteria specified that participants must care for a child under the age of 18 and to decrease ambiguity the term 'diagnosis of dysphagia' was defined as the need for modified (thickened) fluids. Exclusion criteria: caring for an adult over the age of 18; diet and fluid modifications for reasons other than dysphagia (e.g. for symptomatic treatment of Gastro-oesophageal reflux disease (GORD)). Participants were interviewed within their homes using a semi-structured questionnaire and data was analysed using a descriptive phenomenological approach through use of thematic coding and constant comparison. Themes and relationships were inductively generated from the data.

### Results

Participants universally expressed a desire to be involved with their child's multidisciplinary team; this study identified the following facilitators and barriers to collaboration: Accessing Services, Professional Knowledge, and Professional Skillset. Participants described three means of responding to these barriers: Reacting Emotionally, Seeking Solutions, and Making Decisions.

### Conclusions:

This study recorded in-depth reports of participants' experiences of working with healthcare providers. Despite government-driven efforts towards person-centred health and social care, participants shared accounts of times when this has not occurred, describing a negative impact on the wellbeing and quality of life of their child and family.

The study protocol and consent procedure were approved by the local institution ethics committee (LC/2011/007).

### Data sharing:

No additional data available

### Strengths and Limitations of this Study

- Evidence of facilitators and barriers to effective parent-professional collaboration
- Provision of parents' own report of experiences with multidisciplinary teams
- Supports literature relating to the need for holistic, patient-centered care and provides skills and attributes required of professionals in multidisciplinary working
- Small-scale study encouraging further research in this area
- Self-selecting sample involving outside agencies in initial recruitment

## Background

1  
2  
3  
4 Swallowing difficulties (dysphagia) can vary in aetiology, symptomology and severity and  
5 affect children with a variety of medical diagnoses. Up to 90% of children with  
6 neurodevelopmental disorders such as cerebral palsy and Down syndrome experience signs of  
7 dysphagia including coughing, choking, chest infections, poor weight gain and  
8 breathlessness[1], often from birth or early infancy. Children with GORD and those born  
9 prematurely are also at increased risk of childhood dysphagia[2-4]. Thus dysphagia can be a  
10 symptom of different underlying medical conditions and is diagnosed and treated by a variety  
11 of medical specialists.  
12

13  
14 Children with complex and pervasive needs require support in a range of in- and outpatient  
15 specialist settings including hospitals, clinics and schools. Children may be in contact with a  
16 range of health and care professionals including Paediatricians, GPs, Speech and Language  
17 Therapists, Physiotherapists, Dieticians and Social Workers; for these children and their  
18 families well-coordinated input is essential for provision of individualised care[5-7].  
19 Multidisciplinary teams (MDTs) are commissioned to provide joined up, patient-centred  
20 support and seek to place children and their families at the centre of decision-making  
21 processes[4,8,9]. Government initiatives such as the Early Support keyworking scheme[6]  
22 and the Common Assessment Framework[10] have been set up throughout the UK to improve  
23 care quality by providing a framework for regular MDT discussion; avoiding repetition of  
24 information and reducing carer burden; and providing a single point of contact for better  
25 coordination of care and support[6].  
26  
27  
28  
29

30 A number of studies have explored parent experience of caring for children with dysphagia  
31 although typically research has focused on the needs of carers of children with complex needs  
32 which may or may not involve dysphagia as a symptom[11-15], or has been confined to  
33 specific settings such as schools[9,16,17] or Child Development Centres[18]. Mahant et  
34 al[19], Craig et al[20,21] and Sullivan et al[22] have studied the experiences of parents of  
35 children requiring gastrostomy feeding; these studies highlighted the importance and value  
36 placed by parents on oral feeding[19,22], and acknowledged the complexities involved in  
37 decision-making when considering how to balance risks of oral intake with maximising QoL  
38 for children with dysphagia[19-21]. Recommendations for practice include the need for good-  
39 quality information and support for families and the need for professionals to understand  
40 caregiver's perspectives and priorities and to adopt a model of partnership working with the  
41 families under their care [19-21,23]. Studies looking at specialist feeding clinics within the  
42 USA and UK[24-27] describe the intricate and multifaceted nature of feeding and swallowing  
43 disorders and highlight the importance of multidisciplinary working to ensure holistic, child-  
44 and family-centred assessment, treatment and support. This paper seeks to build on this  
45 research and explore the issues pertinent to families caring for children with dysphagia in the  
46 UK, and to gain their perspectives on the care they have received.  
47  
48  
49  
50

## 51 52 Method

### 53 54 Participants

55 This cross-sectional study involved parents and carers of children with a diagnosis of  
56 dysphagia, aged between two and 11 years. Information about the study was distributed  
57 through special schools, charities and local and national support groups in the form of letters,  
58  
59  
60



online forums and newsletters. Parents self-selected by contacting the researcher based on the information provided, and gave written consent to participate in the study. Fifteen parents were initially recruited; one interview was discounted from analysis as the individual with dysphagia was 24 years old. Analysis was completed with interviews from 14 parents; the children's characteristics are summarised in table 1.

Table 1: Individual Child Characteristics

Parent ID number	Medical diagnoses	Age at diagnosis of dysphagia	Nutritional intake	Route to recruitment
1	CP epilepsy, GORD	Under 1 year	Oral diet	School
2	Lissencephaly	18 months	Oral diet	School
3	No diagnosis	8 months	Oral diet	School
4	CP, hydrocephalus, epilepsy, VI, HI	Under 1 year	PEG plus oral tastes.	School
5	CP, Chronic Lung Disease, GORD	1 year	Oral diet (previously PEG)	School
6	Alagille Syndrome	Under 1 year	Half oral, half PEG	School
7	DS, CHD	Under 1 year	Oral diet	Charity
8	DS, GORD	5 years	Oral diet	Charity
9	Congenital cytomegalovirus, GDD	1 year	Oral diet	Family worker
10	DS, CHD, GORD, HI	Under 1 year	Oral diet	Charity
11	DS	Under 1 year	Oral diet	Charity
12	DS	Under 1 year	Oral diet (previously PEG)	School
13	DS, GORD, VI, HI	2 ½ years	Oral diet	School
14	DS, Hirschprung's Disease, GORD	3 years	Oral diet	Charity

Key: CP: Cerebral Palsy  
 DS: Downs Syndrome  
 VI: Visual Impairment  
 CHD: Congenital Heart Disease  
 GORD: Gastro Oesophageal Reflux Disease  
 GDD: Global Developmental Delay  
 HI: Hearing Impairment

#### Procedure

The local institution research ethics committee approved the study protocol and consent procedure (LC/2011/007). Audio-recorded, in-depth interviews were considered the most appropriate form of data collection; providing participants with dedicated time and space to share their individual experiences and perceptions[28, 29].

Participants were contacted and interviews were scheduled at their convenience. Thirteen parents were interviewed at the family home and one parent was interviewed at her place of work. Although all participants consented to audio recording, each parent was reminded of their right to withdraw from the study at any time. Given the emotive nature of the issues being discussed, breaks were offered throughout the interview process to enable a period of time 'off recording' if required. Informal discussion prior to and following each interview allowed for debriefing and reflection without participants feeling under pressure of being recorded.

1  
2  
3  
4 Semi-structured questionnaires formed the basis of interviews; this provided a degree of  
5 structure and standardisation in questioning whilst allowing for deviation from the 'script'.  
6 Adopting a semi-structured approach allowed for more natural conversation during  
7 interviews, avoiding an overtly formal interview style and maximising the richness of each  
8 participants' account[30,31]. Given the sensitivity of the topics discussed, freedom to deviate  
9 from structured, formal questioning was essential[29]. Parents were asked questions,  
10 including open/closed and content-/dimension-mapping questions[29], to gain both general  
11 and more specific information relating to their child's swallowing history, initial support  
12 received, ongoing needs and current support. Interviews took approximately one hour and  
13 each audio recording was transcribed prior to analysis.  
14  
15

16  
17 The researcher kept a journal for additional notes throughout the data collection process[28,  
18 32, 29]. Although journal entries were not formally used in data analysis, they were used to  
19 document preliminary codes and themes that began to emerge at the time of each interview,  
20 as well as notes on follow-up questions that had been asked, and general attitudes of  
21 interviewees at the time (e.g. positivity / negativity)[29].  
22  
23

#### 24 Analysis

25 Interviews were transcribed and returned to participants to verify accuracy. Two parents  
26 made minor clarifications to comments within their manuscript; one parent providing further  
27 detail of the chronology of her daughter's medical interventions and another providing the  
28 full name of their child's thickener. The parent's amendments were recorded prior to coding.  
29  
30

31 Qualitative analysis methods were identified as most appropriate for this dataset, given the  
32 richness of participants' accounts and the complexity of issues discussed[19]. Descriptive  
33 phenomenology was selected in order to best describe participants' experiences and to  
34 uncover common themes within and between participants' accounts[33]. Methods of thematic  
35 coding and constant comparison were employed to generate codes inductively from the data,  
36 rather than impose preconceived themes constructed by the researcher [28,34]. In turn, the  
37 codes that emerged led to the construction of themes. During coding a transcript was selected  
38 at random and manually coded line by line with short phrases summarising each 'unit';  
39 examples included *negative emotions*, *creative problem solving* and *service flexibility*. Units  
40 varied in length; comprising of phrases, sentences or a number of lines, with one code applied  
41 to each unit.  
42  
43  
44

