

Patient and carer involvement in evaluating a toothbrushing programme for children and young people with neurological motor impairment

R Emanuel,¹ E Ray-Chaudhuri,² J Parry,³ L Borthwick,⁴
D Sellers⁵ and S Dobson⁶

1. Consultant in Special Care Dentistry, 2. Specialty Registrar in Paediatric Dentistry, 3. Consultant in Paediatric Dentistry, 4. Senior Dental Nurse, 5. Senior Specialist Speech and Language Therapist/Research Fellow, 6. Lead Nurse; Chailey Clinical Services, East Sussex, UK

Abstract

Background: People with cerebral palsy (CP) can have difficulty with eating and drinking safely and efficiently. A toothbrushing regime which includes routine use of suction and non-foaming toothpastes may be beneficial to reduce foam, debris and aspiration risk during brushing. This project sought to obtain feedback from children and young people with severe motor impairment, their parents or guardians and care staff of a toothbrushing programme, which introduced the use of nonfoaming paste and suction.

Method: Two participant groups were invited to contribute to evaluate a toothbrushing programme based on non-foaming toothpaste and suction for children and young people with cerebral palsy who are unable to eat and drink safely. The groups were: Care staff involved in providing daily oral care to children and young people with CP, and twelve children and young people with CP who are unable to eat or drink safely and who use community dental services based at the specialist centre for children and young adults with neurological and motor impairment.

Results: Lack of co-operative motor ability was identified by care staff as the greatest obstacle to thorough oral hygiene practice for children and young people with neurological motor impairment. Before the service evaluation, over 66% of staff thought that use of non-foaming toothpaste and suction would be useful. Some staff were concerned that suction use may be unpleasant for some children with sensory oral issues. A patient/carer oral hygiene education programme, using non-foaming toothpaste and suction, resulted in positive feedback from the carers or family members providing oral hygiene.

Key words: *Cerebral palsy, toothbrushing, carers*

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Introduction

Chailey Heritage Foundation (CHF) is a pioneering UK charity which encompasses Chailey Heritage School, Chailey Heritage Residential and Futures@Chailey Heritage (<http://www.chf.org.uk/>). It is one of the UK's leading centres for children and young adults with neurological motor impairment such as cerebral palsy. Access to an on-site dental unit is available for the children and young people attending the school and living in the Chailey residences.

The vast majority of children and young adults within the school and residences require daily oral care provision by care staff. A number of these children have severe eating and drinking difficulties which can make oral care provision challenging. Difficulty with oral hygiene (OH) practice related to the difficulty of clearing toothpaste foam and secretions from the mouth has been noted by the authors providing dental care for this patient group.

The prevalence of eating and drinking difficulties in patients with cerebral palsy is estimated to range between 27% (Waterman *et al.*, 1992) to 90% (Reilly *et al.*, 1996) of patients. In order to describe the full range of eating and drinking ability of people with cerebral palsy, the Eating and Drinking Ability Classification System (EDACS) was developed in 2014 by Sellers *et al.*, (2014). This system uses the key features of safety and efficiency to classify the whole range of functional eating and drinking ability from the age of three years, in one of five levels. Level I indicates that someone is able to eat and drink safely and efficiently, through to Level V where someone is unable to eat or drink safely because taking food or drink into their mouths will cause harm (Table 1).

Good oral hygiene is the cornerstone of good dental health. Removal of the plaque biofilm is essential in removing potentially harmful bacteria from the mouth, which can cause dental disease if left to proliferate (Lang *et al.*, 2009). In those with swallowing difficulties, there is the additional risk that oral bacteria aspirated into the lungs may lead to aspiration pneumonia with a direct effect on someone's general health (Weir *et al.*, 2009).

