

Balancing safety and enjoyment: current practice when recommending tastes for people with intellectual disabilities who are non-orally fed

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Highlights

- Oral tastes are small amounts of food or drink given to the enterally nourished
- Practice and decision-making information about giving tastes was collected
- Tastes were being given to enterally nourished people with intellectual disabilities
- The wellbeing of the person underpinned practitioner decision-making
- Balancing the benefits and risks inherent in oral taste programmes was evident

Abstract

Eating and drinking problems are common among people with intellectual disabilities. Having a compromised swallow or being at risk of inadequate nutrition are two reasons for introducing non-oral feeding. Such procedures involve creation of an external opening for food and drink to be delivered directly into the stomach through a tube. In recent years maintenance of the swallow and quality of life issues have led to introduction of small amounts of food and drink (oral tastes) for people who are non-orally fed. Little evidence exists about the reasoning used to inform this decision or the types of oral tastes offered. This study aims to address these omissions. An exploratory survey, distributed via email, was used to gather information from speech and language therapists and dietitians about their current practice and their decision-making processes when offering oral tastes to people who are non-orally fed. Data presented here reflect the responses from respondents working primarily with people with intellectual disabilities (55 out of 158 respondents). Oral tastes were being offered and clinical decision-making around this centred on balancing the wellbeing and wishes of the person with intellectual disabilities and their carers with the risks to wellbeing inherent in implementing and supporting an oral taste programme.

Keywords

Enteral nutrition, Dysphagia, Intellectual disabilities, Speech & Language Therapy, Decision making

Background

This study reports the findings from a survey gathering information about the practice of giving oral tastes of food and drink to people who are non-orally nourished and the decision-making inherent in this process. Being able to eat, drink and swallow unhindered is a fundamental aspect of people's lives. In addition to providing nourishment and satiety, it provides pleasure and has been symbolically linked to self-esteem and a sense of belonging, community and the sharing of life (Ekberg et al., 2002; Murcott, 1982).

Nutritional status is an ongoing concern for many people with intellectual disabilities (ID). In addition to the high prevalence of obesity amongst this population (Gravestock, 2000; Hove, 2004; Wood, 1994), under-nutrition is also more prevalent in people with ID (Gravestock, 2000; Hove, 2004; Simila & Niskanen, 1991; Wood, 1994) than in the non-disabled population, and may cause mortality unless alternative forms of nutrition are introduced (Beange, 2002). Under-nutrition as indicated by low BMI is also more prevalent in people with severe and profound ID (Hove, 2004). Thus, a greater proportion of people with ID have been found to be outside of what is considered the ideal weight range, with a disproportionately higher amount of obesity and under-nutrition evident from the literature.

The term dysphagia refers to eating, drinking and swallowing problems, which are common among people with ID (Chadwick & Jolliffe, 2009; Rogers et al. 1994; Sheppard and Hochman 1989, cited in Sheppard, 2006). In the UK, dysphagia assessment and intervention is typically considered part of the clinical work carried by speech and language therapists (Petheram & Enderby, 2001; Reilly & Ward, 2005) often alongside other practitioners, including dietitians, physiotherapists and nurses (Jolliffe et al., 1989). Along with undernutrition, more severe dysphagia is also associated with increasing severity of cognitive impairment in adults with ID (Chadwick & Jolliffe, 2009). There is limited research around dysphagia and its relation to nutritional status specifically in people with ID. However, a higher prevalence of poorer nutritional status is likely in people with dysphagia and ID. Undernutrition, as indicated by a BMI below 20, was found in 40 per cent of people with ID and dysphagia, with over 10 per cent having a BMI < 16, whilst 32 per cent of people with dysphagia were found to be overweight (BMI > 25) (Chadwick & Evans, 2003).

Aspiration of food into the airway is a key aspect of pharyngeal dysphagia in adults with ID (Chadwick & Jolliffe, 2009; Rogers et al., 1994) and has been implicated in the development of respiratory disease in this population (Carter & Jancar, 1984; Hollins et al., 1998). Respiratory disease, often associated with pneumonia is one of the most common causes of death in adults with ID (Patja et al., 2001; Richards & Siddiqui, 1980), and it has been suggested that aspiration due to pharyngeal dysphagia coupled with reduced immune response can lead to pneumonia. Pharyngeal dysphagia, where the airway is inadequately protected, secondary to neurologic disorders, and/or being at risk of inadequate nutrition are two reasons for the introduction of non-oral feeding (Ciocon et al., 1988; Grey & Kimmel, 2006; Stroud et al., 2003).

Non-oral, enteral or tube feeding involves a person's nutrition and hydration being delivered via a tube, therefore omitting eating, drinking and swallowing. The occurrence of such feeding in adults with ID is said to be relatively high (Rogers et al. 1992) though contemporary prevalence figures for the people with ID and for people with ID and dysphagia are not apparent in the research literature. Enteral feeding incorporates use of: (i) Nasogastric (NG) tubes which are typically used for short-term non-oral feeding (<4-6 wks^b) (ii) Percutaneous endoscopic gastrostomy (PEG) or jejunostomy (PEJ) which are typically used for long-term non-oral nutrition. Like surgical gastrostomy, PEG involves tube feeding directly into the stomach whereas PEJ involves tube feeding further down in the gut and can help prevent reflux (Stroud et al., 2003). PEG and PEJ are quicker and less invasive methods of tube feeding than surgical gastrostomy and are more common in recent years (Stroud et al., 2003).

The effectiveness of enteral nutrition has had support from research investigations and reviews (Potter et al., 1998; Kennedy et al., 2007) though complications can occur (Campbell-Taylor & Fisher, 1987). Many people who have enteral feeding introduced already have a compromised health, thus prognosis may already be poor and as a result it is difficult to be clear about the cause of high mortality following introduction of enteral nutrition (Stroud et al., 2003).

