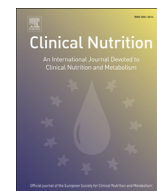


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Short communication

Thickened fluids: Investigation of users' experiences and perceptions[☆]

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SUMMARY

Background & aims: Fluid thickeners are an important and commonly-used strategy to manage swallowing difficulties however there are no reports of the perceptions and experiences of parents of children using thickeners.

Methods: Semi-structured interviews of 14 parents having a child using fluid thickeners due to swallowing difficulties.

Results: Parents reported improvements in quality of life and health through the use of thickeners. They also reported persistent difficulties in the use of thickeners.

Conclusions: Results showed unanimous goodwill and positive attitudes towards thickeners and their observed benefits, tempered by common difficulties with thickeners (variability and unpredictability). There remains scope for improvements of commercial thickeners and in information conveyed to users.

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1. Introduction

Children experience difficulties swallowing as a result of neurological and structural disorders. Being unable to safely swallow sufficient food and fluid impacts on both health and quality of life¹ and may necessitate enteral feeding.² Health effects include malnutrition, dehydration and chest infections from aspiration (food or fluid entering the lungs) which can be fatal if unidentified or untreated. Quality of life effects include restriction of diet choice, social exclusion during mealtimes, and coughing and choking.

The most prevalent intervention to facilitate safe swallowing is texture modification, including thickening of fluids.^{3,4} This is an important aspect of care for parents whose children require thickeners, however no studies have yet documented their views and experiences.

2. Methods

This cross-sectional exploratory study used semi-structured interviews (Table 1) to obtain the opinions of 14 parents⁵ who regularly use thickeners to prepare drinks for their children.

The parents self-selected to participate from information sheets distributed through schools and non-governmental organisations.⁶ One parent was interviewed per child. The interviews were face-to-face, approximately 1 h, and arranged at the parents' convenience within their homes or workplace.

Interviews were recorded and transcriptions were validated by the parents, then analysed using thematic coding and constant comparison.^{5,7} Half of the interviews were validated by an independent researcher. No changes were made to the transcriptions following parental review, and the codes were not changed following independent validation.

The study protocol and consent procedure were approved by the local institutional Research Ethics Committee.

3. Results

The children were aged 2–12 with chronic medical conditions and had been using thickeners for over 10 months (Table 2). A range of thickeners were used (Table 3) and two children received a combination of oral and enteral nutrition (Table 2). One child was

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Table 1
Questions guiding discussion in semi-structured interview.

Background information regarding your child:
1. Age
2. Medical diagnosis/diagnoses (if any)
3. Brief history of swallowing difficulties – when did your child first start having problems with his/her swallowing?
4. Symptoms of swallowing difficulties
5. Current nutrition and hydration (i.e. orally, or via a tube or PEG)? If enteral nutrition, any oral intake?
Thickener:
1. Thickener used
2. Age when began to use drinks thickeners?
3. Were you given any instructions to help you prepare drinks with thickener?
4. Did anyone demonstrate how to prepare a drink with thickener?
5. Were you told to use different amounts of thickener for different drinks (e.g. hot/cold drinks) or at different times (e.g. if your child is unwell)?
6. How confident did you feel when you first started using thickeners
7. How confident do you feel now when using thickeners
Use of thickener:
1. Do you experience difficulties when using thickener?
2. Do you feel that using thickener helps your child?

prescribed thickeners for oral-stage difficulties; three for pharyngeal difficulties and ten for combined oral-pharyngeal difficulties. Aspiration on normal fluids had been identified for ten children prior to commencing thickeners. Of the fourteen children, three were recommended thickeners to manage both swallowing and reflux-related symptoms.

Three themes emerged from the interview coding and are summarised below (number in parenthesis after quotation refers to the parent, detailed on Table 2, who made the comment):

1. Challenges at the early stage of using thickeners

During the early stage of using thickeners, parents struggled with both the emotional and practical aspects. Seven parents reported being given no information on how to mix thickeners to obtain the optimum consistency beyond the generic information on the container of thickener. In contrast three parents were given demonstrations on mixing thickeners by their Speech and Language Therapist and all reported that this was helpful. Parents reported going into school and providing 'demonstrations'

Table 2
Biographical information.