45 Additional transcripts were then added to the set and manually coded, with codes being  
46 continually compared within and between scripts and amended where required[28]. As  
47 analysis progressed codes were grouped into broader themes. For reliability of the coding,  
48 25% of the coded transcripts were validated by an independent researcher with experience in  
49 qualitative data analysis.  
50  
51

#### 52 Results

53 Fourteen participants completed the study; participants cared for a child between the ages of  
54 two and 11 years old; mean age 5.8 years. Of the 14 participants involved, 12 were under the  
55 care of a paediatrician when their child's swallowing difficulties were first investigated; 13  
56 had contact from a Speech and Language Therapist; eight from Physiotherapy; eight from  
57 dietetics and seven were seen by an Occupational Therapist. Eight families had contact from a  
58  
59  
60

1  
2  
3 health visitor; eight from the GP; four had involvement from school or nursery staff; one  
4 family had input from a school nurse and one from respite staff.  
5

6  
7 One overriding theme emerged from the data, present in all 14 interviews: all parents and  
8 carers expressed their desire to be involved in their child's care through close involvement in  
9 the MDT. Three sub-themes emerged relating to factors particularly facilitating or hindering  
10 their ability to be involved within the MDT. A further three sub-themes emerged as parents  
11 described their responses to the barriers they have experienced (figure 1). Participants' quotes  
12 are provided verbatim alongside their identifying number as allocated in table 1.  
13

#### 14 Being involved within the MDT

15 Without exception, parents reported a desire to be recognised as a key member of their child's  
16 MDT. Parents valued the specialist knowledge and opinion of healthcare professionals, but  
17 wanted to be identified as the expert about their child.  
18  
19

20 'My son is my number one subject' (14)

21 'I'm the one dealing with it everyday. If you want to ask something it's better to ask me.'  
22 (10)

23 'We know our children better than [professionals] do as individuals; they have to take  
24 our views on board and respect our opinions.' (7)  
25  
26

#### 27 Facilitators and barriers

28 The facilitators and barriers to parents' collaboration with the MDT were categorised into  
29 three separate sub-themes: (i) accessing services, (ii) professional knowledge and (iii)  
30 professional skillset, as below:  
31  
32

##### 33 *i) Accessing services*

34 Parents described three main issues around their ability to access services; time, staffing, and  
35 flexibility of service delivery. When asked how satisfied they were with the support they had  
36 received for their child's dysphagia, nine parents reported some degree of dissatisfaction with  
37 service accessibility and availability,  
38  
39

40 'They won't come and see him at home, which is a real shame.' (2)

41 'My daughter was ill for the whole winter. [The community Speech and Language  
42 Therapist] came as a favour to check her swallow, but there's a fine line now she's in  
43 school, with whose remit it is.' (12)

44 'They said they didn't have enough staff [in hospital] to give support with her feeding.'  
45 (3)

46 'It was quite a few years before they had a permanent Speech and Language Therapist at  
47 school.' (4)  
48  
49

50 Those who had felt largely satisfied with their support acknowledged the same qualities as  
51 important; reporting easier access to help and advice due to flexibility and availability of  
52 health and care staff,  
53  
54

55 'The [respiratory] physios are really good. They come in [if she is unwell] and monitor  
56 her sats. It saves going to A&E and they take swabs that can be sent off.' (5)

57 'When we went for the Videofluoroscopy the Speech and Language Therapist came with  
58  
59  
60

us...Every six weeks she comes here to see him.’ (7)

‘We’re lucky that we have had support. They’re always at the other end of the phone if we need it’ (11)

‘We have much more support now.’ (10)

### ii) *Professional Knowledge*

Parents attributed their health and care professionals with a level of expertise and specialist knowledge; however, some parents felt that this knowledge was poorly demonstrated by professionals at crucial time points when it was needed; particularly in the early stages of seeking support and specialist advice for their child. Five parents received misdiagnoses of their child’s dysphagia, which resulted in a wait of up to five years for an accurate diagnosis and to receive specialist intervention,

‘I kept showing her feeding to so many different consultants and no one spotted it ...they kept saying ‘it’s a virus, she’s fine’. Thirteen times in her first year she was on antibiotics for chest infections.’ (3)

‘I’m surprised the paediatrician didn’t signpost [specialist assessment] more clearly; she knew what [Lissencephaly] was and its implications.’ (2)

‘I just couldn’t believe it took them so many years to take it seriously; it amazed me.’ (8)

Those with positive experiences also highlighted the importance of well-demonstrated expert knowledge. These families reported an increase in their knowledge of their child’s condition as a result,

‘[The specialist’s] advice, which I found useful was that there were three things to look at: if he was getting pneumonias...if he was failing to thrive...or if it as taking a very long time to feed him’ (2)

‘[The specialist] had lots of questions; over the phone I was talking to her and she said my daughter had reflux and dysphagia, just from the phone call.’ (8)

### iii) *Professional Skillset*

Parents provided a list of qualities they value in healthcare professionals (table 2), placing the greatest importance on communication skills. Parents valued professionals who demonstrated a willingness to listen and who actively sought their opinions.

Table 2: Valued Professional Qualities

ID number	Qualities Listed
1	Accessible; two-way communication; being honest without being too negative.
2	Flexibility in appointments; listening and walk alongside you; treating you as a thinking person; addressing my son at appointments.
3	Interacting with my daughter; working well with other professionals; following through with what they say; talking to who they say they will; when you feel they want to help you and are on your side; making notes and giving you copies; being contactable; being approachable; being honest; not being overworked.
4	Being there; being contactable; liaising with each other; being trustworthy.
5	Being caring, friendly; knowing my child so I don’t need to repeat myself; record keeping.
6	Good people skills, sensitive to my child’s needs and my concerns; good communication; sympathy; seeing my child as an individual.

7	Listen and take the parents' views seriously; communication with parents; explaining jargon; sharing information.
8	Showing expertise in their field; treating children as individuals; not labelling children
9	Professionals working together; putting my child first; sharing information.
10	Listen to parents; being reliable
11	Approachability; being able to explain things.
12	Honesty; encouragement; new ideas; continuity.
13	Approachability; friendliness; warms; engaging our child; active, unhurried listening; empathy.
14	Asking questions of me; active listening; acting on what we say; not labelling our child.

'Parents have the answers even if we don't have the terminology.' (12)

'More the medical side than the community side have no respect or value for what the parents have to say...it's quite nice when you find people who actually listen.' (10)

'The interpersonal (skills) are as important as the clinical (skills).'

 (13)

Parents also described the importance of a positive working relationship between healthcare professionals, themselves and their child:

'In the medical profession it'd hurt me when they wouldn't even address my son at appointments; they would talk to me about him, in front of him, without even saying hello.' (2)

'[I value] people that are good at interacting with my daughter...people who work with her rather than just talking to mum.' (3)

'Every six weeks [our Speech and Language Therapist] comes here to see [my son] ... he really likes her.' (7)

Parents with negative experiences described times when they felt unheard and 'on a different page' to professionals. Parents raised concerns that too strong a focus was placed on health and risk, at times to the detriment of their child's emotional wellbeing and QoL.

'I felt that [the professionals] were very risk-averse...their first concern was to ensure the risk was minimized completely and utterly, rather than recognising that there was a risk but that it wasn't too great yet.' (2)

'We told school that if the children are having any treats, our daughter can have them too... There was an event where all the children were having hot chocolate with marshmallows. They wouldn't let our daughter have one and she got upset.' (8)

Parents discussed the importance of information sharing, identifying a need for up-to-date, jargon-free information to maximise their understanding and involvement. Parents reported a similar need for more effective information sharing between professionals within the MDT. Parents identified times when poor collaboration had negatively impacted upon the wellbeing of their child, or upon themselves as caregivers,

'[The professionals] don't liaise with each other at all...although they are all in the same building.' (4)

'I repeat myself all the time...it's hard to keep bringing up the past.' (5)

'In school there is a lack of communication...at one time they had stopped feeding her. I felt so upset by it.' (6)

### Responses to Barriers

Parents' responses to the challenges they have faced were summarised in the following themes: (i) reacting emotionally, (ii) seeking solutions, and (iii) making decisions.

#### *i) Reacting Emotionally*

Parents who had encountered barriers to support reported high levels of anxiety, frustration and distress and feelings of being unheard. Parents who experienced difficulties at the early stages of their child's care described associated feelings of guilt and helplessness at their child's failure to thrive, and frustration in their search for answers. All parents with these experiences reported a significant impact on their emotional wellbeing.