Groher (1990) notes that historically oral and non-oral feeding were viewed as mutually exclusive. In more recent years though there has been increased introduction of small amounts of food and drink (oral tastes, sometimes called tasters) for people who are non-orally fed, anecdotally linked to maintenance of the swallow and quality of life issues (e.g. choice, social ritual).

In those without ID, exclusive tube feeding has been said to diminish a person's quality of life (Langmore, 1999). It is likely that people who are enterally nourished due to aspiration risk, who previously enjoyed oral intake, will experience the loss of this mode of intake negatively. Evidence suggests that, for some people with ID and dysphagia, reduced and modified oral intake can be experienced negatively (Chadwick et al., 2006). In this qualitative study some indicated a preference for continued oral intake and unmodified food and drinks and commented that modification of meals and drinks can lead to feelings of difference, stigmatization and exclusion. It is likely then, that some people with ID who are enterally nourished would choose to continue to have small amounts of oral intake despite potential risks to their health. However, little evidence exists about this phenomenon, the decision to introduce oral tasters, or the types of oral tasters offered.

From the preceding discussion it is clear that in recent years, maintenance of the swallow and choice and quality of life issues have led to introduction of oral tastes for people who are non-orally fed. However, despite this, the research evidence around eating, drinking and swallowing difficulties for people with ID remains extremely limited. Moreover, little evidence exists about: (1.) the prevalence of introducing oral tastes to people who are none orally fed; (2.) the evidence and reasoning used to inform this decision; and (3.) the frequency, quantity, texture, and types of oral tastes

offered. This study aims to address these omissions using a survey to gather information about current practice and the decision-making process.

Research Questions

Providing advice and guidance around the nutrition of people who are non-orally fed increasingly involves both dietitians and speech and language therapists. Therefore, the survey was distributed to both speech and language therapists and dietitians to gather data to answer the following research questions:

1. Are practitioners working with people with ID recommending oral tastes?
2. What factors influence decision-making when considering the introduction of oral tastes?
3. What are the characteristics of the tastes recommended?

Method

Design

This study is a descriptive investigation using a specifically devised survey to gather information from speech and language therapists and dieticians about their current practice around giving oral tastes to people who are non-orally fed. In this study a 'taste' is defined as giving small amounts of food and drinks to people who are non-orally nourished. A critical realist ontology and a modified realist epistemology underpin this research study, whereby the researcher believes that an objective reality can be tapped and understood via data, though this relationship between objective reality and the data is not perfect and should be subject to critical scrutiny (Guba & Lincoln, 2008).

Participants and Procedure

An opportunity sample of speech and language therapists and dieticians working with people who have dysphagia was recruited. In order to distribute the survey as widely as possible the Royal College of Speech and Language Therapists (RCSLT) and British Dietetics Association (BDA) were contacted and agreed to distribute the survey via special interest group email lists and lists of senior practitioners. The RCSLT distributed the survey via two e-mail lists for practicing speech and language therapists in the UK. An introductory letter was attached to the e-mails, explaining the study background and objectives. Participants were asked to return the survey within eight weeks. Each survey was given a code number, and was kept in a locked filing cabinet, separate from participants contact details. A follow up reminder e-mail was sent after two weeks. Data returned within 6 months of initial distribution of the survey was included within the data analysis. Ethical approval for the project was granted by the National Research Ethical Committee (ref: 05/MRE09/30).

Survey Design & Piloting

The design of the survey was informed by a previous survey designed for an unpublished MSc. Project (Y. Macleman, Manchester Metropolitan University University, 2008) and discussions with experienced speech and language therapists and dieticians. The survey, prior to distribution, was piloted in Greater Manchester by two senior speech and language therapists and two senior dieticians, so that the survey could be refined for clarity and ease of use. These practitioners also completed the first draft of the survey and fed back on its utility and relevance. Their comments were incorporated and the survey was re-drafted twice more to address their recommendations regarding wording of particular questions.

The survey contained open and closed questions gathering information about: (i) whether therapists offered oral tastes to people who were non-orally nourished; (ii) factors that influenced this decision; and (iii) the characteristics of the food and drinks offered. The survey is available upon request from the author.

Data Analysis

Quantitative data collected from the surveys was analysed using descriptive statistics. Closed questions are presented as proportion of respondents giving a particular answer. Comments written alongside closed questions were analysed and

summarised using content analysis (Carley, 1990), which involved grouping the additional qualitative data by identifying themes in the responses, with the proportion of respondents fitting each group being reported.

Thematic Network Analysis (Attride-Stirling, 2001) was employed to analyse the data gathered using open-ended questions, about why practitioners would or would not choose to implement an oral taste programme. This process incorporates familiarisation and coding of the text to first identify (i) basic themes within the data. These are subsequently thematically grouped together into (ii) organising themes. Finally, the organizing themes are groups under (iii) global themes; the broad central concerns and issues across the data. With regard to trustworthiness checks (Shenton, 2004), credibility relied upon the use of established methods and analytic procedures. As a check of coding confirmability, a proportion of the surveys (10%; N=5) were secondary coded by a Speech and Language Therapist known to the author. Agreement was apparent for the coding of the open-ended textual responses for the basic themes. No other trustworthiness checks were made.

Results

Of the 158 practitioners who responded to the survey 132 (83.5%) were speech and language therapists and 26 (16.5%) were dietitians. Fifty-five (34.8%) of the surveys were returned by speech and language therapists (n=53) and dietitians (n=2) who worked primarily with people with ID (>50% of reported caseload), these form the data set that is analysed in the remainder of this paper. Most of these worked with adults with ID (n=43, 78.2%) with the remaining 12 (21.8%) working with children with ID.