Evidence exists which demonstrates a link between poor oral hygiene and increased risk of aspiration pneumonia, however, the majority of studies focus on elderly populations. A review article by Pace and McCullough in 2010, found that in elderly institutionalised patients, there was a possible association between poor oral hygiene and respiratory pathogens. A link was also found between a decreased incidence of respiratory complications in patients who are provided with improved oral care. Langmore *et al.*, (1998) found that in a population of elderly institutionalised patients, the number of decayed teeth, tube feeding and dependence on others for oral care all appeared to act as risk factors for aspiration pneumonia. In a study by Farrell and Petrik (2009) which evaluated the effects of an oral care programme on lung status, 77% of patients admitted with aspiration pneumonia showed improvement after receiving oral care using the new programme.

With reference to the paediatric population, a study of 27 special needs children with and without gastrostomy was carried out by Jawadi *et al.*, (2004). It found that the children with a gastrostomy appeared to have not only more plaque and calculus, but also higher levels of oral bacteria often implicated with aspiration pneumonia. The effect of not eating and drinking normally may lead to increased plaque and calculus deposits for a number of reasons including the lack of abrasive nature of foods mechanically 'cleaning' the teeth when eating, and/or poor oral function of masticatory muscles including the tongue which leads to less efficient clearing of debris by the patient's own oral tissues.

The aim of the project was to involve users, parents / guardians and care staff in the process of evaluating a tooth cleaning programme for patients with known swallowing difficulties. In an effort to reduce residue in the oral cavity and aspiration, introduction of non foaming toothpaste and suction of saliva and debris during and after brushing were central elements of the programme. Non foaming toothpaste is toothpaste without the foaming agent sodium laurel sulphate added to its ingredients.

Table 1: Eating and Drinking Ability Classification System (EDACS) Sellers *et al.*, (2014).

Level I	Eats and drinks safely and efficiently
Level II	Eats and drinks safely but with some limitations to efficiency
Level III	Eats and drinks with some limitations to safety; there may be limitations to efficiency
Level IV	Eats and drinks with significant limitations to safety
Level V	Unable to eat or drink safely – tube feeding may be considered to provide nutrition.

Two participant groups were invited to contribute to the development of the toothbrushing programme which was based on non-foaming toothpaste and suction for children and young people with cerebral palsy classified as unable to eat and drink safely, EDACS V (Sellers *et al.*, 2014). The groups were:

- The care staff involved in providing daily oral care to the children and young people
- Twelve children and young people classified EDACS Level V (Table 1), along with their parents / guardians, who use community dental services based at the specialist centre for children and young adults with neurological and motor impairment.

Method

Care staff feedback

Assessment of staff attitudes and opinions towards oral care provision was gathered from 20 staff at an oral health training session given prior to starting the main project with the patients. All staff were involved in caring for children and young people engaged in the project. Questions included priority given to oral care, opinions of the task of tooth cleaning and barriers to providing oral care. Staff were also questioned regarding their confidence in oral care provision, previous training and their opinion regarding the introduction of a regime using non-foaming toothpaste, suction and a child specific oral care plan.

Toothbrushing programme

All 22 children and young people who attended Chailey Heritage and identified with known swallowing difficulties (EDACS V), along with their parents / guardians were invited to participate and feedback on a toothbrushing programme. The programme was based on encouraging the use of non foaming toothpaste and where possible and appropriate, the removal of tooth brushing debris with suction. The toothpaste used was oraNurse® non flavoured (and non foaming) and the suction was provided by portable units assigned to the child/young person.

At an arranged appointment, a standard dental check up was carried out. Oral hygiene was assessed using a simple

subjective five point scale of very good to very poor, and medical factors which might be associated with aspiration such as respiratory health. The toothbrushing programme was then explained via structured oral hygiene instruction. This involved demonstrating the correct technique for brushing including the principle of carrying out the brushing in small manageable steps; applying a small (pea-sized) amount of non foaming toothpaste to the brush and using the suction at regular intervals to reduce the amount of debris.