'I struggled with it; it was awful. It made me extremely depressed because I just didn't know what was going on, and no one seemed to be paying any attention.' (3)

'I felt that this was very poorly handled in terms of the emotional impact it can have on a parent, to say you might not be able to feed your child yourself.' (2)

'[The Speech and Language Therapist] was only focussed on communication. She asked us every time how feeding was going; I dreaded her asking me that...I hated telling her he just couldn't eat, but she just said to keep trying. It was so demoralising...' (13)

#### *ii) Seeking Solutions*

All parents described times when they had adopted a proactive approach towards seeking and receiving help: researching into their child's medical conditions, recommended treatment, medication and available support. Parents report using the knowledge they had gained to actively request or refuse specific services or interventions,

'It's been more parent-driven; no one takes ownership of the problems.' (13)

'Things take a long time. I work with children with disabilities and have some knowledge, but even with knowledge you need to do a lot of pushing.' (10)

Parents reported the value of peer support and identified times when they have felt empowered by the knowledge they have gained from other parents and carers in a similar situation,

'At first I didn't want a PEG but...I spoke to other parents who said they're really good.' (6)

'It's been useful meeting other parents, to talk about things with them and share experiences.' (11)

'I wrote to the GP and asked [for thickener], because somebody else used it and gave me some sachets.' (1)

'Talking to other parents [helps] too, not just professionals' (4)

Some parents used the knowledge they had gained to directly challenge professional advice or seek second opinions; six parents contacted private professionals for second opinions and two families contacted overseas specialists for advice,

'I see a private person because I'm unhappy with the support I get.' (3)



1  
2  
3 'I discovered a Speech and Language Therapist in Brazil... she said my daughter has  
4 [dysphagia]...I was shocked; she'd had problems all that time and we had been told it  
5 was nothing.' (8)  
6  
7

### 8 iii) *Making decisions*

9 Parents described times when they had taken matters 'into their own hands' in the day-to-day  
10 management of their child's difficulties. Parents reported developing their own strategies  
11 based on a 'trial and error' approach with their child; employing a range of techniques to  
12 maximise their child's swallowing safety. Techniques included postural adaptations, changes  
13 to mealtime utensils and environmental strategies.  
14

15  
16 'We had been spoon-feeding him water...he was alright with spoonfuls; any more and he  
17 coughs' (5)

18 'She would have rice pudding and I would give her a dummy after to help her  
19 swallow...when we put the dummy in then she would initiate the swallowing action.' (6)

20 'I take her drink away for a second [between sips] to give her a chance to breathe before  
21 carrying on.' (10)  
22  
23

24 A similar approach was used to manage difficulties encountered with fluid thickeners. Parents  
25 reported a range of difficulties using thickeners on an everyday basis including lumpiness;  
26 problems maintaining fluid consistency over time; managing liquid medications and  
27 modifying their child's diet or fluid consistency when unwell or tired. Parents described a  
28 number of techniques that they developed using their knowledge and experience of their  
29 child, in order to avoid such difficulties.  
30  
31

32 'We use a lower dose [of thickener] in milk, it's just enough to slow it down. In his juice  
33 we use slightly more because the cups have bigger holes in.' (7)

34 'We recognise when it needs to be thicker, like when she's poorly.' (13)

35 'We do thicken some of his medication...we give medication in a syringe too so we can  
36 control how he has it.' (11)  
37  
38  
39

## 40 Discussion

41  
42 This study proceeded with explorative aims to seek parents' experiences of their involvement  
43 with their MDT. As a qualitative study this does not seek to generalise findings to the wider  
44 population, particularly considering the age ranges of children involved and the geographical  
45 spread. Qualitative methodologies employed were deemed appropriate for a study of its size  
46 and nature[34,28]. Reliability and validity were established during analysis through inter-rater  
47 agreement and participant validation.  
48  
49  
50

51 Participants acknowledged the need for multidisciplinary working to ensure holistic  
52 management of their child's difficulties, as reported elsewhere within the literature[23-27,35].  
53 Parents encountered a number of barriers to accessing appropriate services in the early stages  
54 of their child's life and described a range of negative physical and emotional effects on  
55 themselves and their children. Whilst resources may be limited, improved staffing and time  
56 for direct family support may have reduced the impact of these barriers. Shared resources  
57 such as shared workspaces for health professionals may serve to improve collaboration and  
58  
59  
60



1  
2  
3 reduce carer burden. More flexible models of service delivery, such as improved crossover  
4 between school and community services, may have enabled some families to access support  
5 quicker and encounter fewer moments of delay and procedural 'red tape'.  
6

7  
8 Families who received repeated misdiagnoses of their child's condition described higher  
9 levels of dissatisfaction in the MDT and negative impacts on child and family health and  
10 wellbeing. Participants reported their frustration and upset in knowing there was 'something  
11 wrong' with their child's health yet failing to receive appropriate support and diagnostics. It  
12 could be argued that the parents who sought second opinions from private and overseas  
13 professionals, did not receive advice that could not have been provided by their child's MDT.  
14

15  
16 Participants expressed their need for healthcare professionals to work proactively, particularly  
17 in the early stages of seeking and receiving a diagnosis of dysphagia. Previous work has  
18 shown that professionals who work holistically and proactively are better able to anticipate a  
19 child's needs, referring for specialist intervention before a critical need arises[35]. Parents  
20 acknowledged the importance of communicative and interpersonal skills in facilitating a  
21 trusting relationship between family members and professionals, particularly when balancing  
22 considerations around risk and QoL. This issue was particularly pertinent for parents caring  
23 for children considered for PEG feeding; an issue requiring great sensitivity and discussed  
24 elsewhere in the literature[20,21,36]. The need for good-quality information was highlighted  
25 to enable informed decision-making [23] and effective communication was considered to  
26 reduce the burden on parents to repeat their child's medical information to different members  
27 of the MDT[37]. Keyworking schemes such as Early Support[5,6] and shared documentation  
28 may be one step towards this end in order to streamline communication and to provide a  
29 single point of contact for families caring for children with complex needs; however with  
30 current financial and structural changes to the health and social care system such resources  
31 may be limited.  
32  
33  
34

35  
36 The emotional, financial and physical burdens of caring for a child with a disability are well  
37 reported[11-13]. Parents reported a significant impact on the emotional and physical  
38 wellbeing of themselves and their children, acknowledging a need for proactivity on the part  
39 of the MDT, particularly in the early stages of receiving diagnoses and requesting specialist  
40 support. Parents utilised a range of creative approaches in managing the everyday difficulties  
41 of using thickening agents[38] and drew upon the experiences of themselves and others to  
42 develop solutions that worked for them.  
43  
44

45  
46 Limitations: As a self-selecting cohort the sample in this study is open to a degree of bias  
47 [39]. Because other agencies such as schools, charities and support groups were involved in  
48 disseminating the information a response rate could not be calculated as it was unclear how  
49 many parents had come into contact with the initial information regarding the study. Social  
50 demographics were not taken for this study; further research exploring the experiences of  
51 socially isolated families would be beneficial. Parents were invited to check the accuracy of  
52 transcripts; this feature of the study was not accounted for in the initial stages and as such  
53 may have been considered an additional burden which had not been anticipated by parents at  
54 the recruitment stage.  
55

56  
57 Further developments of this research exploring in more depth the different types of service  
58 provided to families with children with dysphagia would be beneficial. Similarly although  
59  
60

1  
2  
3 social demographics were not taken for this study further research, this study could be  
4 expanded by studying socially isolated or 'hard to reach' families.  
5

6  
7 Acknowledgements: The authors acknowledge all parents who participated and the schools  
8 and organisations that provided information to appropriate parents. The authors also  
9 acknowledge the help of J. Wood for advice regarding qualitative analysis, and A. Dixon-  
10 Dewfall as an independent coder during data analysis.  
11

#### Contributorship statement:

12  
13 A brief description of each author and their contribution towards the manuscript are detailed  
14 below. E Jebson and C Smith accessed the data for the study in its entirety prior to and during  
15 write-up; B Hanson had access to any data required whilst revising and approving draft and  
16 final copies of the manuscript. All authors are accountable for the accuracy and integrity of  
17 the work'.  
18

- 19  
20  
21 i.) E Jebson: Responsible for participant recruitment, data collection and  
22 analysis, write-up of manuscript. Had access to all data  
23 ii.) B Hanson: Contributed to the conception and design of the study, critical  
24 revision of draft versions of manuscript and approval of final version  
25 iii.) C Smith: Contributions towards research design; provided advice and  
26 supervision on research processes and data write-up. Critically revised and  
27 approved the manuscript (draft and final versions).  
28

29 Additional contributors, J. Wood and A. Dixon-Dewfall, were involved in the study during  
30 data analysis and interpretation. Both are acknowledged in the 'acknowledgements' section at  
31 the end of the paper.  
32

#### Competing interests:

33  
34 No competing interests  
35

#### Funding:

36  
37 This research received no specific grant from any funding agency in the public, commercial  
38 or not-for-profit sectors.  
39

#### Data sharing:

40  
41 No additional data available  
42  
43  
44  
45  
46  
47  
48  
49  
50

#### References

51 1 Schwarz M. Feeding Disorders in Children with Developmental Disabilities. *Infants Young*  
52 *Child* 2003;16:317-330.  
53

54 2 Wolf L, Glass R. Feeding and Swallowing Disorders in Infancy: Assessment and  
55 Management. San Antonia: Therapy Skills Builders; 1992.  
56  
57  
58  
59  
60