Introducing oral tastes

Just over three quarters of the 55 respondents working primarily with people with ID had recommended tastes to those who are enterally fed (n=43, 78.2%). Around three-quarters of both those working with adults (n=34, 79.1%) and those working with children (n=9, 75.0%). Lack of experience and being outside of their job role were the main reason given for not recommending tastes (N=10).

Factors that would prompt or prevent instigation of a taste programme

The Thematic Network Analysis resulted in the abstraction of two primary networks or global themes respondents reported as influential in this decision making process.

INSERT TABLE 1 AROUND HERE

Global Theme 1: Impact on the person's wellbeing

The factors most often mentioned as influencing the decision to introduce oral tastes related to the person's wellbeing and wishes. This global theme was the most extensively written about in the survey responses and comprised five organising themes: (i) risk assessment; (ii) risks and benefits to physical wellbeing; (iii) choice and motivational response; (iv) risks and benefits to emotional wellbeing; and (v) development, planning and prognosis (*see Table 1*). The global theme of prescribing tastes to enhance wellbeing incorporated the five global themes where respondents made comments about how they weighed up the risks of introducing oral tastes to the person's quality of life and more specifically to their physical and emotional wellbeing, safety and liberty. Taste programmes were likely to be introduced if it was considered safe and the benefits were perceived to outweigh the risks and were not introduced if the risks were deemed to be great based on a number of salient factors.

Risk Assessment

Responses often implicitly reflected a **risk assessment** process that occurs and informs this decision. This organizing theme comprises two basic themes, with consideration evident not only of the *risks of negative events* occurring, e.g. exacerbating an existing respiratory condition, but also of the *losing or gaining of benefits that would enhance quality of life and wellbeing*, e.g. reduced opportunity for

social interaction at mealtimes or improved emotional wellbeing following re-introduction of oral intake.

Risks & Benefits to Physical Wellbeing

The second organising theme, **risks and benefits to physical wellbeing**, contained four basic themes. The first basic theme reflected the influence of the person's **current and ongoing general health status** in the decision. If the person was in good current state of health then tastes were more likely to be introduced. If the person was unwell, in a consistently poor current state of health or tastes were considered a considerable risk to the person's health then a taste programme would not be implemented. Related to this the stability of health status was also reported as a consideration. If the person had stable health and was not considered very vulnerable to poor health and health problems such as chest infections then it was more likely that tastes would be initiated.

The second basic theme pertained to **seizure activity, alertness and fatigue** of the person. Whether the person had epilepsy was reported as important to the decision, in particular the extent to which seizure activity was controlled and how frequently seizures occurred, both influenced the decision. Seizure activity appeared to be deemed important primarily because of the associated reduction in alertness and feelings of fatigue that follow seizures which, in turn, can compromise the swallow and increase the risk of aspiration. Therefore when seizure activity was not well controlled and seizures occurred frequently, tastes were unlikely to be recommended. Alertness and fatigue were also mentioned in relation to both the person's general status and their dysphagia and energy expenditure when eating and drinking. Some people become very tired during the eating and drinking process, especially on large quantities, and again this might compromise the safety of the swallow. When alertness was an issue tastes were less likely to be offered, however for people who tired on large quantities, tastes were considered a useful alternative.

Oral sensitivity and hygiene were discussed and formed the third basic theme. Oral sensitivity and aversion to oral intake and stimulation were reported by a number of therapists when asked about what influenced their decision-making. In situations where people were very sensitive and found it difficult to cope with oral stimulation, taste programmes would only be considered if a desensitisation programme had occurred first, or if tastes were thought to be an integral part of reducing aversion to oral intake and stimulation. This factor was often mentioned in conjunction with refusal of oral intake. Tastes were also considered helpful in providing oral stimulation to people with profound and multiple disabilities and as a pleasurable experience alongside enteral nourishment. Oral hygiene issues were also a factor. Tastes were less likely to be introduced if maintaining oral hygiene was challenging when working with the individual or was overlooked by carers.

Dysphagia severity and associated health risks, was the fourth basic theme and was mentioned as a fundamental aspect of physical wellbeing influencing decision-making. If the person in question was believed to have more severe dysphagia, tastes were less likely to be recommended. Aspects of oral, pharyngeal and

oesophageal dysphagia were mentioned by responding practitioners as influential in the decision-making process. The degree to which people experienced oral stage difficulties and their oro-motor functioning and skills affected the decision. Specifically, if people could anticipate, manipulate and control food and drinks whilst in the mouth, therapists were more likely to suggest tastes, but not if the person was considered unable to orally manage tastes.

Of all the aspects of dysphagia, pharyngeal stage problems, and the potential negative health consequences and risks associated with these, seemed to be one of the most commonly considered issues when deciding upon a taste programme. The function and safety of the person's swallow was frequently taken into account. Those with a swallow which was functionally unreliable, variable, inconsistent, weak or absent, and were therefore considered unsafe due to the increased aspiration risk, were less likely to have tastes. In addition to the swallow the person's cough was mentioned by a few practitioners. A person's ability to cough and clear their trachea, when they had swallowed food or drink into the trachea, is crucial to preventing aspiration, choking and asphyxia. Thus those with absent or weak cough may not be offered tastes.

Linked closely to the functioning of the swallow and cough, aspiration severity and risk appeared to be one of the core factors therapists took into account when making the decision. A number of speech and language therapists reported that tastes would not be offered in situations where the risk of aspiration was deemed high and ongoing, but would when risk was low. If significant aspiration was observed to occur on all consistencies and amounts, tastes were less likely to be initiated. However, despite some consistency in what speech and language therapists reported around willingness to give tastes when people aspirated, there were also discrepancies. Some therapists would only recommend tastes if there was no or very low aspiration on the tastes offered and where the individual could manage small amounts with no signs of aspiration. Other therapists appeared willing to accept some level of aspiration risk, for example if the person did not always aspirate. For many other therapists the risk of aspiration was weighed up against aspects of quality of life, support and choice. In such cases some therapists reported that they would offer tastes when the person was at mild to moderate risk of aspiration. What mild to moderate means exactly was not detailed. Silent aspiration was also an issue considered in the decision, if it was thought that the person silently aspirated some therapists stated that they would not introduce tastes.

