

Effect of an Experiential Dysphagia Workshop on Caregivers' Knowledge, Confidence, Anxiety and Behaviour During Mealtimes

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ABSTRACT

Purpose: Children with cerebral palsy who have associated feeding difficulties are at risk of aspiration and poor nutrition. This study aimed to measure the changes in knowledge, confidence, anxiety and behaviour among 25 Sri Lankan mothers with responsibility for feeding children diagnosed with cerebral palsy, after they attended an experiential workshop.

Method: Data collection was done through pre- and post-workshop questionnaires, observations and semi-structured interviews.

Results: There was a significant improvement in reported levels of knowledge and confidence and a decrease in the caregivers' level of anxiety during mealtimes. The qualitative data analysis indicated changes in participant knowledge, particularly about the signs of aspiration and positioning during mealtimes. Observations showed better adherence to recommendations on communication, bolus size and utensils.

Conclusion: The findings support the utility of experiential training for caregivers, to ensure that children with cerebral palsy are fed safely.

Key words: cerebral palsy, dysphagia, caregivers, knowledge, confidence, anxiety, Sri Lanka

INTRODUCTION

Cerebral palsy often presents challenges in eating and drinking for the individual and his/her caregiver. It can affect speech and communication skills, movement and posture as well as independence in activities of daily living, including eating and drinking (Granet et al, 1997; Gangil et al, 2001; Workinger, 2005). The

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prevalence of feeding-related issues among children with cerebral palsy ranges from 40% to 90% (Reilly et al, 1996; Trier & Thomas, 1998; Morrow et al, 2007), possibly reflecting the type of cerebral palsy (e.g. spastic, ataxic). Cerebral palsy is often associated with feeding difficulties resulting from, for example, lack of coordination of the suck-swallow-breath synchrony, inadequate lip closure, tongue thrust, delayed or absent tongue lateralisation (Wilson & Hustad, 2009) and oral, pharyngeal or oesophageal phase swallowing disorders including immature chewing patterns and aspiration (Reilly et al, 1996), poor nutrition and hydration, drooling and failure to thrive (Dahl et al, 1996; Reilly et al, 1996; Granet et al, 1997; Sullivan et al, 2000; Fung et al, 2002; Yousafzai et al, 2003; Workinger, 2005; Ramelli et al, 2007; Adams et al, 2011), gastroesophageal reflux and/or constipation (Granet et al, 1997; Workinger, 2005; Erkin et al, 2010) and poor self-feeding skills (Sullivan et al, 2000; Field et al, 2003). The high level of dependence of a child with cerebral palsy on his/her caregiver influences the social experience of mealtimes, making these instances stressful for the child and for his/her caregiver and family (Reilly et al, 2000; Adams et al, 2011). It also makes caregivers of children with disabilities more susceptible to experiencing psycho-social issues (Mobarak et al, 1999; Chimarusti, 2002; Guyard et al, 2011).

There is anecdotal evidence that the occurrence of aspiration pneumonia in children with cerebral palsy results in unexpected fatalities. Better caregiver awareness and understanding of strategies to manage dysphagia encourages adherence to speech and language therapy recommendations (Leiter & Windsor, 1996). In recent times, the focus of dysphagia management has moved towards training healthcare professionals and caregivers (Sullivan et al, 2000; Samuels & Chadwick, 2002; Crawford et al, 2007; Adams et al, 2011).

A low-cost workshop training programme for caregivers in Bangladesh, another resource-poor country, found an increase in the children's respiratory health, cooperation during mealtimes and in their mood (Adams et al, 2011). Additionally, a significant reduction was found in caregiver stress post-training, with inconsistent results on growth based on pre- and post-measures of nutritional status, respiratory status and feeding-related stress as well as observations of feeding. The authors also noted a significant difference between the participant groups that were given training sessions along with advice, as compared to the group which was given only advice, thereby highlighting the need for caregiver training.

Similarly, in a pilot study evaluating adherence to speech and language therapy recommendations by caregivers at day centres, Crawford et al (2007) found more compliance with direct support advice (100%) compared to those on utensils (64%). This discrepancy between caregivers' knowledge and practice has implications for dysphagia training of care staff. However, it must be acknowledged that there could be differences between paid carers undertaking feeding as 'work' at a care-home compared to parents at home. Nevertheless, one way of addressing this disparity between knowledge and practice may be via training workshops with experiential learning opportunities to increase caregivers' knowledge.

In contrast to the study by Crawford and colleagues (2007), a study by Chadwick and colleagues (2006) showed that caregivers recognised modifying food and drinks, using prompting strategies (e.g. pacing) and positioning adults with learning difficulties during mealtimes as challenging. The authors recommend that caregivers be given additional training on their roles and responsibilities to ensure safe oral intake, and monitoring of adults with learning difficulties.

The transformation of new knowledge - acquired via training workshops - into behaviour, by caregivers has been less clear (Morch, 1990; Leiter & Windsor, 1996; Chadwick et al, 2003). Miller and Krawczyk (2001) stress the need to engage participants as 'active learners' in training, employing a combination of teaching styles, thus promoting reflection on 'their own experience, try things out in practice and apply theoretical learning to practical situations' (pg. 381). The authors connect these suggestions about pedagogical styles with Kolb's (1984) assertion of an 'experiential learning cycle', which includes components of practical experience and reflection.

The purpose of the current study was to evaluate potential changes in knowledge, confidence, anxiety and mealtime behaviour among mothers following an experiential dysphagia workshop.

Research questions

The research study aimed to answer the following questions:

1. Can an experiential workshop increase the level of mothers' knowledge and confidence while supporting children with cerebral palsy and related feeding difficulties?

2. Can an experiential workshop decrease the level of anxiety experienced by mothers supporting children with cerebral palsy and related feeding difficulties?
3. Can an experiential workshop encourage adherence to speech and language therapy recommendations regarding mealtimes?

METHOD

Participants

Twenty-five Sri Lankan mothers of children with cerebral palsy who experienced feeding-related difficulties, were invited to attend an experiential workshop on dysphagia. The majority were from poorer socio-economic backgrounds in Colombo (the capital city), who attended either a local support centre or a specialist centre. One participant was a Principal cum teacher of a special school and 2 others were Special Education teachers from the same school. All 3 teachers had children with cerebral palsy who had associated eating and drinking difficulties. The mix of mothers and teachers was an attempt to promote a multidisciplinary approach to the management of dysphagia in children with cerebral palsy.