- 1  
2  
3 3 Vohr B et al. Neurodevelopmental Outcomes of Extremely Low Birth Weight Infants <32  
4 Weeks' Gestation between 1993 and 1998. *Pediatrics* 2005;116(3):635-643.  
5  
6 4 Bell H, Sheckman Alper B. Assessment and Intervention for Dysphagia in Infants and  
7 Children: Beyond the Neonatal Intensive Care Unit. *Semin Speech Lang* 2007;28:213-222.  
8  
9 5 Department for Education and Skills, Department of Health. National Service Framework  
10 for Children, Young People and Maternity Services: Disabled Children and Young People  
11 and those with Complex Health Needs. 2004.  
12  
13 6 Department for Education and Skills. Aiming High for Disabled Children: better support for  
14 families.  
15 <http://webarchive.nationalarchives.gov.uk/20130401151715/http://www.education.gov.uk/publications/eOrderingDownload/PU213.pdf> [Accessed online May 2014]. 2007.  
16  
17  
18 7 Department of Health. Better Care, Better Lives: Improving outcomes for children, young  
19 people and their families living with life limiting and life threatening conditions. 2008.  
20  
21 8 Reeves S et al. Interprofessional Education: effects on professional practice and healthcare  
22 outcomes. *Cochrane Database Syst Rev* 2013;3:CD002213.  
23  
24 9 Angell M, Bailey R, Stoner J. Family Perceptions of Facilitators and Inhibitors of Effective  
25 School-Based Dysphagia Management. *Lang Speech Hear Serv Sch* 2008;39:214-226.  
26  
27 10 Department for Education and Skills. Every Child Matters. 2003.  
28  
29 11 Raina P et al. The Health and Well-being of Caregivers of Children with Cerebral Palsy.  
30 *Pediatrics* 2005;115:626-636.  
31  
32 12 Roberts K, Lawton D. Acknowledging the Extra Care Parents Give their Disabled  
33 Children. *Child Care Health Dev* 2001;27(4):307-319.  
34  
35 13 Fisher H. The Needs of Parents with Chronically Sick Children: a literature review. *J Adv*  
36 *Nurs* 2001;36(4):600-607.  
37  
38 14 Meester-Delver A et al. Predicting Additional Care in Young Children with  
39 Neurodevelopmental Disability: a systematic review. *J Adv Nurs* 2001;36:600-607.  
40  
41 15 Cass H et al. Supporting Children with Multiple Disabilities. *Child Care Health Dev*  
42 1999;25(3):191-211.  
43  
44 16 Arvedson J, Homer E. Managing Dysphagia in the Schools. *The ASHA Leader*  
45 2006;11(13):8-30.  
46  
47 17 Harding C, Halai V. Providing Dysphagia Training for Carers of Children who have  
48 Profound and Multiple Learning Disabilities. *British Journal of Developmental Disability*  
49 2009;55(108):33-47.  
50  
51 18 Burland L. Feeding Issues in Children with Neurodevelopmental Difficulties:  
52 implementation of nutritional care and dysphagia guidelines at St James University Hospital  
53 Child Development Centre. *Dev Med Child Neurol* 2011;53(S3):44-45.  
54  
55 19 Mahant S, Jovcevska V, Cohen E. Decision-Making Around Gastrostomy-Feeding in  
56 Children with Neurologic Disabilities. *Pediatrics* 2011;127(6):e1471-81.  
57  
58  
59  
60

- 1  
2  
3 20 Craig G, Scambler G, Spitz L. Why Parents of Children with Neurodevelopmental  
4 Disabilities Requiring Gastrostomy Feeding Need More Support. *Dev Med Child Neurol*  
5 2003;45(3):183-188.  
6  
7 21 Craig G. Psychosocial Aspects of Feeding Children with Neurodisability. *Eur J Clin Nutr*  
8 2013;67:S17-20  
9  
10 22 Sullivan P, Juszczak E, Bachlet AM, Thomas AG, Lambert B, Vernon-Roberts A, Grant  
11 HW, Eltumi M, Alder N, Jenkinson C. Impact of Gastrostomy Tube Feeding on the Quality  
12 of Life of Carers of Children with Cerebral Palsy. *Dev Med Child Neurol* 2004;46(12):796-  
13 800.  
14  
15 23 Stoner J, Bailey R, Angell M. Perspectives of Parents/Guardians of Children with  
16 Feeding/Swallowing Problems. *J Dev Phys Disabil* 2006:333-353  
17  
18 24 Puntis JW. Specialist Feeding Clinics. *Arch Dis Child* 2008;93(2):164-167.  
19  
20 25 Ayoob KT, Barresi I. Feeding Disorders in Children: Taking an Interdisciplinary  
21 Approach. *Ped Ann* 2007;36(8):478-483.  
22  
23 26 Simonsmeier V, Rodriguez M. Establishment of an Interdisciplinary Pediatric Oral-  
24 Motor- Sensory Feeding Clinic Team. *Infants Young Child* 2007;20(4):345-354.  
25  
26 27 Martin C, Southall A, Shea E, Marr A. The Importance of a Multifaceted Approach in the  
27 Assessment and Treatment of Childhood Feeding Disorders: A Two-Year-Old In-Patient  
28 Case Study in the U.K. National Health Service. *Clin Case Stud* 2008;7:79-99.  
29  
30 28 Silverman D. *Doing Qualitative Research* (2nd ed) London: Sage; 2005.  
31  
32 29 Ritchie J, Lewis J. *Qualitative Research Practice: A Guide for Social Science Students and*  
33 *Researchers*. London: Sage; 2003.  
34  
35 30 Denzin N, Lincoln Y. *Collecting and Interpreting Qualitative Materials*. London: Sage;  
36 1998.  
37  
38 31 Walliman N. *Research Methods: The Basics*. London: Routledge; 2011.  
39  
40 32 Meloy J. *Writing the Qualitative Dissertation*. New Jersey: Lawrence Elbaum; 1994.  
41  
42 33 Reiners G. Understanding the Differences between Husserl's (Descriptive) and  
43 Heidegger's (Interpretive) Phenomenological Research. *J Nurs Care* 2012 doi:10.4172/2167-  
44 1168.1000119  
45  
46 34 Sandelowski M. Whatever Happened to Qualitative Description? *Res Nurs Health*  
47 2000;23:334-340.  
48  
49 35 Arvedson J. Assessment of Pediatric Dysphagia and Feeding Disorders: Clinical and  
50 Instrumental Approaches. *Dev Dis Res Rev* 2008;14:118-127.  
51  
52 36 Petersen M et al. Eating and Feeding are not the same: caregivers' perceptions of  
53 gastrostomy feeding for children with cerebral palsy. *Dev Med Child Neurol* 2006;48(9):713-  
54 717.  
55  
56 37 Dick J. 'Dysphagia Severity Score' System: Clinical Outcomes in Paediatric Dysphagia. *Int*  
57 *J Lang Commun Disord* 1998;33(S1):268-272.  
58  
59  
60

38 Smith C, Jebson E, Hanson B. Thickened Fluids: Investigation of users' experiences and perceptions. *Clin Nutr* 2014;33(1):171-174.

39 Polgar E, Thomas S. Introduction to Research in the Healthcare Sciences (4th ed). London: Elsevier; 2000.

For peer review only

1  
2  
3  
4  
5  
6  
7  
8  
9  
10  
11  
12  
13  
14  
15  
16  
17  
18  
19  
20  
21  
22  
23  
24  
25  
26  
27  
28  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

1  
2  
3 What do parents of children with dysphagia think about their MDT?  
4 A qualitative study  
5  
6  
7  
8

9 Authors

10 Emma Jebson, Speech and Language Therapy, Royal Free Hospital, London, UK  
11 Ben Hanson, Department of Mechanical Engineering, University College London, UK  
12 Christina H Smith, Language and Communication, Division of Psychology and Language  
13 Sciences, University College London, UK  
14

15  
16  
17  
18 Corresponding Author

19 Christina H Smith  
20

21 Address

22 Division of Psychology & Language Sciences  
23 Chandler House  
24 2 Wakefield Street  
25 London  
26 WC1N 1PF  
27 Email: [christina.smith@ucl.ac.uk](mailto:christina.smith@ucl.ac.uk)  
28 Telephone: +44 20 7679 4233  
29 Fax: +44 20 7679 4238  
30  
31  
32  
33

34 Word Count

35 Main text (excluding title page, abstract, references, quotes, tables): 2858  
36  
37  
38  
39

40 Keywords: parent, multidisciplinary team, paediatric, dysphagia, qualitative  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

## Abstract

### Objectives:

To seek the experiences and perspectives of parents caring for children with dysphagia, with emphasis on their experiences of working within their child's multidisciplinary team (MDT)

### Setting:

This research was completed in community settings, within families' homes across the UK.

### Participants:

Fourteen families self-selected to participate in the study. Criteria specified that participants must care for a child under the age of 18 and to decrease ambiguity the term 'diagnosis of dysphagia' was defined as the need for modified (thickened) fluids. Exclusion criteria: caring for an adult over the age of 18; diet and fluid modifications for reasons other than dysphagia (e.g. for symptomatic treatment of Gastro-oesophageal reflux disease (GORD)). Participants were interviewed within their homes using a semi-structured questionnaire and data was analysed using a descriptive phenomenological approach through use of thematic coding and constant comparison. Themes and relationships were inductively generated from the data.

### Results

Participants universally expressed a desire to be involved with their child's multidisciplinary team; this study identified the following facilitators and barriers to collaboration: [Accessing Services, Professional Knowledge, and Professional Skillset](#). Participants described three means of responding to these barriers: Reacting Emotionally, Seeking Solutions, and Making Decisions.

### Conclusions:

This study recorded in-depth reports of participants' experiences of working with healthcare providers. Despite government-driven efforts towards person-centred health and social care, participants shared accounts of times when this has not occurred, describing a negative impact on the wellbeing and quality of life of their child and family.

The study protocol and consent procedure were approved by the local institution ethics committee (LC/2011/007).