To supplement the verbal instruction, each child/young person was provided with a laminated set of instructions which could be placed in the bathroom at home to act as a reminder of the technique. Additionally signposting to a specially produced YouTube video (https://youtu.be/9j_DI1FzhTQ) prepared by the team, acted as an additional instruction tool for carers and family members. The information was recorded on a questionnaire (Table 2).

A review appointment was made for three months after the initial appointment, to discuss satisfaction and ease of use of the toothbrushing programme (Table 3).

Patient and carer experience

Additionally, carer and patient experience of oral hygiene procedures was sought and recorded pre and post introduction of the programme. To obtain feedback from the children and young people, a communication tool based on Talking Mats (Murphy and Cameron, 2008) was used for children and young people unable to communicate using speech to answer questions about their experience and preferences. Talking Mats (<http://www.talkingmats.com>) are a method of overcoming communication problems by asking closed questions and allowing patients to indicate their preference when presented with a series of symbols. We used

Table 2: Pre-programme Recording Sheet.

Name:	<input type="text"/>	Age:	<input type="text"/>
Current type of toothbrush:	Electric <input type="checkbox"/>	Manual	<input type="checkbox"/>
What brand of toothpaste do you currently use?	<input type="text"/>		
Use of Suction unit ?	Yes <input type="checkbox"/>	No <input type="checkbox"/>	School Only <input type="checkbox"/>
Current level of oral hygiene.			
<input type="checkbox"/>	Very good – none or very little plaque visible		
<input type="checkbox"/>	Good - small amounts of plaque visible		
<input type="checkbox"/>	Fair – moderate amounts of plaque starting to cover the majority of the cervical region of the tooth in many of the teeth.		
<input type="checkbox"/>	Poor – plaque extensively covering most of the teeth in the mouth.		
<input type="checkbox"/>	Very poor – as poor but with extensive food debris too		
Respiratory Health.			
<input type="checkbox"/>	Prophylactic antibiotics	<input type="checkbox"/>	Past problems with respiratory health and frequent chest infections.
Other health issues:			
<input type="checkbox"/>	Reflux	<input type="checkbox"/>	Seizures
Carer/patient experience.			
Carer.			
Do you currently have problems with supplying oral hygiene?	Yes <input type="checkbox"/>	No	<input type="checkbox"/>
If yes why?	<input type="text"/>		
Please circle All of the behaviours that you notice when you clean the teeth:			
Opens mouth easily?	Yes <input type="checkbox"/>	No	<input type="checkbox"/>
Keeps head still?	Yes <input type="checkbox"/>	No	<input type="checkbox"/>
Remains relaxed throughout?	Yes <input type="checkbox"/>	No	<input type="checkbox"/>
Bites on Toothbrush?	Yes <input type="checkbox"/>	No	<input type="checkbox"/>
Tongue pushes brush away?	Yes <input type="checkbox"/>	No	<input type="checkbox"/>

Table 2: Pre-programme Recording Sheet. (continued...)

