

### Collecting patient evidence to inform and contextualise treatment choices:

## Thickened liquids from the perspective of people with dysphagia post stroke

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# Oropharyngeal dysphagia

#### In stroke

Common morbidity following stroke - over 56 million people in the United States and Europe (Rofes *et al.* 2011)

Estimated that at 1 month post-stroke 15% of patients continue to have swallowing disorders (Geeganage *et al.* 2012)

#### Consequences

↑risk of poor outcomes including aspiration, pneumonia, malnutrition, dehydration and mortality (Altman *et al.* 2010, Arnold *et al.* 2016, Perry & Love 2001, Smithard *et al.* 2007).

## Aspiration



- Aspiration evident in approx. 1/3 of stroke patients on instrumental exam (Smith Hammond et al. 2009)
- 1/3 of people with dysphagia (PWD) who aspirate develop pneumonia (Armstrong & Mosher 2011, Sellars *et al.* 2007, Terrae & Mearin 2006)
- Early detection / management in patients with acute stroke shown to reduce complications, length of hospital stay and overall healthcare expenditures (Altman *et al.* 2010, Martino *et al.* 2005).

### **Management options**

#### Includes.....

### and bolus modification technique of.....



### **Thickened liquids**



#### Use

#### An embedded compensatory treatment used by SLTs internationally (Jones et al. 2017,

McCurtin & Healy 2017, Smithard et al. 2013)

Ranks in top three preferred dysphagia treatments overall (McCurtin & Healy, 2017)

#### Mechanism

A thickening agent (either starch or gum-based and pre-packaged or mixed on-site) is added to liquids to increase viscosity in an attempt to reduce the risk of penetration to the airway

Designed to slow bolus speed and increase swallow safety (Clav'e et al. 2006, Newman et al. 2016), thus minimizing aspiration risk

### **Current context**

A lack of robust empirical evidence to support the therapeutic benefits of TL

Limited evidence from people who have had strokes as to the lived experience and acceptability of using thickeners

Several reported adverse effects including  $\uparrow$  oral /pharyngeal residue, effects on oral and pharyngeal transit times,  $\downarrow$  palatability and  $\uparrow$  risk of dehydration (Clav'e *et al.* 2006, Finestone *et al.* 2001, Newman *et al.* 2016, Steele *et al.* 2015)

### Current user evidence

#### PWD post-stroke

Systematic search covering 2001–16 retrieved two papers with both including stroke patients as a subset of their samples



### **Current evidence**

### PWD generally

### Non-compliance rates vary between 40% and 80%

(Colodny 2005, Sharp & Bryant 2003).

#### Logemann et al 2008

 Aspirators preferred non-TL interventions

#### Lim et al 2016

 Non dysphagic patients and health professionals would sacrifice multiple years of life rather than use TL

### Methodology

#### Intent

Knowledge-building exercise in an area of evidence gaps

Contribute to collective patient voice re TL

Build evidence anthology

#### Method

Recruited through Stroke Support groups

Semi structured interviews

Inductive thematic analysis



### Outcomes

### Uncertainty

# An unpleasant experience

### A trade off



### Uncertainty

#### Table 2. Theme 1: Uncertainty

Subtheme	Subcategory	n	Participant	Example participant quotes
Participation in decision-making	Decision to commence treatment	13	A	'There was no decision—I was just told'
			G	'[I] don't think the decision was ever up to me'
	Routine treatment	5	K	'I'd say everyone gets it that has a stroke'
			D	'It came automatically'
	Health professionals who prescribed	14	М	'It was the doctor recommending them'
			Е	"The hospital must have"
			N	'Somebody gave it to me'
Lack of understanding	No swallowing problem	4	С	'I didn't have a problem'
2			Ι	'I didn't have a swallowing difficulty at all'
	Perceived lack of communication	4	N	'I didn't understand [why] really'
		2	K	'Nobody told me anything'
	Acute condition		L	'I wouldn't have known at the time'

Note: n, Number of participants who commented on a category/subcategory; participant = participant to whom the quote is attributable.