### Data sharing:

No additional data available

### Strengths and Limitations of this Study

- Evidence of facilitators and barriers to effective parent-professional collaboration
- Provision of parents' own report of experiences with multidisciplinary teams
- Supports literature relating to the need for holistic, patient-centered care and provides skills and attributes required of professionals in multidisciplinary working
- Small-scale study encouraging further research in this area
- [Self-selecting sample involving outside agencies in initial recruitment](#)

## Background



1  
2  
3  
4 Swallowing difficulties (dysphagia) can vary in aetiology, symptomology and severity and  
5 affect children with a variety of medical diagnoses. Up to 90% of children with  
6 neurodevelopmental disorders such as cerebral palsy and Down syndrome experience signs of  
7 dysphagia including coughing, choking, chest infections, poor weight gain and  
8 breathlessness[1], often from birth or early infancy. Children with GORD and those born  
9 prematurely are also at increased risk of childhood dysphagia[2-4]. Thus dysphagia can be a  
10 symptom of different underlying medical conditions and is diagnosed and treated by a variety  
11 of medical specialists.  
12

13  
14 Children with complex and pervasive needs require support in a range of in- and outpatient  
15 specialist settings including hospitals, clinics and schools. Children may be in contact with a  
16 range of health and care professionals including Paediatricians, GPs, Speech and Language  
17 Therapists, Physiotherapists, Dieticians and Social Workers; for these children and their  
18 families well-coordinated input is essential for provision of individualised care[5-7].  
19 Multidisciplinary teams (MDTs) are commissioned to provide joined up, patient-centred  
20 support and seek to place children and their families at the centre of decision-making  
21 processes[4,8,9]. Government initiatives such as the Early Support keyworking scheme[6]  
22 and the Common Assessment Framework[10] have been set up throughout the UK to improve  
23 care quality by providing a framework for regular MDT discussion; avoiding repetition of  
24 information and reducing carer burden; and providing a single point of contact for better  
25 coordination of care and support[6].  
26  
27

28  
29 A number of studies have explored parent experience of caring for children with dysphagia  
30 although typically research has focused on the needs of carers of children with complex needs  
31 which may or may not involve dysphagia as a symptom[11-15], or has been confined to  
32 specific settings such as schools[9,16,17] or Child Development Centres[18]. Mahant et  
33 al[19], Craig et al[20,21] and Sullivan et al[22] have studied the experiences of parents of  
34 children requiring gastrostomy feeding; these studies highlighted the importance and value  
35 placed by parents on oral feeding[19,22], and acknowledged the complexities involved in  
36 decision-making when considering how to balance risks of oral intake with maximising QoL  
37 for children with dysphagia[19-21]. Recommendations for practice include the need for good-  
38 quality information and support for families and the need for professionals to understand  
39 caregiver's perspectives and priorities and to adopt a model of partnership working with the  
40 families under their care [19-21,23]. Studies looking at specialist feeding clinics within the  
41 USA and UK[24-27] describe the intricate and multifaceted nature of feeding and swallowing  
42 disorders and highlight the importance of multidisciplinary working to ensure holistic, child-  
43 and family-centred assessment, treatment and support. This paper seeks to build on this  
44 research and explore the issues pertinent to families caring for children with dysphagia in the  
45 UK, and to gain their perspectives on the care they have received.  
46  
47  
48  
49

## 50 51 52 Method

### 53 54 Participants

55 This cross-sectional study involved parents and carers of children with a diagnosis of  
56 dysphagia, aged between two and 11 years. Information about the study was distributed  
57 through special schools, charities and local and national support groups in the form of letters,  
58  
59  
60

online forums and newsletters. Parents self-selected by contacting the researcher based on the information provided, and gave [written consent](#) to participate in the study. Fifteen parents were initially recruited; one interview was discounted from analysis as the individual with dysphagia was 24 years old. Analysis was completed with interviews from 14 parents; the children's characteristics are summarised in table 1.

Table 1: Individual Child Characteristics

Parent ID number	Medical diagnoses	Age at diagnosis of dysphagia	Nutritional intake	Route to recruitment
1	CP epilepsy, GORD	Under 1 year	Oral diet	School
2	Lissencephaly	18 months	Oral diet	School
3	No diagnosis	8 months	Oral diet	School
4	CP, hydrocephalus, epilepsy, VI, HI	Under 1 year	PEG plus oral tastes.	School
5	CP, Chronic Lung Disease, GORD	1 year	Oral diet (previously PEG)	School
6	Alagille Syndrome	Under 1 year	Half oral, half PEG	School
7	DS, CHD	Under 1 year	Oral diet	Charity
8	DS, GORD	5 years	Oral diet	Charity
9	Congenital cytomegalovirus, GDD	1 year	Oral diet	Family worker
10	DS, CHD, GORD, HI	Under 1 year	Oral diet	Charity
11	DS	Under 1 year	Oral diet	Charity
12	DS	Under 1 year	Oral diet (previously PEG)	School
13	DS, GORD, VI, HI	2 ½ years	Oral diet	School
14	DS, Hirschprung's Disease, GORD	3 years	Oral diet	Charity

Key: CP: Cerebral Palsy  
 DS: Downs Syndrome  
 VI: Visual Impairment  
 CHD: Congenital Heart Disease  
 GORD: Gastro Oesophageal Reflux Disease  
 GDD: Global Developmental Delay  
 HI: Hearing Impairment

#### Procedure

The local institution research ethics committee approved the study protocol and consent procedure (LC/2011/007). [Audio-recorded, in-depth interviews were considered the most appropriate form of data collection; providing participants with dedicated time and space to share their individual experiences and perceptions\[28, 29\].](#)

Participants were contacted and interviews were scheduled at their convenience. Thirteen parents were interviewed at the family home and one parent was interviewed at her place of work. [Although all participants consented to audio recording, each parent was reminded of their right to withdraw from the study at any time. Given the emotive nature of the issues being discussed, breaks were offered throughout the interview process to enable a period of time 'off recording' if required. Informal discussion prior to and following each interview allowed for debriefing and reflection without participants feeling under pressure of being recorded.](#)

1  
2  
3  
4 Semi-structured questionnaires formed the basis of interviews; this provided a degree of  
5 structure and standardisation in questioning whilst allowing for deviation from the 'script'.  
6 Adopting a semi-structured approach allowed for more natural conversation during  
7 interviews, avoiding an overtly formal interview style and maximising the richness of each  
8 participants' account[30,31]. Given the sensitivity of the topics discussed, freedom to deviate  
9 from structured, formal questioning was essential[29]. Parents were asked questions,  
10 including open/closed and content-/dimension-mapping questions[29], to gain both general  
11 and more specific information relating to their child's swallowing history, initial support  
12 received, ongoing needs and current support. Interviews took approximately one hour and  
13 each audio recording was transcribed prior to analysis.  
14  
15

16  
17 The researcher kept a journal for additional notes throughout the data collection process[28,  
18 32, 29]. Although journal entries were not formally used in data analysis, they were used to  
19 document preliminary codes and themes that began to emerge at the time of each interview,  
20 as well as notes on follow-up questions that had been asked, and general attitudes of  
21 interviewees at the time (e.g. positivity / negativity)[29].  
22  
23

#### 24 Analysis

25 Interviews were transcribed and returned to participants to verify accuracy. Two parents  
26 made minor clarifications to comments within their manuscript; one parent providing further  
27 detail of the chronology of her daughter's medical interventions and another providing the  
28 full name of their child's thickener. The parent's amendments were recorded prior to coding.  
29  
30

31 Qualitative analysis methods were identified as most appropriate for this dataset, given the  
32 richness of participants' accounts and the complexity of issues discussed[19]. Descriptive  
33 phenomenology was selected in order to best describe participants' experiences and to  
34 uncover common themes within and between participants' accounts[33]. Methods of thematic  
35 coding and constant comparison were employed to generate codes inductively from the data,  
36 rather than impose preconceived themes constructed by the researcher [28,34]. In turn, the  
37 codes that emerged led to the construction of themes. During coding a transcript was selected  
38 at random and manually coded line by line with short phrases summarising each 'unit';  
39 examples included *negative emotions*, *creative problem solving* and *service flexibility*. Units  
40 varied in length; comprising of phrases, sentences or a number of lines, with one code applied  
41 to each unit.  
42  
43  
44

45 Additional transcripts were then added to the set and manually coded, with codes being  
46 continually compared within and between scripts and amended where required[28]. As  
47 analysis progressed codes were grouped into broader themes. For reliability of the coding,  
48 25% of the coded transcripts were validated by an independent researcher with experience in  
49 qualitative data analysis.  
50  
51

#### 52 Results

53 Fourteen participants completed the study; participants cared for a child between the ages of  
54 two and 11 years old; mean age 5.8 years. Of the 14 participants involved, 12 were under the  
55 care of a paediatrician when their child's swallowing difficulties were first investigated; 13  
56 had contact from a Speech and Language Therapist; eight from Physiotherapy; eight from  
57 dietetics and seven were seen by an Occupational Therapist. Eight families had contact from a  
58  
59  
60

health visitor; eight from the GP; four had involvement from school or nursery staff; one family had input from a school nurse and one from respite staff.

One overriding theme emerged from the data, present in all 14 interviews: all parents and carers expressed their desire to be involved in their child's care through close involvement in the MDT. Three sub-themes emerged relating to factors particularly facilitating or hindering their ability to be involved within the MDT. A further three sub-themes emerged as parents described their responses to the barriers they have experienced (figure 1). Participants' quotes are provided verbatim alongside their identifying number as allocated in table 1.

#### Being involved within the MDT

Without exception, parents reported a desire to be recognised as a key member of their child's MDT. Parents valued the specialist knowledge and opinion of healthcare professionals, but wanted to be identified as the expert about their child.