For inclusion in the study, the participant had to be:

- A caregiver to a child with cerebral palsy who had feeding difficulties
- Willing to fill in the questionnaire either independently or with help in reading and writing
- Willing to be observed during mealtimes
- Willing to be interviewed, if required.

The participants included in the study were between 22 and 45 years of age. The majority were 'stay-at-home' mothers, many of whom said they gave up work to look after their child with cerebral palsy. They had not had previous access to any information about cerebral palsy or related feeding difficulties. Some key demographic details are provided in Table 1. Due to the limited number of qualified Speech and Language Therapists working in the country at present, and the even smaller number offering a paediatric dysphagia service, these mothers reported not having accessed any services regarding feeding issues prior to the consultative meeting and workshop. One of the mothers had been given advice on optimal positioning during mealtimes by a Physiotherapist but reported 'not

understanding' the importance of it. Given the socio-economic background of the majority of mothers, they would have little access to information about cerebral palsy or related feeding difficulties. Of the staff at the centre, none of them were specifically trained to support children experiencing feeding difficulties.

All the mothers were offered an initial consultation with a feeding assessment of the child and brief advice. This was followed by the training workshop and individual follow-up meetings. All the mothers took up the individual consultative meetings following the training (on the insistence and support of the centre management). The workshop was the first to be offered at the centre, with the possibility of term reviews by the co-investigators. These meetings included close observation of the caregiver and child during mealtimes, with the offer of individualised speech and language therapy advice.

Table 1: Demographic details of the Participants (N = 25)

Code	Mother's age	Mother's occupation	Diagnosis of child and severity	Child's age	Child's gender
P1	27	Part-time teacher	Athetoid/Moderate	11;02	M
P2	22	Part-time seamstress	Mixed/Severe	3;02	M
P3	24	Stay-at-home mother	Mixed/Severe	3;06	F
P4	42	Stay-at-home mother	Spastic diplegia/Moderate	15;03	M
P5	34	Teacher	Athetoid/Moderate	11;00	M
P6	22	Stay-at-home mother	Mixed/Severe	3;06	M
P7	26	Stay-at-home mother	Athetoid/Moderate	4;04	F
P8	31	Part-time teacher	Spastic diplegia/ Moderate	9;01	M
P9	38	Stay-at-home mother	Spastic quadriplegia/ Severe	13;00	M
P10	36	Stay-at-home mother	Spastic quadriplegia/ Severe	13;02	M
P11	45	Stay-at-home mother	Spastic quadriplegia/ Severe	24;00	M
P12	28	Stay-at-home mother	Spastic quadriplegia/ Severe	7;05	M
P13	34	Stay-at-home mother	Spastic quadriplegia/ Severe	11;03	M
P14	24	Stay-at-home mother	Mixed/Severe	4;02	F
P15	28	Vegetable seller	Mixed/Severe	4;06	F

P16	40	Stay-at-home mother	Spastic quadriplegia/ Severe	5;07	M
P17	40	Stay-at-home mother	Hypotonia/Moderate	5;05	M
P18	35	Assistant teacher	Spastic quadriplegia/ Severe	6;00	F
P19	35	Stay-at-home mother	Athetoid/Severe	5;07	M
P20	32	Stay-at-home mother	Athetoid/Severe	3;05	F
P21	40	Stay-at-home mother	Hypotonia/Moderate	4;05	F
P22	40	Stay-at-home mother	Ataxia/Moderate	6;06	M
P23	35	Stay-at-home mother	Athetoid/Severe	9;03	M
P24	35	Stay-at-home mother	Athetoid/Moderate	9;02	M
P25	40	Stay-at-home mother	Ataxia/Moderate	3;9	M

Note: The diagnosis was based on medical notes and physiotherapy notes.

The Dysphagia Workshop

A needs assessment was undertaken through semi-structured interviews with 15 mothers of children diagnosed with cerebral palsy to uncover mothers' perceptions of the mealtime experience. The lack of awareness among the mothers on cerebral palsy in general, as well as about optimal positioning during feeding, potential signs of aspiration and client-specific strategies recommended by speech and language therapists emerged as areas of concern. These aspects were included as the key learning objectives of the workshop, which contained the following sub-sections:

- Cerebral palsy and associated difficulties
- Phases of the 'normal' swallow
- The development of eating and drinking skills in children
- Potential difficulties at each phase for a child with cerebral palsy
- Dysphagia and related health issues
- Potential signs of aspiration
- Client-centred strategies during mealtimes; positioning; the pace of offering food; prompts to swallow and texture modification
- Communication during mealtimes
- Experiential activities on the pace of feeding and the posture and positioning during mealtimes

- 'Question and Answer' session on individual difficulties encountered when feeding their child

The two workshops for 15 participants and 10 participants respectively, ran for 3 hours each in the morning at a community centre or a special centre accessed by the participants. The ratio of instructor to participants was 3:15 and 2:10 respectively in the two workshops. The workshops included a mixture of basic theory in the form of a PowerPoint presentation, experiential learning activities, modeling of important procedures and an interactive 'Question and Answer' session. A decision was made to keep the theoretical level very basic and clear, based on the level of knowledge unearthed during the needs assessment. A majority of the participants were stay-at-home mothers, not engaged in paid work and from a poorer socio-economic background, thus making the simple technical level more favourable. The participants, in pairs and in small groups, were offered experiential learning activities related to posture, food textures, and client-centred strategies (e.g. pacing; lack of choices). These included opportunities to 'role play' as feeder and the person being fed, trials with different food textures (e.g. commercial milk drinks; biscuits; yoghurt) and different postures (e.g. head in extension; head tilted to a side). Techniques of posing target questions (Gathercole & Baddeley, 1993) in-line with 'top-down processing' and pictorial support and activities connected to different learning styles (Kolb, 1984) were used to foster learning.

The workshop was conducted by both the authors - one a Speech and Language Therapist and the other a Bobath-trained Physiotherapist - together with the Community Centre Manager who was a Special Education Therapist cum Social Worker. The latter was also the official translator during the first workshop, being fluent in English as well as Sri Lankan Tamil. The first-investigator-Speech and Language Therapist is a fluent speaker of Sinhala and English while the second-investigator-Physiotherapist is trilingual (i.e. Sri Lankan Tamil, English and Sinhala). Interaction during the workshop was favourable as the Centre Manager was familiar with all the participants who visited one of the community centres. An attempt was made to promote the multidisciplinary team approach through this group of instructors. As a first-language speaker of Sri Lankan Tamil and Physiotherapist, and as a fluent speaker of Sinhala and Speech and Language Therapist, the two investigators conducted the second workshop together.