### An unpleasant experience

Subtheme	Subcategory	n	Participant	Example participant quotes
Sensory perspective	The taste of thickened liquids	13	F	'Revolting'
	-		В	'Disgusting'
			L	'Like poison'
			Н	'There was no difference between a cup of tea and a cup of coffee'
	Altered consistency	6	В	'It looked like frog spawn'
			J	'It was like wallpaper paste that's what it looked like, that what it tasted like'
			F	'It's like ice-cream'
	Preparation issues	3	J	'[You] had to keep stirring it, [it would] go into little balls and be terrible'
			Α	'It went to the bottom of the glass'
	Strong emotional responses	4	Ι	'Looking at the tin is making me cringe'
	с .		Α	'It made me feel sick'
			D	'Wicked altogether'
Modifying and terminating the treatment	Reduced fluid intake	5	D	'Wouldn't be drinking as much, certainly not as much water or tea'
			J	'I just hated drinking it, I didn't drink it'
	Premature treatment cessation	4	Ĺ	'I didn't stay too long on it because I couldn't get no satisfaction from it'
			Н	'I decided not to take it'.
	Treatment modification	2	F	'I should be putting two-and-a-half spoons in the water to make it thick, but I said "No I'll put two in it"

#### Table 3. Theme 2: An unpleasant experience

Note: *n*, Number of participants who commented on a category/subcategory; participant = participant to whom the quote is attributable.

### A trade off





"Everything's a tradeoff — now that I can walk upright, I can't wiggle my ears any more.<sup>16</sup>

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Table 4. Theme 3: A trade-off

Subtheme	Subcategory	n	Participant	Example participant quotes
Serving a purpose	Helping recovery	3	J G	'It must have helped in my recovery' 'I presume at the time I needed something like that'
	Making the swallow better	2	А	'There was something wrong with my swallow'
			Е	'It made me swallow better'
	Avoiding respiratory problems	6	Н	'It would sort out the coughing and avoid a chest infection'
			L	'If I'm drinking water I get coughing'
			С	'For not making you cough'
			Ι	So that it didn't go into your lungs'
Recommending to others	A good experience	2	А	'It was very good'
			F	'It's a good experience'
	No choice	4	G	'It was better than nothing'
			J	'I wanted to live as long as I could, so'
			B	'You had to'
	Try the treatment	3	А	'Just try it'
	,		F	'Take the thickener'
	Gives confidence	2	D	'I would recommend them of course to give her confidence to swallow 'cos certainly after a stroke you lose your confidence'
			F	'It gains you confidence'

Note: *n*, Number of participants who commented on a category/subcategory; participant = participant to whom the quote is attributable.

### For your consideration...

### Treatment burden

### Treatment options

Patient involvement / ownership



Acute stage of illness and genuine dislike of treatment

Non-adherence/modification = results in adverse patient outcomes /impacts on clinical resources and outcomes  $\rightarrow$  financial cost to system (Altman *et al.* 2010, Martino *et al.* 2005)

Attempt to ease burden by nonadherence/treatment modification TL firmly embedded (practice evidence)

Product development  $\rightarrow$  may improve treatment adherence and hydration (Penney 2013)

Targeted application (e.g. based on understanding of mechanism of action) and outcomes e.g. instrumentation

Consider and trial other treatment options for managing aspiration, both alongside TL and in isolation from it. Water protocols / Postural changes / Less utilised bolus techniques such as carbonation Patient involvement / ownership

# Limited involvement – acute illness/communication difficulties/older people tend to be less involved in decisions (Deber et al 2007, McCurtin et al 2017)

# Standard responses to which is shared decision making

Patient education insufficient/untimely Irrespective needs attention and problem resolution especially given knowledge of impact of nontreatment issues on outcomes (Hubble et al 2005)

### PLUS.....SLT profession implications

The participants in this study did not appear to associate the TL treatment with the SLT profession specifically

#### **Implications:**

- Public knowledge of SLT role
- For treatment success. Patients who dislike the treatment, for example, might not know who to discuss their concerns with, which may contribute to their early treatment cessation



The PWD evidence from this study suggests TL, the treatment of choice for aspiration, may be a burdensome intervention

PWD *profoundly dislike* the treatment mainly due to its inherent sensory properties and *paint a picture of uncertainty* surrounding treatment prescription

A number of participants *modified or prematurely ceased the intervention* in response to perceived issues. Such modifications have the potential to *impact treatment outcomes* 

It is important to consider *ways in which the TL treatment burden can be reduced* for patients and, where possible, pay *due consideration to a wider range of treatment options* for treating aspiration resulting from dysphagia.

### Learning outcomes

#### Did you.....

- Understand the experiences of people with dysphagia poststroke regarding the intervention of thickened liquids (TL)
- Reflect on the use of TL in dysphagia management
- Consider whether TL is a minimally disruptive or burdensome treatment.
- Consider using patient evidence (individual and collective) to improve/augment clinical decision making and practice





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