'My son is my number one subject' (14)

'I'm the one dealing with it everyday. If you want to ask something it's better to ask me.' (10)

'We know our children better than [professionals] do as individuals; they have to take our views on board and respect our opinions.' (7)

#### Facilitators and barriers

The facilitators and barriers to parents' collaboration with the MDT were categorised into three separate sub-themes: (i) accessing services, (ii) professional knowledge and (iii) professional skillset, as below:

##### *i) Accessing services*

Parents described three main issues around their ability to access services; time, staffing, and flexibility of service delivery. When asked how satisfied they were with the support they had received for their child's dysphagia, nine parents reported some degree of dissatisfaction with service accessibility and availability,

'They won't come and see him at home, which is a real shame.' (2)

'My daughter was ill for the whole winter. [The community Speech and Language Therapist] came as a favour to check her swallow, but there's a fine line now she's in school, with whose remit it is.' (12)

'They said they didn't have enough staff [in hospital] to give support with her feeding.' (3)

'It was quite a few years before they had a permanent Speech and Language Therapist at school.' (4)

Those who had felt largely satisfied with their support acknowledged the same qualities as important; reporting easier access to help and advice due to flexibility and availability of health and care staff,

'The [respiratory] physios are really good. They come in [if she is unwell] and monitor her sats. It saves going to A&E and they take swabs that can be sent off.' (5)

'When we went for the Videofluoroscopy the Speech and Language Therapist came with

us...Every six weeks she comes here to see him.’ (7)

‘We’re lucky that we have had support. They’re always at the other end of the phone if we need it’ (11)

‘We have much more support now.’ (10)

### ii) *Professional Knowledge*

Parents attributed their health and care professionals with a level of expertise and specialist knowledge; however, some parents felt that this knowledge was poorly demonstrated by professionals at crucial time points when it was needed; particularly in the early stages of seeking support and specialist advice for their child. Five parents received misdiagnoses of their child’s dysphagia, which resulted in a wait of up to five years for an accurate diagnosis and to receive specialist intervention,

‘I kept showing her feeding to so many different consultants and no one spotted it ...they kept saying ‘it’s a virus, she’s fine’. Thirteen times in her first year she was on antibiotics for chest infections.’ (3)

‘I’m surprised the paediatrician didn’t signpost [specialist assessment] more clearly; she knew what [Lissencephaly] was and its implications.’ (2)

‘I just couldn’t believe it took them so many years to take it seriously; it amazed me.’ (8)

Those with positive experiences also highlighted the importance of well-demonstrated expert knowledge. These families reported an increase in their knowledge of their child’s condition as a result,

‘[The specialist’s] advice, which I found useful was that there were three things to look at: if he was getting pneumonias...if he was failing to thrive...or if it as taking a very long time to feed him’ (2)

‘[The specialist] had lots of questions; over the phone I was talking to her and she said my daughter had reflux and dysphagia, just from the phone call.’ (8)

### iii) *Professional Skillset*

Parents provided a list of qualities they value in healthcare professionals (table 2), placing the greatest importance on communication skills. Parents valued professionals who demonstrated a willingness to listen and who actively sought their opinions.

Table 2: Valued Professional Qualities

ID number	Qualities Listed
1	Accessible; two-way communication; being honest without being too negative.
2	Flexibility in appointments; listening and walk alongside you; treating you as a thinking person; addressing my son at appointments.
3	Interacting with my daughter; working well with other professionals; following through with what they say; talking to who they say they will; when you feel they want to help you and are on your side; making notes and giving you copies; being contactable; being approachable; being honest; not being overworked.
4	Being there; being contactable; liaising with each other; being trustworthy.
5	Being caring, friendly; knowing my child so I don’t need to repeat myself; record keeping.
6	Good people skills, sensitive to my child’s needs and my concerns; good communication; sympathy; seeing my child as an individual.



7	Listen and take the parents' views seriously; communication with parents; explaining jargon; sharing information.
8	Showing expertise in their field; treating children as individuals; not labelling children
9	Professionals working together; putting my child first; sharing information.
10	Listen to parents; being reliable
11	Approachability; being able to explain things.
12	Honesty; encouragement; new ideas; continuity.
13	Approachability; friendliness; warms; engaging our child; active, unhurried listening; empathy.
14	Asking questions of me; active listening; acting on what we say; not labelling our child.

'Parents have the answers even if we don't have the terminology.' (12)

'More the medical side than the community side have no respect or value for what the parents have to say...it's quite nice when you find people who actually listen.' (10)

'The interpersonal (skills) are as important as the clinical (skills).'

 (13)

Parents also described the importance of a positive working relationship between healthcare professionals, themselves and their child:

'In the medical profession it'd hurt me when they wouldn't even address my son at appointments; they would talk to me about him, in front of him, without even saying hello.' (2)

'[I value] people that are good at interacting with my daughter...people who work with her rather than just talking to mum.' (3)

'Every six weeks [our Speech and Language Therapist] comes here to see [my son] ... he really likes her.' (7)

Parents with negative experiences described times when they felt unheard and 'on a different page' to professionals. Parents raised concerns that too strong a focus was placed on health and risk, at times to the detriment of their child's emotional wellbeing and QoL.

'I felt that [the professionals] were very risk-averse...their first concern was to ensure the risk was minimized completely and utterly, rather than recognising that there was a risk but that it wasn't too great yet.' (2)

'We told school that if the children are having any treats, our daughter can have them too... There was an event where all the children were having hot chocolate with marshmallows. They wouldn't let our daughter have one and she got upset.' (8)

Parents discussed the importance of information sharing, identifying a need for up-to-date, jargon-free information to maximise their understanding and involvement. Parents reported a similar need for more effective information sharing between professionals within the MDT. Parents identified times when poor collaboration had negatively impacted upon the wellbeing of their child, or upon themselves as caregivers,

'[The professionals] don't liaise with each other at all...although they are all in the same building.' (4)

'I repeat myself all the time...it's hard to keep bringing up the past.' (5)

'In school there is a lack of communication...at one time they had stopped feeding her. I felt so upset by it.' (6)

### Responses to Barriers

Parents' responses to the challenges they have faced were summarised in the following themes: (i) reacting emotionally, (ii) seeking solutions, and (iii) making decisions.

#### *i) Reacting Emotionally*

Parents who had encountered barriers to support reported high levels of anxiety, frustration and distress and feelings of being unheard. Parents who experienced difficulties at the early stages of their child's care described associated feelings of guilt and helplessness at their child's failure to thrive, and frustration in their search for answers. All parents with these experiences reported a significant impact on their emotional wellbeing.

'I struggled with it; it was awful. It made me extremely depressed because I just didn't know what was going on, and no one seemed to be paying any attention.' (3)

'I felt that this was very poorly handled in terms of the emotional impact it can have on a parent, to say you might not be able to feed your child yourself.' (2)

'[The Speech and Language Therapist] was only focussed on communication. She asked us every time how feeding was going; I dreaded her asking me that... I hated telling her he just couldn't eat, but she just said to keep trying. It was so demoralising...' (13)

#### *ii) Seeking Solutions*

All parents described times when they had adopted a proactive approach towards seeking and receiving help: researching into their child's medical conditions, recommended treatment, medication and available support. Parents report using the knowledge they had gained to actively request or refuse specific services or interventions,

'It's been more parent-driven; no one takes ownership of the problems.' (13)

'Things take a long time. I work with children with disabilities and have some knowledge, but even with knowledge you need to do a lot of pushing.' (10)

Parents reported the value of peer support and identified times when they have felt empowered by the knowledge they have gained from other parents and carers in a similar situation,

'At first I didn't want a PEG but... I spoke to other parents who said they're really good.' (6)

'It's been useful meeting other parents, to talk about things with them and share experiences.' (11)

'I wrote to the GP and asked [for thickener], because somebody else used it and gave me some sachets.' (1)

'Talking to other parents [helps] too, not just professionals' (4)

Some parents used the knowledge they had gained to directly challenge professional advice or seek second opinions; six parents contacted private professionals for second opinions and two families contacted overseas specialists for advice,

'I see a private person because I'm unhappy with the support I get.' (3)



1  
2  
3 'I discovered a Speech and Language Therapist in Brazil... she said my daughter has  
4 [dysphagia]...I was shocked; she'd had problems all that time and we had been told it  
5 was nothing.' (8)  
6

7  
8 iii) *Making decisions*

9 Parents described times when they had taken matters 'into their own hands' in the day-to-day  
10 management of their child's difficulties. Parents reported developing their own strategies  
11 based on a 'trial and error' approach with their child; employing a range of techniques to  
12 maximise their child's swallowing safety. Techniques included postural adaptations, changes  
13 to mealtime utensils and environmental strategies.  
14

15  
16 'We had been spoon-feeding him water...he was alright with spoonfuls; any more and he  
17 coughs' (5)

18 'She would have rice pudding and I would give her a dummy after to help her  
19 swallow...when we put the dummy in then she would initiate the swallowing action.' (6)

20 'I take her drink away for a second [between sips] to give her a chance to breathe before  
21 carrying on.' (10)  
22

23  
24 A similar approach was used to manage difficulties encountered with fluid thickeners. Parents  
25 reported a range of difficulties using thickeners on an everyday basis including lumpiness;  
26 problems maintaining fluid consistency over time; managing liquid medications and  
27 modifying their child's diet or fluid consistency when unwell or tired. Parents described a  
28 number of techniques that they developed using their knowledge and experience of their  
29 child, in order to avoid such difficulties.  
30

31  
32 'We use a lower dose [of thickener] in milk, it's just enough to slow it down. In his juice  
33 we use slightly more because the cups have bigger holes in.' (7)

34 'We recognise when it needs to be thicker, like when she's poorly.' (13)

35  
36 'We do thicken some of his medication...we give medication in a syringe too so we can  
37 control how he has it.' (11)  
38

39  
40 Discussion  
41

42  
43  
44  
45 Discussion  
46

47 This study proceeded with explorative aims to seek parents' experiences of their involvement  
48 with their MDT. As a qualitative study this does not seek to generalise findings to the wider  
49 population, particularly considering the age ranges of children involved and the geographical  
50 spread. Qualitative methodologies employed were deemed appropriate for a study of its size  
51 and nature[34,28]. Reliability and validity were established during analysis through inter-rater  
52 agreement and participant validation.  
53  
54

55 Participants acknowledged the need for multidisciplinary working to ensure holistic  
56 management of their child's difficulties, as reported elsewhere within the literature[23-27,35].  
57 Parents encountered a number of barriers to accessing appropriate services in the early stages  
58  
59  
60

1  
2  
3 of their child's life and described a range of negative physical and emotional effects on  
4 themselves and their children. Whilst resources may be limited, [improved staffing and time](#)  
5 [for direct family support may have reduced the impact of these barriers](#). Shared resources  
6 [such as shared workspaces for health professionals may serve to improve collaboration and](#)  
7 [reduce carer burden](#). More flexible models of service delivery, such as improved crossover  
8 [between school and community services, may have enabled some families to access support](#)  
9 [quicker and encounter fewer moments of delay and procedural 'red tape'](#).