Data Collection Tools

As the study aimed to evaluate the effectiveness of the workshop on mothers' knowledge, confidence, feeder anxiety and behaviour during mealtimes, data were collected through self-administered questionnaires, structured observations and semi-structured interviews with key informants.

The authors devised a questionnaire specific to the Sri Lankan context rather than use a questionnaire from a different country. The questions were influenced by the findings of the previous qualitative study of parent interviews (Hettiarachchi, 2011) and were refined by the Centre Manager who translated them from English to Sri Lankan Tamil. The questionnaire, available in English, Sinhala and Sri Lankan Tamil, had a quantitative section containing 15 statements, with Likert-scaled responses ranging on a 5 point scale of 'very little' to 'very good' or 'a lot'. Sample questions included:

How confident do you feel about feeding your child safely?

How much knowledge do you have of feeding difficulties associated with cerebral palsy?

The qualitative section was made up of 12 open-ended questions, which included the following:

What are the potential implications of cerebral palsy on eating and drinking skills?

What do you understand by 'aspiration' during mealtimes?

What are the possible outward signs of 'aspiration'?

The questionnaire was pre-tested with 3 mothers, each of whom had a child diagnosed with cerebral palsy and dysphagia. One question (no.9) on the categorisation of food was made simpler as two of the mothers requested clarifications. The rest of the questions generated the information sought.

Questionnaire data was collected pre- and post-workshop. The second author and the Centre Manager were both available as translators for Sri Lankan Tamil-speaking participants. The first author supported the Sinhala or English-speaking participants.

Semi-structured Interviews

Interviews were conducted with 9 key informants (5 mothers from the first workshop including 3 teachers and 4 from the second, which included 1 teacher). A topic guide was used to aid data collection.

Structured Observations during Mealtimes

After the workshop, 11 of the children continued to be monitored during mealtimes. They are supported by their teachers at school, with structured observations arranged with the mothers. Observations were made on positioning, pace of offering food, prompts to swallow, texture modification and any recommended techniques, and on the awareness of overt signs of aspiration.

Three of the children were observed with their primary caregivers at a special school which they attend part-time.

Ethical Issues

Ethical approval was obtained from the Ethical Research Committee of the Faculty of Medicine, University of Kelaniya, Sri Lanka (P048/2011). Each participant was given an information sheet in simple Sri Lankan Tamil, Sinhala or English, and was expected to fill in a written consent form prior to data collection.

Data Analysis

The first author analysed the English and Sinhala responses to the questionnaire. The Sri Lankan Tamil responses were translated into English by the interpreter and the second author. The questionnaire aimed to gain information on the following:

- **Knowledge:** Understanding of feeding-related issues in cerebral palsy
- **Confidence:** Self-belief in one's own skills at feeding a child with cerebral palsy
- **Anxiety:** Uncertainty connected to feeding a child with cerebral palsy.

The quantitative section with Likert-type responses were converted into numbers (i.e., Very little=1; Very good=5) to ascertain any changes in each participant's knowledge, confidence or anxiety. Line graphs were used for each of the 12 items on the questionnaire. In addition, statistical analyses using non-parametric Wilcoxon tests were undertaken on the group Likert-scaled responses collected pre- and post-workshop, that reported on knowledge, confidence and anxiety.

The thematic analysis undertaken on the qualitative section of the questionnaire and the interview data using aspects of *Framework Analysis* (Ritchie & Spencer, 1994) uncovered changes in knowledge on cerebral palsy, associated eating and

drinking difficulties, posture and positioning during mealtimes, aspiration, and client-centred strategies pre- and post-workshop.

The data was subjected to the five stages recommended by Ritchie and Spencer (1994) involving the identification of a thematic framework, indexing, charting, mapping and interpretation .

RESULTS

The quantitative data documented changes in the participants' views of their knowledge, confidence, and anxiety. The qualitative data uncovered the difference in participants' knowledge before and after the workshop.

Quantitative Data

In all, the participants identified 14 factors that influenced the mealtime experience. These included factors related to the child, such as choking, coughing or potential aspiration, independence and swallowing; factors related to the caregiver, such as confidence of the feeder as well as the high level of anxiety experienced; and factors related to feeding, such as the duration (Table 2).

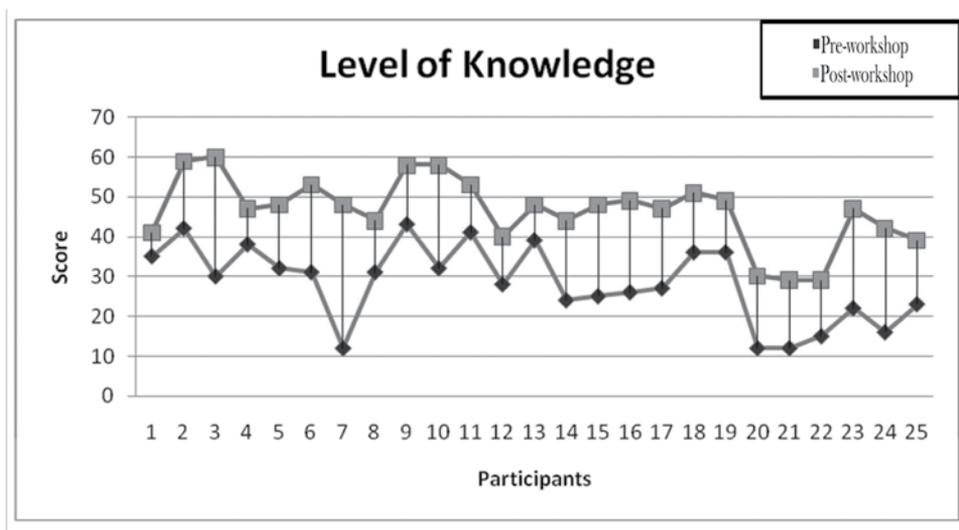
Table 2: Factors influencing the Mealtime Experience (N = 25)

Factors related to the child	Factors related to the caregiver	Factors related to feeding
Choking, coughing or potential aspiration = 20	Confidence of feeder = 17	Food textures = 14
Swallowing = 20	Anxiety of feeder = 15	Duration = 19
Chewing = 15		Positioning = 22
Drinking from a cup = 5		
Independence = 19		
Nutrition = 12		
Hydration = 11		
Constipation = 11		
Vomiting = 3		
Changes to breathing = 2		

Knowledge

Of the 12 items on levels of knowledge in the questionnaire, all the participants indicated a positive change on the same 6 items. A majority (18/25 or 72%) reported gains in knowledge on all 12 items. Four participants noted an increase in 11 of the 12 items (Graph 1).