The reason aspiration was considered so important was alluded to in some responses where aspiration and the likelihood of offering tastes was linked to risk of specific health conditions such as aspiration pneumonia, respiratory distress, choking and asphyxia, chest status, recurrent infections and reflux. Reflux, which would reduce the likelihood of a taste programme being introduced, was also mentioned in conjunction with the fear, distress and pain experienced by people when they reflux oral intake, as well as the possibility of chest conditions due to aspiration of refluxed intake. Those with stable, good chest statuses with lower likelihood of choking, aspiration pneumonia or reflux occurring, were described as more likely to have a taste programme implemented.

Linked to oral and pharyngeal stage problems, Management of secretions and the ability to cope orally and to safely swallow the secretions that would be prompted by oral intake was considered important by a number of therapists. Management of saliva appeared to be taken as an indicator of oral and swallow function. If the person was unable to swallow secretions or the food presented as part of the taste programme and would require suctioning of resulting residue then tastes would be considered contra-indicated by some speech and language therapists.

Choice & Motivational Response

The substance of the third organizing theme, **choice, motivation and understanding** reflected the orientation of the person to tastes. It also incorporated their comprehension of the programme and its potential consequences, the value people placed on food, and their reactions to the notion of introducing a taste programme. Information about choices and motivation was gained via verbal expressive communication from some people with ID, but for others with limited expressive communication, behavioural observation was relied upon. Thus, orientation, values and reactions incorporated both active motivation or rejection of tastes and less overt, but observable, positive and negative reactions to taste programmes. This organising theme was closely linked to the emotional wellbeing of the person and to aspects of physical wellbeing relating to discomfort. It included three basic themes.

The *choice and wishes of the person with ID* were considered central to the decision to introduce oral tastes and formed the first basic theme. This choice making could manifest in numerous ways, most obviously in verbal communication from people that they desired or did not want tastes. However, for people who were not able to express their choice verbally, observed behavioural responses were relied upon. Some people when asked about oral tastes refused them verbally, whilst others refused physically when offered the tastes. Gathering of such information was considered fundamental to instigation of a taste programme.

For some therapists, and in some instances, choice seemed to overrule health and dysphagia related issues in the decision-making process. However, the weighting given to choice differed across therapists, and some therapists did not mention choice at all. Choice appeared to play more of a role when the person for whom tastes were being considered was more cognitively able and could communicate verbally. For other people, who were often more severely and profoundly cognitively impaired, less obvious behavioural cues were used to determine the person's *awareness and interest*. For these people, interest and awareness were used to inform the decision as a proxy for their wishes. This formed the second basic theme.

The third basic theme related to the importance of *understanding the risks* of tastes prior to introducing tastes. Understanding was described as occurring alongside expressing a desire and was considered by therapists to be synonymous with informed decision-making by the person with intellectual disabilities.

Risks & Benefits to Emotional Wellbeing

Fundamental to decision-making was the perceived **impact on the emotional and interpersonal wellbeing** of the individual. This involved exploration by the professional of the positive and negative emotional impact that oral intake could have on the person's wellbeing and comprised three basic themes.

Whether or not oral intake caused the person to become ***distressed or anxious*** was mentioned by a number of speech and language therapists. Two different causes of distress linked to oral intake were evident. The first reflected those people for whom managing oral intake was physically difficult, causing upset and distress, for example gagging on food, aspirating food or reflux. The second cause was distress and upset due to lack of or insufficient oral intake. Examples of this included situations where the person became distressed when they smelled food, or when they had a taste but wanted a full meal, or if there had been observed distress and depression following the loss of oral intake when enteral feeding was introduced.

The decision was also informed by the apparent ***comfort and enjoyment*** of the person when having oral intake, which were also intrinsically linked to the emotional wellbeing of the person. Enjoyment seemed to comprise three interlinked but distinct aspects. The first was where the overt signs of comfort and enjoyment were used to judge whether the person is positively or negatively oriented towards oral intake. The second linked more closely to emotional wellbeing where the tastes could be enjoyable for the person and were viewed as potentially enhancing their wellbeing via the associated sensations and social interaction. The third was where the person had previously appeared to enjoy and be motivated by food, and their quality of life was thought to be linked to food enjoyment. Comfort and discomfort were mentioned in conjunction with the oral sensitivity and the nature of the oral tastes (texture, taste, temperature), distress around oral intake, palliative care and physical health.

Inclusion and socialising at mealtimes was another reason given for introducing oral intake. This was linked to quality of life, enjoyment and the social ritual associated with mealtimes. This basic theme also incorporated both concern for the maintenance and development of social relationships and also the ongoing development of social interaction skills.

Development, Planning & Prognosis

The organising theme, **development, planning and prognosis** contained two basic themes and pertained to the development of the person with IDs and planning and expectations around their oral functioning, intake and health. For those working with children with ID ***development and planning around oral skills*** and re-establishing oral intake were taken into account alongside the introduction of the taste programme. It was also reported that the taste programme could potentially be integral to this developmental process. Linked to development were plans to re-introduce oral intake and an understanding that the non-oral nourishment route was not planned to be permanent.

The *predicted prognosis* for the person with ID was also an important consideration, tastes were more likely to be introduced where recovery was expected rather than deterioration. However, a small number of respondents also mentioned that they would introduce tastes even if re-establishing oral intake and associated improvement was not expected, for example, in cases of palliative care.