Access to inside tooth surfaces easy?	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>		
Shows distress?	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>		
Resists teeth cleaning?	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>		
Coughs during teeth cleaning?	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>		
Struggles to swallow?	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>		
Breathing changes?	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>		
Patient: Talking Mats Questionnaire Rating (pre project) Scale at the top. Mark an cells which aren't relevant to the patient e.g. never uses an electric brush as "N/A":						
Manual toothbrush	Like	<input type="checkbox"/>	Unsure/Don't mind	<input type="checkbox"/>	Don't like	<input type="checkbox"/>
Electric toothbrush	Like	<input type="checkbox"/>	Unsure/Don't mind	<input type="checkbox"/>	Don't like	<input type="checkbox"/>
Mint toothpaste	Like	<input type="checkbox"/>	Unsure/Don't mind	<input type="checkbox"/>	Don't like	<input type="checkbox"/>
Unflavoured toothpaste	Like	<input type="checkbox"/>	Unsure/Don't mind	<input type="checkbox"/>	Don't like	<input type="checkbox"/>
Foaming toothpaste	Like	<input type="checkbox"/>	Unsure/Don't mind	<input type="checkbox"/>	Don't like	<input type="checkbox"/>
Non-foaming toothpaste	Like	<input type="checkbox"/>	Unsure/Don't mind	<input type="checkbox"/>	Don't like	<input type="checkbox"/>
Toothpaste collecting in my mouth	Like	<input type="checkbox"/>	Unsure/Don't mind	<input type="checkbox"/>	Don't like	<input type="checkbox"/>
People cleaning my teeth in the same way	Like	<input type="checkbox"/>	Unsure/Don't mind	<input type="checkbox"/>	Don't like	<input type="checkbox"/>
Parents cleaning my teeth	Like	<input type="checkbox"/>	Unsure/Don't mind	<input type="checkbox"/>	Don't like	<input type="checkbox"/>
People I don't know cleaning my teeth	Like	<input type="checkbox"/>	Unsure/Don't mind	<input type="checkbox"/>	Don't like	<input type="checkbox"/>

Table 3: Post Programme Recording Sheet – to be taken at three months after starting programme.

Final level of oral hygiene.

Very good – none or very little plaque visible

Good - small amounts of plaque visible

Fair – moderate amounts of plaque starting to cover the majority of the cervical region of the tooth in many of the teeth.

Poor – plaque extensively covering most of the teeth in the mouth.

Very poor – as poor but with extensive food debris too

Respiratory Health.

Prophylactic antibiotics

No chest infections

Yes chest infections and if so how many

If yes how many courses of antibiotics

Carer/patient experience.

Carer.

Did you find using suction and the non-foaming toothbrush easy to use? Yes No

If no why?

Table 3: Post Programme Recording Sheet – to be taken at three months after starting programme. (continued...)

Did you feel it allowed better visual access for cleaning the patient's teeth?	Yes <input type="checkbox"/>	No <input type="checkbox"/>	
If no why?	<input style="width: 100%;" type="text"/>		
Would you recommend this programme to others with swallowing difficulties?	Yes <input type="checkbox"/>	No <input type="checkbox"/>	
If no why?	<input style="width: 100%;" type="text"/>		
<p>Patient : Talking Mats Questionnaire Rating (post project) Scale at the top. Mark an cells which aren't relevant to the patient e.g. never uses an electric brush as "N/A":</p>			
Manual toothbrush	Like <input type="checkbox"/>	Unsure/Don't mind <input type="checkbox"/>	Don't like <input type="checkbox"/>
Electric toothbrush	Like <input type="checkbox"/>	Unsure/Don't mind <input type="checkbox"/>	Don't like <input type="checkbox"/>
Mint toothpaste	Like <input type="checkbox"/>	Unsure/Don't mind <input type="checkbox"/>	Don't like <input type="checkbox"/>
Unflavoured toothpaste	Like <input type="checkbox"/>	Unsure/Don't mind <input type="checkbox"/>	Don't like <input type="checkbox"/>
Foaming toothpaste	Like <input type="checkbox"/>	Unsure/Don't mind <input type="checkbox"/>	Don't like <input type="checkbox"/>
Non-foaming toothpaste	Like <input type="checkbox"/>	Unsure/Don't mind <input type="checkbox"/>	Don't like <input type="checkbox"/>
Toothpaste collecting in my mouth	Like <input type="checkbox"/>	Unsure/Don't mind <input type="checkbox"/>	Don't like <input type="checkbox"/>
People cleaning my teeth in the same way	Like <input type="checkbox"/>	Unsure/Don't mind <input type="checkbox"/>	Don't like <input type="checkbox"/>
Parents cleaning my teeth	Like <input type="checkbox"/>	Unsure/Don't mind <input type="checkbox"/>	Don't like <input type="checkbox"/>
People I don't know cleaning my teeth	Like <input type="checkbox"/>	Unsure/Don't mind <input type="checkbox"/>	Don't like <input type="checkbox"/>

a number of symbols representing both current oral health items and those specific to the new plan. The symbols were created by the Speech and Language Therapy Team who regularly use this communication method with this group of children and young people (Figure 1). The children and young people were asked to show a preference for each symbol associated with an oral hygiene question and rate them, positively, 'unsure/don't mind' and negatively.