Graph 1: Demonstrated level of Knowledge pre- and post-workshop

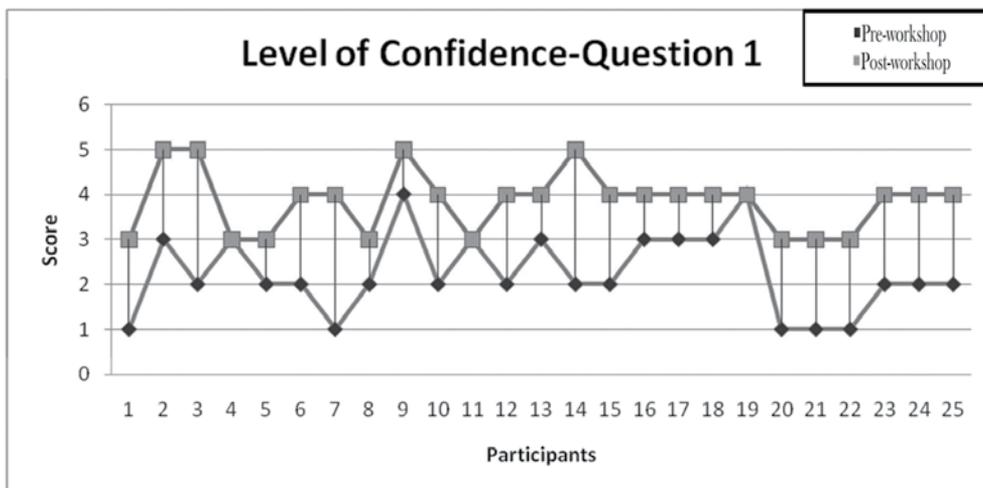


The mean score of the group of mothers with regard to knowledge was 28.72 before the workshop and 44.00 after the training. This change in the level of knowledge as a group was highly significant at $t(24) = 24.06, p < 0.000$.

Confidence

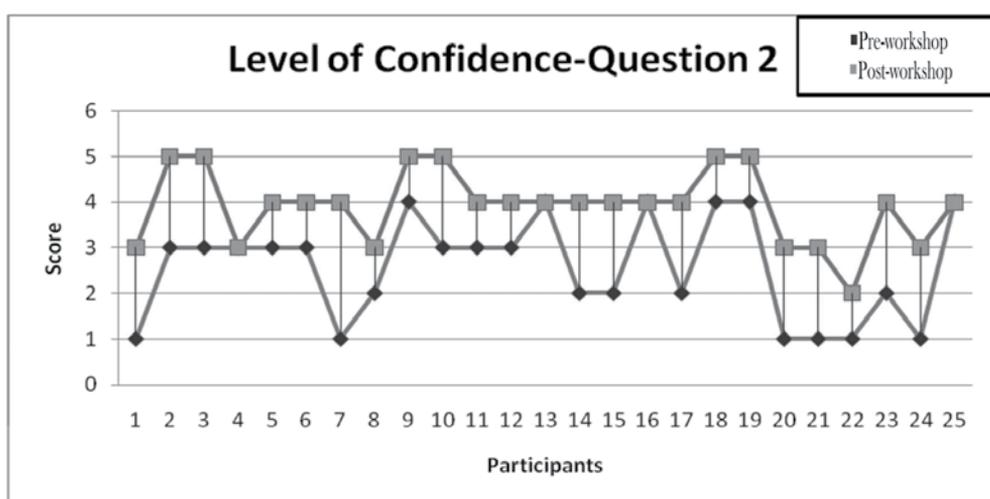
There were 2 items pertaining to confidence in feeding a child with cerebral palsy. 22 participants expressed a positive change on the first item, while 3 participants noted no change in relation to their level of confidence (Graph 2).

Graph 2: Demonstrated level of Confidence pre- and post-workshop - Question 1



On the second item, 21 participants noted a change in their confidence levels, while 4 participants noted no change (Graph 3).

Graph 3: Demonstrated level of Confidence pre- and post-workshop - Question 2



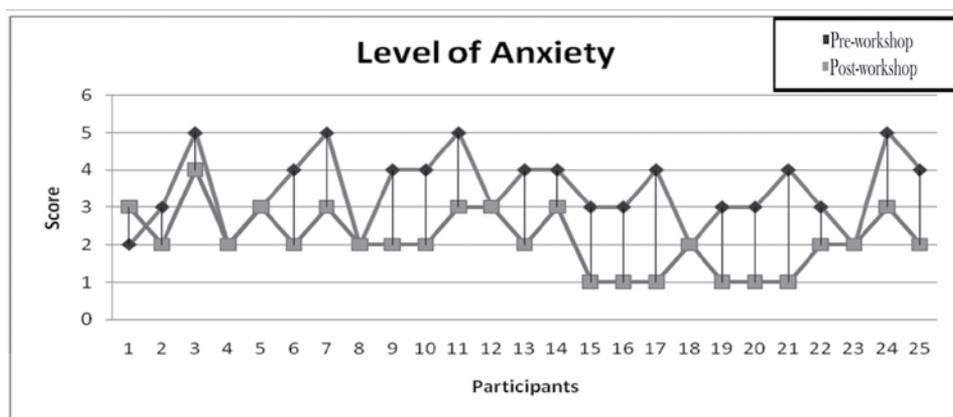
The mean score on the level of confidence reported by the mothers as a group was 4.68 pre-workshop and 7.64 following the training. This positive

change in the grouped data reached statistical significance at $t(24) = 27.67$, $p < 0.000$.

Anxiety

There was one item on the questionnaire concerning caregiver anxiety during mealtimes. Eighteen participants expressed a marked decrease in the level of anxiety they felt after the workshop (Graph 4). Six of the mothers noted no difference in their anxiety levels, while 1 reported a slight increase. This participant, who is also a teacher, reported that she felt more anxious as she realised that she was *'doing things wrong in the school'* (P1).