Global Theme 2: Support for Taste Programme Implementation

This global theme centred around practitioners' views of three groups of stakeholders involved in the introduction, support and maintenance of ongoing taste programmes, caregivers (paid and unpaid), multidisciplinary team members and other medical professionals. The primary focus though, was on the direct caregivers. Often considered fundamental to introduction of tastes were the attitudes of the caregivers who would be responsible for implementing the programme and their willingness and ability to do this safely. Two organising themes emerged for this global theme stakeholder support and orientation and taste programme adherence, which together encompassed seven basic themes.

Stakeholder Support & Orientation

The organising theme **stakeholder support and orientation** reflected the influence of stakeholders other than the person who was non-orally fed who were involved in the decision and contained four basic themes. The ***views, wishes and orientation of caregivers*** were considered important to the decision to introduce oral tastes. The clearest expressions of carer orientation towards tastes were their motivation to implement a taste programme and their commitment to the programme. Motivation and commitment appeared to be influenced by carer attitudes towards eating and mealtimes, their enjoyment of interacting with the person of family member that they support at mealtimes, and their interpretation of the person's behaviour around food. This motivation manifested in willingness to, or preference not to, implement the programme.

The ***adequacy and variability of carer support*** provided also influenced the implementation of the taste programmes. Inadequate and inconsistent levels of support would prohibit introduction of oral tastes, for example if caregivers were varied in the support they provided or they did not provide sufficient support to the person recommended tastes at mealtimes. Being unable to monitor paid and family carers was also reported to inhibit introduction of tastes. Conversely, speech and language therapists were much more likely to introduce tastes if the person had stable, sufficient and supportive caregivers.

Carer confidence and fear was another basic theme relating to support and orientation. The confidence caregivers had giving people tastes also impacted upon the support people received. This was tied to caregiver fears and worries about safety and the risks of giving tastes and caregivers' beliefs about their own competence in modifying food and giving people tastes safely.

The *input, support and resource availability in the wider context* surrounding the introduction of tastes were also considered important. This was reflected in whether advice, guidance and reviews were available from the multidisciplinary team, community services, medical staff and other professionals. Related to this, the support and resources available within the multidisciplinary team influenced decision-making. This included the ability of the multidisciplinary team to oversee implementation of the taste programme and the extent to which they worked closely together and could adequately review the taste programmes and monitor outcomes. This was considered particularly important in cases deemed complex.

Taste Programme Adherence

Mentioned alongside orientation and support was the final organizing theme, **taste programme adherence**. This was a critical factor in the decision-making process around tastes and comprised three interlinked basic themes. First, respondents reported that *following taste programme recommendations appropriately and consistently* was crucial. In situations where staff and family caregivers found it difficult, or were unable, to follow the taste programme consistently tastes were typically not introduced. Linked to this, if there were known issues with adherence to previous programmes and interventions, implementation of tastes was less likely. Moreover, if the speech and language therapist believed that the caregiver would find it difficult to consistently achieve the correct consistency for tastes when modifying food, tastes would be unlikely to be introduced.

Second, in addition to following the taste recommendations, *understanding of the requirements of the intervention* by either the paid or family carers was also considered a necessary prerequisite for taste programme implementation.

A final basic theme focused on *consideration of risk*, as risk understanding and response were integral to taste programmes. Decision-making was influenced by perceptions of how well carers would understand, monitor and respond to risks inherent in providing tastes to vulnerable, often health compromised people.

Describing Oral Taste Programmes

Practitioners were also asked what textures and types of food and drink were offered as oral tastes (Table 1). Fluid texture was typically modified to stage 3 (See Appendix 1 for full description), described as more cohesive fluid needing to be taken from a spoon. The types of fluid offered varied with no types being completely excluded. Fruit based drinks were offered more often than milk based and water based drinks, other types relating to the person's preferences were also included.

INSERT TABLE 2 AROUND HERE

Although not always considered by respondents, neutral pH of food was preferred for tastes offered, though alkaline and acid were also offered. Acid foods were recommended least, with two practitioners commenting that they had fears over

recommending acid food due to reflux risk. The temperature didn't appear to be especially important to the practitioners with both hot and cold tastes being given. Comments indicated that the preference of the person receiving the tastes was paramount. The need to consider the oral sensitivity of the person being given tastes also needed consideration when deciding on temperature of tastes. Most practitioners thought that tastes should be between 1 and 3 teaspoons, though many offered between 3 and 6 and some offered as much as 6-9 teaspoons. Few offered less than a teaspoon or more than 9 teaspoons. Some practitioners commented that the amount may increase, demonstrating the progressive, trial based nature of introducing taste programmes.

With regard to consistency of food, a smooth, uniform, moist consistency was preferred as reflected in stages A, B and C of the 2002 National descriptors (see Appendix 1 for descriptions) which were most often offered. Only a small number of practitioners reported introducing more traditional consistencies for food.

Discussion

The findings demonstrate that introduction of oral taste programmes is occurring for people with ID who are non-orally nourished. The prevalence rate of 78.2 per cent found here is likely to be an overestimate in terms of occurrence as there is probably a self selecting bias in those who respond to the survey. Those with limited experience of enteral nutrition and who have never introduced oral tastes are less likely to complete and return the survey as they may believe they have little information to provide. The responses from the two dietitians were fairly limited and they appeared to view themselves as supporting the decision-making process which they viewed as more central to the work of the speech and language therapists. Future studies surveying random samples of practitioners would give a more accurate insight into the extent to which tastes are recommended. Despite this though, it is clear that people with ID and dysphagia who are primarily non-orally nourished are being offered tastes, with the process of introducing taste programmes appearing to consist of assessment, followed by an introductory/trial period, then implementation, and finally a review and monitoring stage. Practitioners tend to recommend 1-6 teaspoons of food and drinks with a smooth, uniform consistency, based on the belief that this will slow the rate of oral and pharyngeal transit.