Results

Initial care staff feedback

Care staff feedback taken prior to the main programme showed 82% of staff felt that oral care was a high priority and the majority did not find providing toothbrushing for the child/young person unpleasant. A number of challenges were identified including lack of time (50%), lack of child co-operation (94%) and in some cases, lack of training and confidence. Over 66% felt that the use of non-foaming toothpaste and suction would be useful. However, a number of staff were concerned that suction use may be unpleasant for children with oral sensory issues.

Number of participants

Of the 22 children and young people classified as EDACS level V who were invited to be involved and contribute to the programme, 16 engaged and attended the initial dental visit, with 12 who were able to attend the follow up session to provide feedback on the programme. The ages ranged between 5 and 23 years with the mean age being 14.5 years old. We obtained

feedback from 10 of 12 carers/parents who were involved in regular oral hygiene provision initially at the first appointment.

At the initial interview, six parents or carers reported problems providing oral hygiene. Issues with providing oral hygiene are noted below with a certain acceptance that some biting on the brush and coughing were considered part of 'normal' brushing rather than a specific problem:

- Poor mouth opening ability (n=4)
- Head movement (n=5)
- Biting on the toothbrush (n=9)
- Pushing the toothbrush away with tongue (n=6)
- Struggling to swallow (n=6), or coughing (n=8) during brushing.

Programme feedback

Overall, the parent and carer experience of the new programme was very positive, with all 10 parents/carers reported a positive experience of using the non foaming toothpaste. Six of the 10 parents/carers felt the use of non-foaming toothpaste allowed better visualisation of teeth. Comments made by parents/carers regarding the reduction in foam included that they felt the children and young people was less distressed during brushing and they considered the technique to be safer. Three parents/carers thought there was no difference or they were unsure, and one parent felt that their main barrier to visualisation was their child opening their mouth and this had not improved. All except one child and young person had continued to use the non foaming toothpaste in place of their previous toothpaste for the duration of the programme.

All 10 of the parents or carers would recommend this regime to parents or carers of other children and young people with severe swallowing difficulties. The positivity was summed up by the comments of one parent who had already been using non foaming toothpaste and suction. They reported that although this was not a new regime for them “they would not be able to manage tooth brushing without it.” Two of the parents/carers advised that although they liked the non-foaming properties they felt that the child or young person missed the taste and would prefer toothpaste with a flavour.

Feedback from children and young people

We used Talking Mats, which were designed in conjunction with the Speech and Language Therapy Team. Despite availability of the tool, we found a large number of the children and young people were not able to communicate effectively about their experience and preferences. Two of the young people provided very useful feedback on experience and things that matter to them.

One child/young patient stated clearly that she did not like the new programme as she did not like the unflavoured, non foaming toothpaste. We were able to suggest using a non foaming but mint flavoured toothpaste. A second child/young person stated that he did not like toothpaste collecting in the mouth, but additionally did not like the use of the suction. He “didn’t mind” the non-foaming paste but disliked the foaming paste.

Discussion

Safety and comfort with toothbrushing is a very important factor to parents and carers of children and young people with severe swallowing difficulties. Adequate comfort when brushing may allow the parent or carer providing oral hygiene to complete more thorough brushing of longer duration at each session. No additional advice was given on the use of finger guards and mouth opening aids.