Graph 4: Demonstrated level of Anxiety pre- and post-workshop



The mean score on the reported level of anxiety by the mothers during feeding was 3.44, which had reduced to a mean score of 2.12 by the end. This decrease in the reported level of anxiety reached statistical significance at $t(24) = 11.43$, $p < 0.000$.

Qualitative Data

The qualitative data from the questionnaire and the interviews were analysed under 3 main headings - knowledge, confidence, and caregiver anxiety. The key findings are presented in the Tables below.

Knowledge

The qualitative responses on the questionnaires before and after the workshop indicated differences in participant knowledge on cerebral palsy, positioning during mealtimes, aspiration, and food textures.

Knowledge about Cerebral Palsy			
Pre-workshop	Post-workshop	Examples	
3/25	16/25	Pre-workshop Sithee (P5): <i>'I'm not sure how you describe cerebral palsy. My child cannot walk or talk. He is dependent on me for everything.'</i>	Post-workshop Sithee (P5): <i>'Cerebral palsy describes a person who has difficulties with movement like standing and walking. It is due to brain damage because of a disease or some mishap at birth.'</i>
		Subojini (P11): <i>'No idea.'</i>	Subojini (P11): <i>'Is a problem of movement because of brain damage.'</i>
		Gowri (P18): <i>'I don't understand my child's condition.'</i>	Gowri (P18): <i>'When the child is in the mother's womb or during birth or after birth due to an infection or accident to the brain, muscles become weak or tight resulting in cerebral palsy.'</i>
Knowledge on Positioning			
3/25	25/25	Pre-workshop Geethika (P9): <i>'...I have no idea. I place him on his back and hold his hands down. It is very difficult to feed him. I don't know if this is the right position for him.'</i>	Post-workshop Geethika (P9): <i>'Face- to- face position. Place the child opposite me and look at her face while feeding. She might then enjoy the experience. Maintain an upright posture if possible at 90/90/90 degrees.'</i>
		Sandya (P1): <i>'It's very difficult to feed X. I have to hold his hands. I lie him down. He does not like it but I don't know how to feed him otherwise.'</i>	Sandya (P1): <i>'Adjusting his posture and controlling his involuntary movements is important during mealtimes. Maintaining an upright posture if possible would benefit X as it may help him not to cough or choke during the meal.'</i>
		Devi (P3): <i>'I don't know how to place her when I feed her. She falls forward. I don't know what to do.'</i>	Devi (P3): <i>'I will be more careful about my child's positioning during meals. I understand why I must support my child to stay upright during meals if possible. I did not know before how dangerous bad positioning could be for her.'</i>
		Sangeeta (P13): <i>'I place him on the mat on the floor. If I sit him on a chair, he moves about and the food goes everywhere. I don't know if I should do this.'</i>	Sangeeta (P13): <i>'I will be more careful about my child's positioning during meals.'</i>
		Brindha (P22): <i>'I lay the child on the floor and tilt him to the left, then hold him down and feed him.'</i>	Brindha (P22): <i>'At this workshop, I learnt how to position my child comfortably and accurately while feeding him.'</i>

Knowledge on Swallow safety			
		Pre-workshop Selvi (P17): <i>'He can swallow food only if we close his nostril.'</i>	Post-workshop Selvi (P17): <i>'I will try to position him better to help him breathe and swallow better.'</i>
Knowledge on Aspiration			
1/25	21/25	Pre-workshop Kamani (P2): <i>'I don't know.'</i>	Post-workshop Kamani (P2): <i>'Food or liquid going down the windpipe into the lungs.'</i>
		Parveen (P6): <i>'I have not heard the word before.'</i>	Parveen (P6): <i>'I understand that aspiration is food and drink going down the wrong way, into the lungs. I worry about X choking on food. I now know what signs to look for. I'll be more vigilant.'</i>
		Priti (P14): <i>'I don't know.'</i>	Priti (P14): <i>'I did not know how dangerous it is to feed X when she is lying down. I will place her upright and look out for signs of difficulty like blinking her eyes, coughing or some change in her breathing.'</i>
		Poonam (P8): <i>'I am worried about how to feed X. Sometimes he coughs when eating and I am scared he will choke. I do not give him any yoghurt or milk. He has a lot of phlegm.'</i>	Poonam (P8): <i>'I learnt how to feed food and give water to my child safely. I must look out for signs of aspiration.'</i>
		Rajini (P16): <i>'Is 'aspiration' about talking to the child and to others?'</i>	Rajini (P16): <i>'It is caused when the food particles or drink travel through the breathing tract.'</i>
Knowledge on Food textures			
1/25	8/25	Pre-workshop Sharmila (P7): <i>'Not sure what food to give my daughter as my child is not chewing food, she may be malnourished, she may choke. I am worried.'</i>	Post-workshop Sharmila (P7): <i>'Offer food of an appropriate texture for her (child)...learnt that food could be categorised into different textures, some easier and some harder for a child to chew and to swallow.'</i>

Confidence

The confidence the mothers felt at feeding their child with cerebral palsy was connected with their knowledge on positioning and the level of pressure they experienced. The comments pre- and post-workshop indicate a qualitative difference in the levels of confidence.

Lack of Confidence			
Pre-workshop	Post-workshop	Examples	
17/25	3/25	Pre-workshop Rukmani (P21): <i>'I am nervous to feed her as she coughs sometimes. If the food does not go down correctly, it will come up in some way. When she has phlegm, the food comes out from her nose.'</i>	Post-workshop Rukmani (P21): <i>'I am now confident at knowing a better way to place her on my lap and feed her. It is easier for her as well.'</i>
Perceived Pressure			
7/25	2/25	Pre-workshop Safna (P17): <i>'There is a lot of pressure on me to feed him. I don't feel confident. Only I can feed him.'</i>	Post-workshop Safna (P17): <i>'I know how to place him on my lap and support his head. I feel a little more confident about feeding him safely.'</i>

Anxiety

Maternal anxiety during mealtimes was related to the level of child dependence. Increase in the demonstrated knowledge showed a reduction in the level of anxiety, as evidenced in the qualitative differences noted after the workshop.