Reported factors which influence the decision to start an oral taste programme with people with ID who are non-orally fed were: (i) client wellbeing and the risks and benefits to the person of receiving oral tastes; and (iii) caregiver orientation and support for the taste programme, which incorporated medical and professional advice and multidisciplinary team organisational monitoring and resource issues.

The global themes developed in this analysis were closely linked and support the idea that, when considering oral tastes, practitioners have to take into account the different types of stakeholder responses to the idea of introducing oral tastes. For the person with ID who is enterally fed, their cognitive, verbal, non-verbal, behavioural, emotional, physical and sensory responses and developmental possibilities all have to be considered. For caregivers, their attitudinal, emotional and behavioural responses must be taken into account prior to introduction and during the trialing of taste programmes. The support and resources available from caregivers, multidisciplinary team and social care professionals also need to be considered. Finally advice from medical personnel and other professionals was also taken into account. These responses, resources and sources of advice contribute to and work alongside the clinical decision-making process, informing speech and language therapists and, to a lesser degree dietitians, about the safety, risks and potential benefits of introducing oral tastes. Thus, decision-making and recommending tastes appears to be a process of balance for practitioners involving weighing up available clinical evidence about risks and benefits.

Decision-making here appeared to reflect the multi-attribute utility theory of decision-making (Keeney, 1992), which describes complex decision-making processes where multiple factors need consideration. Tversky's (1972) conception of elimination of aspects, where only the most important aspects are selected (in this case client wellbeing), may also be being applicable here. The lexical rule of 'doing no harm' also

appeared to be being utilized, as an aspect, relating to wellbeing, which practitioners feel cannot be traded off against other considerations (Baron, 2008). Future empirical application of such social cognitive decision-making theories could help identify the key considerations in the decision to introduce tastes.

There was a large degree of consistency in specific factors identified as influencing the decision to implement taste programmes. The best interests of client seem paramount with the client's health and emotional wellbeing seeming to be at the heart of the decision. The client wellbeing theme provided useful insights into the specific client-led factors that are considered by practitioners in the risk assessment process which inform decision-making.

Despite the large degree of consistency in responses around the important considerations, dysphagia related aspiration risk was used inconsistently across practitioners in decision-making. Some respondents were more likely than others to take this risk by giving tastes to someone who aspirates, but only if the person wished to have tastes. Hence for this decision, risk interacted with choice making with some accepting some level of risk if the person wished to have oral intake. Some appeared to only introduce tastes if no aspiration was apparent. Thus risk acceptance and aversion appeared to vary across respondents. More detailed consideration of individual and situational differences around this phenomenon is indicated.

Further research exploring which risks are acceptable to practitioners, and how different factors that contribute to the decision are weighted and variations in practitioner decision-making is needed. It is clear that this is not an easy decision-making process, and that it involves many different factors and stakeholders. ID is a further complicating factor here, as it can be challenging to discern what the person actually wants due to their expressive communication, or what the family/carers want and are able to do to support the programme and thus whether it is appropriate, viable and safe to implement tastes. Further consideration of people with more complex support needs and more severe cognitive impairment is indicated; if client decision-making, communication, understanding and awareness are considered fundamental does this exclude these people from the opportunity for oral intake?

Some different considerations were evident for speech and language therapists working with paediatric groups who focused more in their responses on developmental aspects of introducing tastes (i.e. skill development, socialisation, parent child interaction). This raises the question, why are developmental considerations overlooked more in the adults with ID? Developmental psychology has long since moved from a childhood focused notion of development, however, despite this, this finding may reflect the notion that it is 'too late' for people to develop after a certain age and that developmental opportunities are less important for adults with ID. Such assumptions should be explored and challenged societally and within caregivers, practitioners and organisations supporting people with ID.

Organizing themes extracted from the data were closely linked in many instances. For example, if individual was had high levels of oral sensitivity or severe pharyngeal dysphagia this may lead to reduced enjoyment of oral intake, in turn, their motivation

and orientation towards food and drinks may be less positive, and their caregivers, on observing this, may also be less inclined to introduce oral tastes as they may believe it would not be beneficial for their emotional wellbeing. This is one example, but in other case studies decision-making may be less straightforward. Case study research containing more challenging decision-making experiences and how through negotiation and discussion concordance is reached is likely to be beneficial for practitioners working in this area, who remain unsure and lack the confidence to introduce a taste programme.

The responding speech and language therapists elaborated about many of the factors in the thematic network. However for some of these organising and basic themes therein, less detail was provided. Further qualitative investigations may help to provide more detail around the aspects of the speech and language therapists' clinical decision, which were not fully elaborated in the data gathered in this study. For example, by providing additional insights into the predictions, and plans that impinge upon the evolving decision-making process, and the ways that multidisciplinary teams, community services and medical and health professionals play a role in the decision-making and implementation process. Some settings appeared to have insufficient multidisciplinary team, organisational and carer resources to implement taste programmes safely.

Finally, much of the above discussion assumes that introducing tastes is potentially beneficial to emotional wellbeing and inclusion in the sharing of life through meals and drinks. However, currently no empirical research exists confirming this clinical experience derived belief. Future case based qualitative research and case-controlled clinical evaluative studies are needed focusing not only on risks but also on wellbeing and development.

Conclusion

Introducing tastes to people who are primarily non-orally nourished is a complex, multifactorial team decision, with the client at the centre of the decision-making process. There appears to be some consistency in the process, tastes offered, and the factors that influence the decision to offer tastes, though some inconsistencies across practitioners were apparent. Weighing up of the risks and benefits is evident with people's physical and emotional wellbeing appearing to be at the heart of the clinical decision-making process. Carer and organisational support also plays a key role. Further empirical research is needed around this understudied practice of introduction of oral tastes.