Parent number	Child's age in years	Child's gender	Medical diagnoses	Nutritional intake	Age first used thickener	Thickener used	Approx number of years thickener used
1	10	Boy	Cerebral palsy, seizures, GORD	Full oral diet	6 months	Thixo-D	9
2	5	Boy	Lissencephaly	Full oral diet	3 years	Thick & Easy	2
3	3	Girl	No medical diagnosis	Full oral diet	9 months	Carobel	2
4	11	Girl	Cerebral palsy, hydrocephalus, seizures, visual & hearing impairment	PEG with oral for pleasure	7 years	ThickenUp	4
5	4	Boy	Cerebral Palsy, chronic lung disease	Full oral diet (previously PEG)	2 years	Thick & Easy	2
6	4	Girl	Alagille syndrome	Half oral and half PEG	18 months	Thick & Easy	3
7	2	Boy	Down's syndrome, congenital heart disease	Full oral diet	15 months	Nutillis	<1 (10 months)
8	12	Girl	Down's syndrome	Full oral diet	6 years	Thick & Easy	6
9	6	Girl	Congenital cytomegalovirus, global developmental delay	Full oral diet	4 years	Vitaquick	2
10	3	Girl	Down's syndrome, congenital heart disease, GORD, hearing impairment	Full oral diet	2 years	ThickenUp	1
11	7	Boy	Down's syndrome	Full oral diet	12 months	Thick & Easy	6
12	5	Girl	Down's syndrome	Full oral diet (previously PEG)	'Baby'	Carobel	4
13	6	Boy	Down's syndrome, GORD, visual and hearing impairments, severe learning disability	Full oral diet	2 years	ThickenUp	4
14	3	Boy	Down's syndrome, Hirschsprung's disease, GORD	Full oral diet	2 years	1	1

Table 3
Fluid thickener.

Name of commercial thickener	Manufacturer of thickener	Website
Thixo-D®	Sutherland Health Care	www.sutherlandhealth.com
Nutillis	Nutricia Nutillis, Danone	www.danone.com
Thick & Easy™	Thick and Easy, Fresenius-Kabi	www.fresenius-kabi.com
RESOURCE®	Nestlé Health Care	www.nestle.com
ThickenUp®		
Carobel	Cow & Gate	www.cowandgate.co.uk
Vita-quick™	Vitaflo®	www.vitaflo.co.uk

to staff to ensure drinks were prepared appropriately for their child.

It made me extremely depressed. (3)

I don't like the thickeners.... I wasn't happy to use them. (5)

We had no information on how or why [thickeners] worked. (4)

I felt that this was very poorly handled in terms of the emotional impact it can have on a parent. (2)

Five families began using thickeners when their child was using a bottle; two of these families experienced unanticipated difficulties finding appropriate teats to manage the increased thickness of fluid. One mother explained,

It didn't occur to me that I'd need wider holes in the teats I was using. This meant that for two days my daughter was really frustrated.... (3)

This mother resorted to widening the holes in teats using a needle. Some families made difficult decisions balancing what they perceived as risk and quality of life

My son can't make choices about anything that he does, everything's done to him, but he can make choices about his food – he can close his mouth and refuse to open it.... There really is nowhere else in his world where he illustrates preferences as much as he does when feeding. We thought that unless the risks are very obvious, we can't deny him this area of life (2)

2. Persistent difficulties with thickeners

Three persistent difficulties were commonly reported by parents. The first (12 parents) was lumpiness and poor mixing of the powder in the drinks; parents used spoons, whisks, sieves, and warmed drinks in efforts to reduce lumps.