Dependence during Mealtimes			
Pre-workshop	Post-workshop	Examples	
15/25	5/25	Pre-workshop Lakshmi (P4): <i>'He cannot move on his own. I have to do everything for him.'</i>	Post-workshop Lakshmi (P4): <i>'I know that he is dependent on me but I learnt today that I must focus on the things I can change to keep him safe. I can also encourage him to hold spoons or a biscuit. It's a slow process.'</i>
		Devi (P3): <i>'I am sad when it takes time to feed X. She can't feed herself. How do we make the child independent to eat on her own? That's my main concern.'</i>	Devi (P3): <i>'I should focus on keeping my child safe, even if I have to feed her. That's the main concern. Eating independently may be possible in the future.'</i>

DISCUSSION

The results indicate that the experiential workshop brought about significant positive changes in the participants' knowledge about cerebral palsy and the accompanying difficulties while eating and drinking, in addition to improving their confidence in feeding their children. Participants also reported decreased levels of anxiety about mealtimes. In addition, there was a marked difference in knowledge about appropriate positioning during mealtimes, signs of aspiration and, to a lesser extent, texture modification. Observations at mealtimes indicated adherence to some strategies connected to pacing, bolus size and better communication.

The qualitative change in knowledge was proportionate to the positive change in the level of confidence reported by the participants. This reduction in levels of stress is similar to that reported by Bangladeshi caregivers following a low-cost training initiative (Adams et al, 2011). However, unlike the Bangladeshi caregivers, the current study did not include a comparison group. It is therefore not possible to determine whether advice alone or advice along with the training session is the more effective intervention option for Sri Lankan caregivers.

The qualitative changes in knowledge gathered were better recall of information on posture and positioning during mealtimes and on the pace of offering food or drink, compared to information on food textures and food modification. However, this was at variance with the findings by Chadwick et al (2002) wherein adherence to recommendations on texture modification was much higher than on positioning, prompting or utensils. Although the study by Chadwick et al (2002) was not on the effectiveness of a training workshop, presumably those caregivers, like the participants in this study, had to recall information given by the speech and language therapist. A subsequent study by the same authors (2006) noted poorer recall of recommendations concerning prompting and socialisation strategies compared to those connected with texture modification. The authors explain this by the possibly 'concrete' nature of the recommendations on texture modification and use of special equipment, since alteration of the consistency of food and drink occurs at every mealtime. Difficulties in recalling advice on modifying textures in the current study was similarly discovered among caregivers of adults with learning difficulties (Chadwick et al, 2006). Since the current workshop did not include modeling of texture modification, it is conceivable that to some extent this contributed to the caregivers' inability to recall information on this aspect.

The improvement in knowledge and confidence could be due to the use of varied teaching methods and simple language (with limited terminology or jargon) during the workshop. A PowerPoint presentation was accompanied by prompt questions, demonstrations, pictorial support, opportunities for role-play and experiential learning, as well as time allotted for questions and reflection. Therefore, the results may be reflective of the weight given to the various components or strategies (e.g. positioning) and “live” demonstrations (e.g. the second author demonstrated optimal positioning using children with cerebral palsy present at the workshop). Procedural knowledge such as the steps of texture modification may be better performed but less well articulated by caregivers (Chadwick et al, 2002). However, findings from the current study indicate that future workshops should incorporate demonstrations of such procedures to support caregiver understanding and recall.

This gains theoretical support from Gathercole and Baddeley (1993) who assert that present schemas should be stimulated prior to offering new information to support storage. This ‘top-down processing’ was encouraged within the workshop by posing questions at the start of the training so as to encourage the participants to think of their own relationship with food and drink as well as to recall personal concerns regarding feeding their children. This use of a combination of teaching styles to encourage ‘active’ learning is also in keeping with the recommendations of Miller and Krawczyk (2001), and in line with the ‘experiential learning cycle’ described by Kolb (1984). Nevertheless, it is not possible to isolate the impact of each of the different teaching styles used within the workshop on caregiver understanding and recall. Additionally, the accessibility of the language used (i.e. simple language with limited terminology or jargon) and the pedagogical methods used including the use of role play, Powerpoint and pictorial support may have also contributed to participant understanding and recall.

Another plausible explanation for better recall of information concerning posture, communication and pace of feeding could be due to the emphasis on the experiential activities included in the workshop. However the different textures of food were not remembered very clearly, possibly because there were no opportunities for trials during the workshop. Thus, devising a training programme that explicitly connects “real life” experiences with factual information appears to benefit caregivers. The participants were found to have better recall on issues they had identified as areas of concern prior to the workshop compared to aspects that were not highlighted as problematic. Participants generally

absorbed new information about their main concern (i.e. positioning their child during mealtimes) rather than information on food modification, which was a minor worry. Therefore, advice that was congruent with their concerns was more memorable and easier to recall.

The point to ponder is whether gains in knowledge and confidence translate to the caregivers' everyday feeding practices. In other words, for there to be any meaningful change by offering an experiential workshop, there should be a commensurate change in strategies used by the participants during mealtimes, in line with reported changes in knowledge and confidence. There is competing evidence on the association between caregiver knowledge and behaviour, with Leiter and Windsor (1996) finding better knowledge than compliance and Morch (1990) reporting the reverse. Adams and her colleagues (2011) recommend at least 4 sessions to influence behaviour changes and long-term consequences.

Chadwick and his colleagues (2006) found that staff (this could be the same for caregivers) could become 'fixed' in the routines established during mealtimes, to the detriment of remembering and following speech and language therapy recommendations. Nevertheless, their study is not easily comparable with the current study due to the difference in client groups (i.e. adults with learning disabilities vs cerebral palsy) with potentially differing levels of concern about posture. In this study, as each participant and her child had been observed and general advice offered in a consultative meeting prior to the workshop, observations of mothers showed some adherence to recommendations.

Limitations

The findings need to be interpreted with caution as the study only investigates the workshop participants' immediate recall of knowledge and short-term observations. This is the main limitation of the study.

Another concern of the present study is that it only offered one training session, emphasising particular aspects of dysphagia management. A series of sessions such as the six-session programme offered by Adams and her colleagues (2011) needs to be strongly considered to influence behavioural changes during mealtimes. A follow-up study using an observational methodology with all participants would be useful to verify compliance with the recommendations and knowledge gained through the workshop. Home visits to observe maternal adherence to recommendations as well as more objective measures of child nutritional status

and respiratory status as used by Adams and her colleagues (2011) also need to be considered in a follow-up study. The current understanding of long-term memory suggests that retention and recall of knowledge is facilitated by opportunities for rehearsal. It may therefore be of benefit to offer a series of follow-up workshops to help consolidate current understanding and to promote adherence to advice.