Obtaining the views of the children and young people involved in the programme was important to us. Unfortunately, we did not feel that the tool developed for dental feedback was an effective enough method of obtaining views in the current format. A number of the words and symbols used may not have been easy to understand such as non-foaming toothpaste. On reflection the style and number of questions could be simplified for future use, as the complexity of the questions may have been above the level of understanding amongst some members of the group. We also found that some patients who had participated well at the initial visit were then not able to or did not want to participate at the review visit. Sometimes this was because the patient was tired or not in the mood to participate.

Although use of non-foaming toothpaste was found to be a fairly easy regime change, use of suction was more problematic as the additional equipment was not always available for use by the patient in either school or at home. Eight of the group reported that they used suction, but not necessarily with every episode of oral care. During the study period only one of the group reported a respiratory tract infection (RTI). This may suggest a reduction in RTI incidence when based on levels of past disease experience. However, this

information is based on verbal reports supplied by the family and carers rather than more careful scrutiny such as type of infection, microbiological analysis proving oral bacterial involvement plus infection severity etc. To investigate this possible association with a greater degree of certainty, a thoroughly planned research project would be needed.

Conclusion

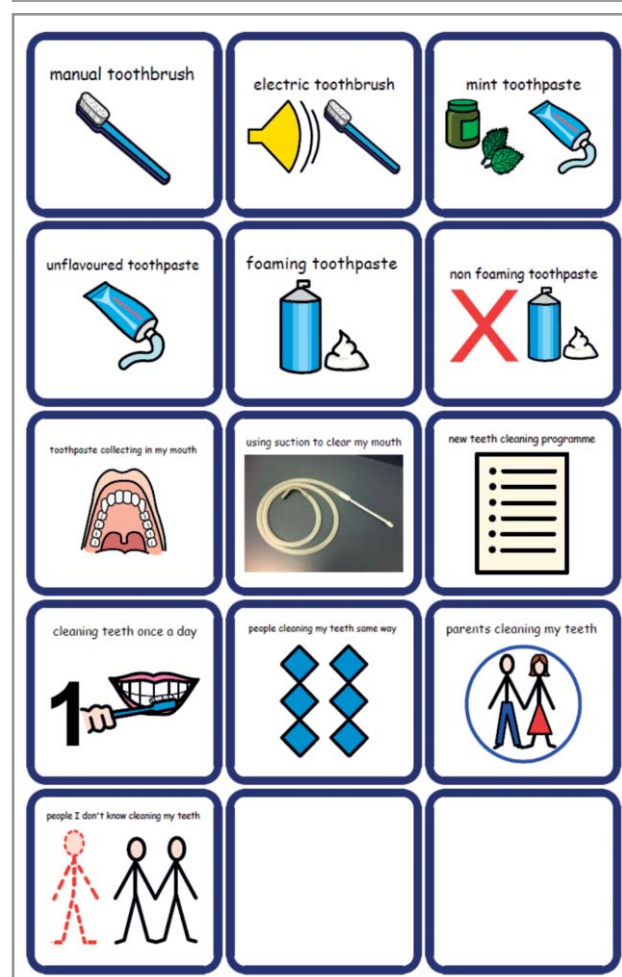
Parents and carers were positive about the use of non-foaming toothpaste and felt this allowed safer brushing, possible reduced aspiration risk and better visualisation of teeth. Of the 10 parents and carers who provided feedback all were positive about the programme.

It would appear that there may be benefits from recommending the use of non-foaming toothpaste and suction where available for children and young patient with severe swallowing difficulties (EDACS level V).

Future research

It would appear that from the results of this project that the use of non flavoured toothpaste was well accepted by children and young people plus their carers and parents. Therefore, the next stage in the research cycle is to begin to investigate with our medical colleagues whether the use of non foaming toothpaste has an effect on the episodes of aspiration pneumonia experienced by this same group of patients.

Figure 1: Symbols for use on Talking Mat



Address for correspondence:

R Emanuel

Haywards Heath Health Centre, Heath Road, Haywards Heath RH16 3BB

Email: Robert.emmanuel@nhs.net

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