Rather than adding a bit of extra powder if it comes out too thin, you might as well just start again, because it never comes out the right consistency. On the other extreme, if it's too thick and you put a bit of water in it, that's a bit more successful, that seems to work. (1)

If you whisk it quick with a fork and add the thickener slowly, it works well. (11)

There's always a couple of lumps in there [juice] that you can't stir out. (7)

The second difficulty reported (8 parents) was obtaining the correct thickness with a variety of different fluids.

...works differently for different fluids... a lot of it is trial and error. The nutritional supplement she has is like a milky drink; if you use the same amount of thickener... it goes like concrete: really, really hard. (9)

...with milk that after it is thickened it does go thinner again over time, whereas with juice it stays. (11)

Even juice I have to slightly warm to get it to dissolve then use a spoon to bash all the lumps out... I have also tried different milkshakes which go horrible; they have watery bits and chunks in it, it looks vile. (3)

The third difficulty reported (9 parents) was change over time, although one parent reported overcoming this by storing drinks in the fridge. (12)

...starts to separate over time. (6)

[problems] The thickening when left to stand. (10)

Two parents reported difficulties with thickening medications and six reported problems when saliva entered the container.

We did have questions about the Movicol, as it doesn't thicken; no one told me this, and it's a big problem. (12)

Saliva: this is a big problem. When saliva gets in it sits on the top of the drink and ruins the thickness, you just need to start again. (1)

Four parents reported a perception of altered taste with thickener

My son doesn't like drinks other than water but the thickener really changes the taste in water. In Ribena you can get away with it more, but it tastes horrible in water. (5)

I know it doesn't really taste, but the thickness feels like a taste. (3)

3. Positive effects of the thickeners

Despite the difficulties in preparing drinks and attaining confidence that the correct thickness was obtained, there was consensus that thickeners helped their children's health

Since we started using [thickener], my goodness, we've had much less chest infections. (8)

...when he wasn't drinking he was suffering with constipation but it was such a challenge to get him to drink. Now he enjoys drinking and that's very important. (7)

They [thickeners] have been a lifesaver for us. (12)

He wasn't drinking before, he had permanent pneumonia. There's been an 80% decrease in his respiration issues and he's drinking is 100% better. (14)

I'm just so grateful that we have access to these things. (13)

Parents also report an improvement in quality of life through the use of thickeners

She came on immediately... feeding was not just a necessity for her to survive from that point; it was something nice for her, something pleasurable. She loves her milk now. (3)

Using the thickener means we can balance my daughter's feeds with the family's diet. (6)

He used to have problems sleeping because he'd be thirsty at night... Our daily routine is better, sleep is better, he's less distressed and has fewer respiratory problems. (14)

4. Discussion

The parents in this study unanimously identified value in fluid thickeners in improving both their child's quality of life by enhancing enjoyment of drinking, and in improved health through, for example, an increase in the amount of fluid drunk, and a reduction in the incidence of chest infections. There was considerable goodwill towards thickeners because of perceived benefits.

However, the parents reported difficulties and frustrations resulting from the variable behaviour of the thickeners with different base fluids; this was compounded by a reported lack of information and support. This issue could be tackled by providing detailed written information about how and why thickeners are used, and a practical tutorial session might assist in parents adjusting to using thickeners. More-detailed information could then be provided online or via helpline: how thickeners perform with different drinks, at different temperatures, over time, and the effect of saliva.⁸ The use of thickeners within this cohort is a long-term endeavour and further information regarding thickeners is required on an on-going basis. Alongside this, further improvements are required from the products themselves. Since people who use and consume thickeners are often disempowered, we would encourage further research and development to incorporate users' views with the aim of improving quality of life for users and families.

Limitations: The population group is hard-to-reach and thus only self-selecting participants were included. Nonetheless, the responses covered a range of opinions and experiences. While small, the study size is appropriate for the methods used.⁹

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Statement of authorship

CS conceived the study and design, contributed to the analysis and wrote the manuscript. EJ assisted with the conception and design, completed the data collection and analysis, and helped draft the manuscript. BH assisted with the conception and design, and helped draft the manuscript. All authors read and approved the final manuscript.

Conflict of interest statement

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