CONCLUSION

A lack of sources of information and knowledge about feeding-related issues and limited confidence in feeding children with cerebral palsy affects the mealtime experiences of the Sri Lankan mothers who participated in the study. The findings support the use of experiential workshops to increase carers' knowledge and confidence, to decrease anxiety and to encourage adherence to speech and language therapy recommendations. Experiential workshops helped participants to understand first-hand the reason for the advice given by healthcare professionals. These findings add to the research on the effectiveness of other parent training programmes to promote language and communication used with Speech and Language Therapy. A combination of teaching methods could support the different learning styles of the participants and encourage better understanding and recall of information. In a country like Sri Lanka where Speech and Language Therapy services are currently limited, other healthcare and educational staff such as community-based rehabilitation workers and teachers could be trained to better support primary caregivers. Although a challenge within a resource-poor country, close and frequent monitoring to ensure the transfer of knowledge to practice needs to be highlighted.

REFERENCES

- Adams MS, Khan NZ, Begum SA, Wirz SL, Hesketh T, Pring TR (2011). Feeding difficulties in children with cerebral palsy: low-cost caregiver training in Dhaka, Bangladesh. *Child: Care, Health and Development*; 38 (6): 878-88. <http://www.ncbi.nlm.nih.gov/pubmed/22082112> <http://dx.doi.org/10.1111/j.1365-2214.2011.01327.x> PMID:22082112
- Chadwick DD, Jolliffe J, Goldbart J (2002). Career knowledge of dysphagia management strategies. *International Journal of Language & Communication Disorders*; 37 (3): 345-357. <http://dx.doi.org/10.1080/13682820210137196> PMID:12201982
- Chadwick DD, Jolliffe J, Goldbart J (2003). Adherence to eating and drinking guidelines for adults with intellectual disabilities and dysphagia. *American Journal of Mental Retardation*; 108 (3): 202-211. <http://www.ncbi.nlm.nih.gov/pubmed/12691599> [http://dx.doi.org/10.1352/0895-8017\(2003\)108<0202:ATEADG>2.0.CO;2](http://dx.doi.org/10.1352/0895-8017(2003)108<0202:ATEADG>2.0.CO;2)

Chadwick DD, Jolliffe J, Goldbart J, Burton MH (2006). Barriers to caregiver compliance with eating and drinking recommendations for adults with intellectual disabilities and dysphagia. *Journal of Applied Research in Intellectual Disabilities*; 19 (2): 153-162. <http://onlinelibrary.wiley.com/doi/10.1111/j.1468-3148.2005.00250.x/abstract>

<http://dx.doi.org/10.1111/j.1468-3148.2005.00250.x>

Chimarusti J (2002). Emotional experiences of parents of children with cerebral palsy. *Dissertation Abstracts International*, AAT 3041793.

Crawford H, Leslie P, Drinnan M (2007). Compliance with dysphagia recommendations by carers of adults with intellectual impairment. *Dysphagia*; 22 (4): 326-334. <http://www.ncbi.nlm.nih.gov/pubmed/17701245> <http://dx.doi.org/10.1007/s00455-007-9108-1> PMID:17701245

Dahl M, Thommessen M, Rasmussen M, Selberg T (1996). Feeding and nutritional characteristics in children with moderate or severe cerebral palsy. *Acta Paediatrica*; 85: 697-701. <http://www.ncbi.nlm.nih.gov/pubmed/8816207> <http://dx.doi.org/10.1111/j.1651-2227.1996.tb14129.x>

Day K, Jancar J (1994). Mental and physical health and ageing in mental handicap: a review. *Journal of Intellectual Disability Research*; 38: 241-256. http://www.academia.edu/321108/Caring_for_Older_People_with_Learning_Disabilities <http://dx.doi.org/10.1111/j.1365-2788.1994.tb00392.x> PMID:8061470

Erkin G, Culha C, Ozel S, Kirbiyik EG (2010). Feeding and gastrointestinal problems in children with cerebral palsy. *International Journal of Rehabilitation Research*; 33 (3): 218-24. <http://www.ncbi.nlm.nih.gov/pubmed/20216224> <http://dx.doi.org/10.1097/MRR.0b013e3283375e10> PMID:20216224

Field D, Garland M, Williams K (2003). Correlates of specific childhood feeding problems. *Journal of Paediatric Child Health*; 39: 299-304. <http://www.ncbi.nlm.nih.gov/pubmed/12755939> <http://dx.doi.org/10.1046/j.1440-1754.2003.00151.x>

Fung EB, Samson-Fang L, Stallings VA, Conaway M, Liptak G, Henderson RC, Worley G, O'Donnell M, Calvert R, Rosenbaum P, Chumlea W, Stevenson RD (2002). Feeding dysfunction is associated with poor growth and health status in children with cerebral palsy. *Journal of the American Dietetic Association*; 102 (3): 361-73. <http://www.ncbi.nlm.nih.gov/pubmed/11902369> [http://dx.doi.org/10.1016/S0002-8223\(02\)90084-2](http://dx.doi.org/10.1016/S0002-8223(02)90084-2)

Gangil A, Patwari AK, Aneja S, Ahuja B, Anand VK (2001). Feeding problems in children with cerebral palsy. *Indian Paediatrics*; 38 (8): 839-46. <http://www.ncbi.nlm.nih.gov/pubmed/11520994>

Gathercole SE, Baddeley AD (1993). *Working Memory and Language*. Hove, England: Lawrence Erlbaum Associates: 1-266.