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Table 1: Summarising the thematic networks developed from the qualitative data gathered around the decision to implement taste programmes for people with intellectual disabilities with accompanying taste programme guidance and illustrative quotations

Global & Organizing Themes	Basic Themes	Basic Theme (Taste Programme Instigated)	Basic Theme (Taste Programme Not Instigated)	Illustrative Quotations
Global Theme 1: Impact on the Person's Wellbeing				
1.1 Risk Assessment Process	Risks of Negative events	If benefits of introducing tastes outweigh the risks	If tastes are judged to be too risky to the person's health	<p><i>"Primarily safety would be considered and balanced with enjoyment" (P 35)</i> <i>"If benefits outweigh risks" (P 84)</i> <i>"If tastes are judged to be too great a risk" (P 34)</i></p>
	Affect on quality of life	If the taste programme improved the persons quality of life and food is linked to wellbeing	If the absence of oral tastes is not reducing the person's quality of life and wellbeing	<p><i>"Obviously I'd introduce tastes if it improved the person's quality of life" (P 60)</i> <i>"quality of life issues, i.e. if the positive effects of having a taster are outweighed by negative consequences, e.g. immediate discomfort cause by coughing, delayed discomfort due to chest infection etc." (P 34)</i></p>
1.2 Risks & Benefits to/Impact on Physical Wellbeing	Current and ongoing general health status	Good and stable health status	Poor and/or fragile health status with susceptibility to health problems	<p><i>"I'd be more likely to introduce tastes if the client was in good health following PEG" (P 16)</i> <i>"Ill health would prevent me from introducing tastes" (P 13)</i> <i>"wouldn't introduce, particularly if they had fragile health status already" (P 84)</i></p>
	Seizure activity alertness & fatigue	No seizures or well managed infrequent seizure activity. Lack of alertness and fatigue at mealtimes not evident.	Frequent or poorly controlled seizure activity. Lack of alertness and fatigue at mealtimes evident.	<p><i>"Frequency of seizures would be important in my decision whether or not introduce oral tastes" (P 29)</i> <i>"Low levels of alertness due to repeated fits" (P 30)</i> <i>"Taste are a good option when fatigue may present on large quantities" (P 48)</i></p>
	Oral sensitivity and hygiene	For pleasurable oral stimulation at mealtimes. If part of an oral desensitisation programme. Oral hygiene managed.	Aversion to oral intake & stimulation Oral desensitisation needed prior to tastes Oral hygiene not well managed	<p><i>"Provide pleasurable stimulation whilst tube feeding" (P 106)</i> <i>"Children with severe sensory feeding difficulties will need desensitisation work prior to tastes" (P 42)</i> <i>"Tastes may be part of a desensitisation programme following periods of hypersensitivity" (P 66)</i> <i>"Wouldn't introduce if they had oral hygiene difficulties" (P 31)</i></p>
	Dysphagia severity and associated health risks	Ability to anticipate, manage and control food in the mouth. Functional swallow. The ability to cough and	Unable to orally manage tastes. Functionally unreliable swallow. Absent or weak cough.	<p><i>"If there is no anticipation and no attempt to manipulate the oral taste once it is in the client's mouth I wouldn't implement a taste programme" (P 34)</i> <i>"I'd go with tastes if they had a reliable oral process and swallow on a 'safe' texture" (P 122)</i> <i>"I wouldn't if they had highly variable swallow function" (P 31)</i> <i>"If they show inconsistent aspiration I would recommend tastes" (P 131)</i> <i>"If there was no initiation of the swallow and the person had and absent or weak cough I</i></p>

		clear food. Aspiration and silent aspiration risk low. Low risk of dysphagia related health risks (aspiration pneumonia, respiratory distress, choking & asphyxia & recurrent chest infections, reflux) Good management of secretions	High risk of aspiration or aspiration or silent aspiration on all consistencies High risk of or evidence of dysphagia related health risks following introduction of enteral feeding/ taste programme. Poor management of secretions.	wouldn't" (P 53) "If they can safely swallow small amounts of solids and liquids without aspirating" (P 77) "A programme is possible where likelihood of aspiration risk is low" (P 62) "Severe dysphagia with an ongoing risk of aspiration would stop it" (P 109) "I wouldn't introduce tastes if there is evidence of aspiration on all consistencies therefore they're unsafe" (P 30) "I'd not if there's a suggestion of silent aspiration at bedside assessment prior to further investigations such as videofluoroscopy" (P 46) "Severe risk of aspiration or choking even on small amounts of modified/safe textures with high risk of this leading to health complications for example aspiration pneumonia, particularly if their health status is fragile already" (P 84) "Prior impact of aspiration on chest status would prevent me from considering tastes" (P 56) "fear for oral feeding as usually results in reflux/gagging/distress" (P 13) "Severe aspiration of own secretions, not managing own secretions leading to increased risk of aspiration from saliva production from tastes" (P 16) "I would introduce if the child would not require regular suctioning of residue" (P 72)
1.3 Choice, Motivation & Understanding	Choice and wishes of the person with ID	Expresses strong desire. Accepts offered tastes.	No observable interest in eating Refuses tastes.	"where the person concerned is asking for oral feeds" (P 119) "The person stating that they didn't want oral tasters" (P 49) "Not if the clients refuses tastes" (P 105)
	Awareness & interest	Aware of lack of oral intake and/or interested in food/drinks	Appears unaware of changes in oral intake and/or is uninterested in food/drinks.	"I'm less likely with children with no awareness that tastes are being presented" (P 42) "I would do it if the patient still very interested in food" (P 109) "If child is in good health and is showing awareness of smells, food etc." (P 104)
	Understanding of risks	Able to make an informed decision, understands potential risks but wishes to eat	Unable to make an informed decision/ understand risks	"Client having great desire coupled with mild/moderate risk of aspiration on one or more tastes consistency, informed consent of patient/carer to trial with regular review" (P 53) "I'll start them when there's a strong client wish to eat, when they've been informed of the potential risks" (P 76)
1.4 Risks & Benefits to/Impact on Emotional Wellbeing	Distress & Anxiety around mealtimes	No evidence of distress or frustration when trialling tastes	Evidence that oral intake leads to distress or frustration	"Where the programme would cause distress to the child" (P 27) "Distress and frustration expressed by the client once taste introduced i.e. feeling they have not receiving sufficient quantities orally" (P 43)
	Comfort & Enjoyment	Previously enjoyed food Comfortable with each taste Enjoys mealtime sensations/interaction	Evidence of dislike of oral intake Uncomfortable with tastes No enjoyment of meal interactions/ sensation	"If quality of life is very linked to food enjoyment" (P 84) "evidence that client enjoys oral input" (P 30) "not having value or enjoyment of food" (P 31) "child could enjoy sensation and interaction and taste" (P 27) "where meal-times and food are a big motivator and are important to clients emotional health, though this is not always the case in ALD" (P 16) "Patient for palliative care and not in discomfort from trials" (P 46)