11 Families who received repeated misdiagnoses of their child's condition described higher  
12 levels of dissatisfaction in the MDT and negative impacts on child and family health and  
13 wellbeing. Participants reported their frustration and upset in knowing there was 'something  
14 wrong' with their child's health yet failing to receive appropriate support and diagnostics. It  
15 could be argued that the parents who sought second opinions from private and overseas  
16 professionals, did not receive advice that could not have been provided by their child's MDT.

18  
19  
20  
21 Participants expressed their need for healthcare professionals to work proactively, particularly  
22 in the early stages of seeking and receiving a diagnosis of dysphagia. Previous work has  
23 shown that professionals who work holistically and proactively are better able to anticipate a  
24 child's needs, referring for specialist intervention before a critical need arises[35]. Parents  
25 acknowledged the importance of communicative and interpersonal skills in facilitating a  
26 trusting relationship between family members and professionals, particularly when balancing  
27 considerations around risk and QoL. This issue was particularly pertinent for parents caring  
28 for children considered for PEG feeding; an issue requiring great sensitivity and discussed  
29 elsewhere in the literature[20,21,36]. The need for good-quality information was highlighted  
30 to enable informed decision-making [23] and effective communication was considered to  
31 reduce the burden on parents to repeat their child's medical information to different members  
32 of the MDT[37]. Keyworking schemes such as Early Support[5,6] and shared documentation  
33 may be one step towards this end in order to streamline communication and to provide a  
34 single point of contact for families caring for children with complex needs; however with  
35 current financial and structural changes to the health and social care system such resources  
36 may be limited.

37  
38  
39  
40 The emotional, financial and physical burdens of caring for a child with a disability are well  
41 reported[11-13]. Parents reported a significant impact on the emotional and physical  
42 wellbeing of themselves and their children, acknowledging a need for proactivity on the part  
43 of the MDT, particularly in the early stages of receiving diagnoses and requesting specialist  
44 support. Parents utilised a range of creative approaches in managing the everyday difficulties  
45 of using thickening agents[38] and drew upon the experiences of themselves and others to  
46 develop solutions that worked for them.

47  
48  
49  
50 Limitations: As a [self-selecting cohort](#) the sample in this study is open to a degree of bias  
51 [39]. Because other agencies such as schools, charities and support groups were involved in  
52 disseminating the information a response rate could not be calculated as it was unclear how  
53 many parents had come into contact with the initial information regarding the study. Social  
54 demographics were not taken for this study; further research exploring the experiences of  
55 socially isolated families would be beneficial. [Parents were invited to check the accuracy of](#)  
56 [transcripts; this feature of the study was not accounted for in the initial stages and as such](#)

1  
2  
3 may have been considered an additional burden which had not been anticipated by parents at  
4 the recruitment stage.

5  
6 Further developments of this research exploring in more depth the different types of service  
7 provided to families with children with dysphagia would be beneficial. Similarly although  
8 social demographics were not taken for this study further research, this study could be  
9 expanded by studying socially isolated or 'hard to reach' families.

10  
11  
12 Acknowledgements: The authors acknowledge all parents who participated and the schools  
13 and organisations that provided information to appropriate parents. The authors also  
14 acknowledge the help of J. Wood for advice regarding qualitative analysis, and A. Dixon-  
15 Dewfall as an independent coder during data analysis.

16  
17  
18  
19 Contributorship statement:

20 A brief description of each author and their contribution towards the manuscript are detailed  
21 below. E Jebson and C Smith accessed the data for the study in its entirety prior to and during  
22 write-up; B Hanson had access to any data required whilst revising and approving draft and  
23 final copies of the manuscript. All authors are accountable for the accuracy and integrity of  
24 the work'.

- 25  
26  
27 i.) E Jebson: Responsible for participant recruitment, data collection and  
28 analysis, write-up of manuscript. Had access to all data  
29 ii.) B Hanson: Contributed to the conception and design of the study, critical  
30 revision of draft versions of manuscript and approval of final version  
31 iii.) C Smith: Contributions towards research design; provided advice and  
32 supervision on research processes and data write-up. Critically revised and  
33 approved the manuscript (draft and final versions).

34  
35 Additional contributors, J. Wood and A. Dixon-Dewfall, were involved in the study during  
36 data analysis and interpretation. Both are acknowledged in the 'acknowledgements' section at  
37 the end of the paper.

38  
39 Competing interests:  
40 No competing interests

41  
42 Funding:  
43 This research received no specific grant from any funding agency in the public, commercial  
44 or not-for-profit sectors.

45  
46 Data sharing:  
47 No additional data available

48  
49  
50  
51  
52  
53  
54 References

1  
2  
3 1 Schwarz M. Feeding Disorders in Children with Developmental Disabilities. *Infants Young*  
4 *Child* 2003;16:317-330.

5  
6 2 Wolf L, Glass R. Feeding and Swallowing Disorders in Infancy: Assessment and  
7 Management. San Antonia: Therapy Skills Builders; 1992.

8  
9 3 Vohr B et al. Neurodevelopmental Outcomes of Extremely Low Birth Weight Infants <32  
10 Weeks' Gestation between 1993 and 1998. *Pediatrics* 2005;116(3):635-643.

11  
12 4 Bell H, Sheckman Alper B. Assessment and Intervention for Dysphagia in Infants and  
13 Children: Beyond the Neonatal Intensive Care Unit. *Semin Speech Lang* 2007;28:213-222.

14  
15 5 Department for Education and Skills, Department of Health. National Service Framework  
16 for Children, Young People and Maternity Services: Disabled Children and Young People  
17 and those with Complex Health Needs. 2004.

18  
19 6 Department for Education and Skills. Aiming High for Disabled Children: better support for  
20 families.  
21 <http://webarchive.nationalarchives.gov.uk/20130401151715/http://www.education.gov.uk/publications/eOrderingDownload/PU213.pdf> [Accessed online May 2014]. 2007.

22  
23 7 Department of Health. Better Care, Better Lives: Improving outcomes for children, young  
24 people and their families living with life limiting and life threatening conditions. 2008.

25  
26 8 Reeves S et al. Interprofessional Education: effects on professional practice and healthcare  
27 outcomes. *Cochrane Database Syst Rev* 2013;3:CD002213.

28  
29 9 Angell M, Bailey R, Stoner J. Family Perceptions of Facilitators and Inhibitors of Effective  
30 School-Based Dysphagia Management. *Lang Speech Hear Serv Sch* 2008;39:214-226.

31  
32 10 Department for Education and Skills. Every Child Matters. 2003.

33  
34 11 Raina P et al. The Health and Well-being of Caregivers of Children with Cerebral Palsy.  
35 *Pediatrics* 2005;115:626-636.

36  
37 12 Roberts K, Lawton D. Acknowledging the Extra Care Parents Give their Disabled  
38 Children. *Child Care Health Dev* 2001;27(4):307-319.

39  
40 13 Fisher H. The Needs of Parents with Chronically Sick Children: a literature review. *J Adv*  
41 *Nurs* 2001;36(4):600-607.

42  
43 14 Meester-Delver A et al. Predicting Additional Care in Young Children with  
44 Neurodevelopmental Disability: a systematic review. *J Adv Nurs* 2001;36:600-607.

45  
46 15 Cass H et al. Supporting Children with Multiple Disabilities. *Child Care Health Dev*  
47 1999;25(3):191-211.

48  
49 16 Arvedson J, Homer E. Managing Dysphagia in the Schools. *The ASHA Leader*  
50 2006;11(13):8-30.

51  
52 17 Harding C, Halai V. Providing Dysphagia Training for Carers of Children who have  
53 Profound and Multiple Learning Disabilities. *British Journal of Developmental Disability*  
54 2009;55(108):33-47.