Gisel EG, Patrick J (1988). Identification of children with cerebral palsy unable to maintain a normal nutritional state. *Lancet*; 6;1(8580): 283-286. <http://www.ncbi.nlm.nih.gov/pubmed/2893092>

Granet KM, Balaghi M, Jaeger J (1997). Adults with cerebral palsy. *New Jersey Medicine*; 94: 51-54. <http://www.ncbi.nlm.nih.gov/pubmed/9040185> PMID:9040185

- Guyard A, Fauconnier J, Mermat M, Cans C (2011). Impact on parents of cerebral palsy in children: A literature review. *Archives of Paediatrics*; 18 (2): 204-214. <http://www.thefreelibrary.com/Appreciating+life%3A+being+the+father+of+a+child+with+severe+cerebral...-a0278760441> <http://dx.doi.org/10.1016/j.arcped.2010.11.008> PMID:21196101
- Helfrich-Miller KR, Rector KL, Straka JA (1986). Dysphagia: its treatment in the profoundly retarded patients with cerebral palsy. *Archives of Physical Medicine and Rehabilitation*; 67 (8): 520-525. <http://www.ncbi.nlm.nih.gov/pubmed/3741076> PMID:3741076
- Hettiarachchi S (2011). 'He is totally dependent on me': Sri Lankan-Tamil mothers' perceptions of the mealtime experience with their children with cerebral palsy. Oral presentation at 'Phonocon 2011' Conference, Delhi, India: 2011.
- Hirst M (1985). Dependency and family care of young adults with disabilities. *Child: Care, Health and Development*; 11: 241-257. <http://dx.doi.org/10.1111/j.1365-2214.1985.tb00467.x> <http://dx.doi.org/10.1111/j.1365-2214.1985.tb00471.x> PMID:2932261
- Kolb DA (1984). *Experiential Learning: Experience as the source of learning and development*. New Jersey: Prentice Hall: 1-256. PMID:6518360
- Leiter AE, Windsor J (1996). Compliance of geriatric dysphagic patients with safe-swallowing instructions. *Journal of Medical Speech-Language Pathology*; 4: 289-300. <http://onlinelibrary.wiley.com/doi/10.1080/13682820210137196/abstract>
- Miller R, Krawczyk K (2001). Dysphagia training programmes: 'fixes that fail' or effective inter-disciplinary working? *International Journal of Language & Communication Disorders*; 36 (suppl.): 379-384. <http://dx.doi.org/10.3109/13682820109177915> PMID:11340816
- Mobarak R, Khan NZ, Munir S, Zaman SS, McConachie H (1999). Predictors of stress in mothers of children with cerebral palsy in Bangladesh. *Journal of Paediatric Psychology*; 25 (6): 427-433. <http://jpepsy.oxfordjournals.org/content/25/6/427.full> <http://dx.doi.org/10.1093/jpepsy/25.6.427>
- Morch WT (1990). Improving treatment in field settings for the mentally retarded: Staff training, behavioural intervention and effect evaluation. Unpublished doctoral dissertation, University of Oslo, Norway.
- Morrow A, Craig J, Quine S (2007). Health professionals' perceptions of feeding related quality of life in children with quadriplegic cerebral palsy. *Child: Care, Health & Development*; 33 (5): 529-538. <http://dx.doi.org/10.1111/j.1365-2214.2006.00709.x> PMID:17725774
- Ramelli GP, Aloysius A, King C, Davis T, Muntoni F (2007). Gastrostomy placement in paediatric patients with neuromuscular disorders: indications and outcome. *Developmental Medicine and Child Neurology*; 49: 367-71. <http://dx.doi.org/10.1111/j.1469-8749.2007.00367.x> PMID:17489811
- Reilly S, Carr L, Wisbeach A. (2000). Assessing feeding in children with neurological problems. In: Southall AM, Schwartz AL, (Eds.) *Feeding Problems in Children: A Guide for Health Professionals*. Oxford: Radcliffe Medical Press; 153-170.
- Reilly S, Skuse D (1992). Characteristics and management of feeding problems of young children with cerebral palsy. *Developmental Medicine & Child Neurology*; 34 (5): 379-388.

<http://www.ncbi.nlm.nih.gov/pubmed/1592191> <http://dx.doi.org/10.1111/j.1469-8749.1992.tb11449.x> PMID:1592191

Reilly S, Skuse D, Poblete X (1996). Prevalence of feeding problems and oral motor dysfunction in children with cerebral palsy: A community survey. *Journal of Paediatrics*; 129: 877-882. <http://www.ncbi.nlm.nih.gov/pubmed/8969730> [http://dx.doi.org/10.1016/S0022-3476\(96\)70032-X](http://dx.doi.org/10.1016/S0022-3476(96)70032-X)

Ritchie J, Spencer L (1994). Qualitative data analysis for applied policy research. In Bryman A, Burgess RG (Eds.), *Analysing Qualitative Data*. London: Routledge, 173-194. http://dx.doi.org/10.4324/9780203413081_chapter_9

Samuels R, Chadwick DD (2002). How I trained others in dysphagia: Fred the head stops mars bars in bed. *Speech and Language Therapy in Practice*; 3: 26-27. issn: 1368-2105

Stallings VA, Charney EB, Davies JC, Cronk CE (1993). Nutritional status and growth of children with diplegic or hemiplegic cerebral palsy. *Developmental Medicine and Child Neurology*; 35: 997-1006. <http://www.ncbi.nlm.nih.gov/pubmed/8444326> <http://dx.doi.org/10.1111/j.1469-8749.1993.tb11582.x> PMID:8224567

Sullivan PB, Lambert B, Rose M, Ford-Adams M, Johnson A, Griffiths P (2000). Prevalence and severity of feeding and nutritional problems in children with neurological impairment: Oxford Feeding Study. *Developmental Medicine and Child Neurology*; 42: 674-80. <http://www.ncbi.nlm.nih.gov/pubmed/11085295> <http://dx.doi.org/10.1017/S0012162200001249>

Trier E, Thomas A (1998). Feeding the disabled child. *Nutrition*; 14: 801-805. <http://www.ncbi.nlm.nih.gov/pubmed/9785366?dopt=Abstract&holding=f1000,f1000m,isrctn> [http://dx.doi.org/10.1016/S0899-9007\(98\)00088-4](http://dx.doi.org/10.1016/S0899-9007(98)00088-4)

Wilson EM, Hustad KC (2009). Early feeding abilities in children with cerebral palsy: A parental report study. *Journal of Medical Speech-Language Pathology*; 17: 31-44. <http://www.ncbi.nlm.nih.gov/pubmed/20046974>

Workinger MS (2005). *Cerebral palsy: Resource guide for speech-language pathologists*. Clifton Park, New York: Thompson Delmar Learning: 1-179.

Yousafzai AK, Filteau S, Wirz S (2003). Feeding difficulties in disabled children leads to malnutrition: experience in an Indian slum. *British Journal of Nutrition*; 90 (6): 1097-1106. <http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=910708> <http://dx.doi.org/10.1079/BJN2003991> PMID:14641969