	Inclusion & Socialising at mealtimes	Inclusion & interaction at mealtimes benefits person's wellbeing and/or development	No apparent positive impact of mealtime inclusion/ interaction	<i>"inclusion in the social setting enhancing quality of life" (P 122)</i> <i>"Client inclusion in oral mealtimes" (P 105)</i> <i>"Having tastes at mealtimes with others can lead to improvement in social interaction" (P 30)</i>
1.5 Development, Planning & Prognosis	Development and planning around oral skills	When taste programme is integral to oral skill development	When oral intake is unlikely to benefit development	<i>"When there is the potential to return or progress to oral feeding...and the taste programme could assist in developing oral skills" (P 27)</i>
	Predicted prognosis	If swallow/ oral skills improve. If the person is unlikely to regain full oral eating.	If deterioration of swallow/oral skills is likely.	<i>"If the swallow improves enough to have oral tastes" (P 31)</i> <i>"Evidence that oral stage control is improving" (P 102)</i> <i>"I wouldn't introduce tastes if the client had a deteriorating condition" (P 131)</i> <i>"if the client is not expected to regain oral feeding" (P 22)</i>
Global Theme 2. Support for Implementation of the Taste Programme				
2.1 Stakeholder Support and Orientation	Views, wishes and orientation of caregivers	Motivated and committed to implement tastes. Wants their family member to have oral intake. Parent-child interaction at meals is viewed as important to relationship	Opposed to or uninterested in introduction of tastes. Does not want their family member to have oral intake. Parent-child interaction at meals is not viewed as important.	<i>"I wouldn't if the patient or family member requests not to have tastes" (P 84)</i> <i>"When motivation for tastes from the carers and family is evident" (P 24)</i> <i>"carer interprets the client's behaviour as a wish to eat" (P 35)</i> <i>"the motivation and commitment from caregivers" (P 28)</i> <i>"parents, teachers and classroom staff's willingness" (P 99)</i> <i>"parent enjoys feeding child" (P 11)</i> <i>"carers interpreting client's behaviour as a wish to eat" (P 35)</i>
	Adequacy & variability of carer support	Sufficient number of trained carers. Consistent staff team.	Insufficient number of trained staff. Fluctuating staff team.	<i>"There needs to be adequate availability of carer support" (P 47)</i> <i>"I wouldn't if there was insufficient support from carers" (P 80)</i> <i>"I wouldn't where monitoring of carers is difficult" (P 4)</i>
	Carer confidence and fear	Carer confident in implementing tastes.	Carer not confident and fearful of tastes.	<i>"if staff were not confident in methods of introducing tastes" (P 43)</i> <i>"carer fears of the risks of feeding" (P 35)</i>
	Input, support & resource availability in the wider context	Multidisciplinary team resources available to provide input and monitor health.	Insufficient multidisciplinary resources to monitor health.	<i>"Whether we introduce tastes or not is a multidisciplinary team decision" (P 82, P 10)</i> <i>"GP or specialist medic indicating that the introduction of oral tasters was contraindicated" (P 49)</i> <i>"I wouldn't introduce one if there is an absence of close multidisciplinary team working or they're untrained and it is difficult for them to provide support in implementing the</i>

		GP/Medic supports decision to introduce tastes.	GP/Medic does not support the decision.	<i>programme” (P 46) “The multidisciplinary team is able to regularly review the implemented taste programme” (P 53)</i>
2.2 Taste Programme Adherence	Following taste programme recommendations appropriately & consistently	Follows taste recommendations consistently Adherence to previous programmes and interventions	Difficulty consistently achieving appropriate consistency of food & drinks Lack of adherence to previous programmes	<i>“when carers aren’t able to implement the programme or do it in a consistently unsafe manner” (P 34) “staff/parents who struggle to follow guidelines and try to feed child.” (P 129) “If there is a consistent staff team which has demonstrated good compliance levels with previous recommendations” (P 56)</i>
	Understanding of the requirements of the intervention	Understands taste programme	Inadequate understanding of taste programme	<i>“Good parental understanding of the intervention” (P 42)</i>
	Consideration of Risk	Understand risks and warning signs Able to monitor risks Able to notice and respond to risks	Unaware of risks when eating and drinking Unable to monitor risks Ignore warning signs and risks	<i>“staff/family are unaware of risks and indicators of aspiration/ penetration and do not know what action to take” (P 116) “The family are unable to safely monitor the person’s health and therefore unable to make a decision on nature of risk thus leaving the person vulnerable” (P 49) “difficulties remain when caregivers ignore warning signs, for example, respiration, pallor changes and ‘going off’ food” (P 39)</i>