- 1  
2  
3 18 Burland L. Feeding Issues in Children with Neurodevelopmental Difficulties:  
4 implementation of nutritional care and dysphagia guidelines at St James University Hospital  
5 Child Development Centre. *Dev Med Child Neurol* 2011;53(S3):44-45.  
6  
7 19 Mahant S, Jovcevska V, Cohen E. Decision-Making Around Gastrostomy-Feeding in  
8 Children with Neurologic Disabilities. *Pediatrics* 2011;127(6):e1471-81.  
9  
10 20 Craig G, Scambler G, Spitz L. Why Parents of Children with Neurodevelopmental  
11 Disabilities Requiring Gastrostomy Feeding Need More Support. *Dev Med Child Neurol*  
12 2003;45(3):183-188.  
13  
14 21 Craig G. Psychosocial Aspects of Feeding Children with Neurodisability. *Eur J Clin Nutr*  
15 2013;67:S17-20  
16  
17 22 Sullivan P, Juszczak E, Bachlet AM, Thomas AG, Lambert B, Vernon-Roberts A, Grant  
18 HW, Eltumi M, Alder N, Jenkinson C. Impact of Gastrostomy Tube Feeding on the Quality  
19 of Life of Carers of Children with Cerebral Palsy. *Dev Med Child Neurol* 2004;46(12):796-  
20 800.  
21  
22 23 Stoner J, Bailey R, Angell M. Perspectives of Parents/Guardians of Children with  
23 Feeding/Swallowing Problems. *J Dev Phys Disabil* 2006:333-353  
24  
25 24 Puntis JW. Specialist Feeding Clinics. *Arch Dis Child* 2008;93(2):164-167.  
26  
27 25 Ayoob KT, Barresi I. Feeding Disorders in Children: Taking an Interdisciplinary  
28 Approach. *Ped Ann* 2007;36(8):478-483.  
29  
30 26 Simonsmeier V, Rodriguez M. Establishment of an Interdisciplinary Pediatric Oral-  
31 Motor- Sensory Feeding Clinic Team. *Infants Young Child* 2007;20(4):345-354.  
32  
33 27 Martin C, Southall A, Shea E, Marr A. The Importance of a Multifaceted Approach in the  
34 Assessment and Treatment of Childhood Feeding Disorders: A Two-Year-Old In-Patient  
35 Case Study in the U.K. National Health Service. *Clin Case Stud* 2008;7:79-99.  
36  
37 28 Silverman D. Doing Qualitative Research (2nd ed) London: Sage; 2005.  
38  
39 29 Ritchie J, Lewis J. Qualitative Research Practice: A Guide for Social Science Students and  
40 Researchers. London: Sage; 2003.  
41  
42 30 Denzin N, Lincoln Y. Collecting and Interpreting Qualitative Materials. London: Sage;  
43 1998.  
44  
45 31 Walliman N. Research Methods: The Basics. London: Routledge; 2011.  
46  
47 32 Meloy J. Writing the Qualitative Dissertation. New Jersey: Lawrence Elbaum; 1994.  
48  
49 33 Reiners G. Understanding the Differences between Husserl's (Descriptive) and  
50 Heidegger's (Interpretive) Phenomenological Research. *J Nurs Care* 2012 doi:10.4172/2167-  
51 1168.1000119  
52  
53 34 Sandelowski M. Whatever Happened to Qualitative Description? *Res Nurs Health*  
54 2000;23:334-340.  
55  
56 35 Arvedson J. Assessment of Pediatric Dysphagia and Feeding Disorders: Clinical and  
57 Instrumental Approaches. *Dev Dis Res Rev* 2008;14:118-127.  
58  
59  
60

1  
2  
3  
4 36 Petersen M et al. Eating and Feeding are not the same: caregivers' perceptions of  
5 gastrostomy feeding for children with cerebral palsy. *Dev Med Child Neurol* 2006;48(9):713-  
6 717.

7  
8 37 Dick J. 'Dysphagia Severity Score' System: Clinical Outcomes in Paediatric Dysphagia. *Int*  
9 *J Lang Commun Disord* 1998;33(S1):268-272.

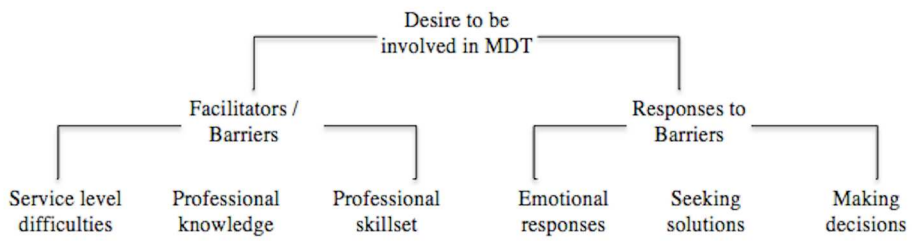
10  
11 38 Smith C, Jebson E, Hanson B. Thickened Fluids: Investigation of users' experiences and  
12 perceptions. *Clin Nutr* 2014;33(1):171-174.

13  
14 39 Polgar E, Thomas S. Introduction to Research in the Healthcare Sciences (4th ed).  
15 London: Elsevier; 2000.

16  
17  
18  
19  
20  
21  
22  
23  
24  
25  
26  
27  
28  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

For peer review only

1  
2  
3  
4  
5  
6  
7  
8  
9  
10  
11  
12  
13  
14  
15  
16  
17  
18  
19  
20  
21  
22  
23  
24  
25  
26  
27  
28  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60



235x67mm (300 x 300 DPI)

peer review only



## COREQ Guidelines

**Research team / reflexivity**

Interviewer/facilitator: Which author/s conducted the interview or focus group?  
All interviews were conducted by researcher and author (Emma Jebson)

Credentials: What were the researcher's credentials? E.g. PhD, MD  
MSc

Occupation: What was their occupation at the time of the study?  
Full time practicing SLT

Gender: Was the researcher male or female?  
Female

Experience and training: What experience or training did the researcher have?  
The researcher is a trained Speech and Language Therapist with 10 years experience working in the field of Learning Disability, Autism Spectrum Disorder and Profound and Multiple Learning Disability. Five years experience working with adults and children with Mental Health difficulties and two years experience working as an Early Support Keyworker prior to training as an SLT. Within her Keyworker role the researcher supported families of children with complex needs, coordinating their care and acting as a single point of contact between families and the MDT. As an SLT the researcher has received training and gained experience in eliciting information from case histories, managing challenging conversations and adapting her communication style, taking into consideration the cultural and linguistic needs of the listener.

**Relationship with participants**

Relationship established: Was a relationship established prior to study commencement?  
Brief telephone conversation with interested parents to share information about study, aims and to allow participants to ask questions.

What did the participants know about the researcher? e.g. personal goals, reasons for doing the Research?  
Participants knew that the research was seeking the lived experiences of families caring for children with dysphagia, with a view to publishing the study once completed, to add to the evidence base.

Interviewer characteristics What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic?  
The author shared information about current working role as an SLT; previous research that had been carried out during completion of MSc; professional interests in swallowing and family support.

**Study design: Theoretical framework**

Methodological orientation and theory: What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis?  
Phenomenology and thematic analysis.

**Participant selection**

Sampling How were participants selected? e.g. purposive, convenience, consecutive, snowball  
Convenience sampling – self-selecting participants

Method of approach. How were participants approached? e.g. face-to-face, telephone, mail, email  
A variety of methods were used in order to reach as many families as possible:

- internet forums
- letters via schools and family workers
- email distribution lists of charities

## COREQ Guidelines

Sample size How many participants were in the study?

Fourteen

Non-participation How many people refused to participate or dropped out? Reasons?

Unable to ascertain response rate: participants were recruited via schools/charities, who did not share how many families had received the letters/information compared to how many had replied. Initially 15 participants were recruited; however data from one participant was later excluded from the study as the participant was caring for an adult child.

**Setting**Setting of data collection Where was the data collected? e.g. home, clinic, workplace

Family homes. One interview was participated at school where parent worked, in a quiet room.

Presence of non-participants Was anyone else present besides the participants and researchers?

No

Description of sample What are the important characteristics of the sample? e.g. demographic data, data

Numerical labels were assigned to participants to anonymised data.

Demographics: geographical location; medical diagnoses; time since onset of dysphagia, nutritional intake.

**Data collection**Interview guide Were questions, prompts, guides provided by the authors?

Semi structured interviews were delivered; questions were asked but not always in the order written on questionnaires (to allow for a more 'normal' conversation rather than overtly formal interview). Where information given was ambiguous or unclear the researcher asked for clarification.

Repeat interviews Were repeat interviews carried out? If yes, how many?

No repeat interviews were completed.

Audio/visual recording Did the research use audio or visual recording to collect the data?

Interviews were audio recorded. Consent was gained from all participants.

Field notes Were field notes made during and/or after the interview or focus group?

Annotations were made on questionnaires during the interview; the researcher also kept a journal to record subjective notes such as main themes that seemed to emerge and to capture the general 'feel' of interviews.

Duration: What was the duration of the interviews or focus group?

Each interview lasted between 30 and 70 minutes

Data saturation Was data saturation discussed?

Although qualitative techniques were used the researcher was not employing a Grounded Theory approach and as such data saturation was not considered essential.

Transcripts returned Were transcripts returned to participants for comment and/or correction?

Transcripts were returned to each participant for comment. Two parents made minor clarifications, both transcripts were amended accordingly.

**Data analysis**Number of data coders How many data coders coded the data?

One primary coder. 25% of the transcripts were then coded separately by an independent researcher to

## COREQ Guidelines

maximise reliability.

Description of the coding tree Did authors provide a description of the coding tree?

Not provided within body of article, in line with presentation of similar articles within the journal.

Derivation of themes Were themes identified in advance or derived from the data?

Themes were derived from the data.

Software What software, if applicable, was used to manage the data?

No software required for coding considering small sample size.

Participant checking Did participants provide feedback on the findings?

See Q23.

**Reporting**

Quotations presented Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. participant number

Verbatim quotes were inserted to illustrate the findings. Participant numbers were used to identify quotes.

Data and findings consistent Was there consistency between the data presented and the findings?

Data and findings were consistent

Clarity of major themes Were major themes clearly presented in the findings?

Findings were reported by explicit description of the major themes.

Clarity of minor themes Is there a description of diverse cases or discussion of minor themes?

Key themes were described within discussion of the major themes. Not all minor themes (i.e. themes relating to fewer than 3 participants) were presented, due to word count limitations.