Understanding mealtime changes for adults with cerebral palsy and the implications for support services*

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Abstract

Background Changes in the swallowing capabilities of adults with cerebral palsy as they age may impact on their health, safety, and well-being.

Method Thirty-two adults with cerebral palsy aged between 30 and 69 years participated in in-depth interviews about their experiences of changes in their swallowing and related management of their mealtimes within the last two years. A constant comparative qualitative analysis of the interviews elucidated the changes they experienced.

Results Changes included increased coughing and choking, digestive or gastro-oesophageal symptoms, diet modification, loss of independence with psychosocial consequences. Participants reported unsatisfactory collaboration with service providers over mealtime management decisions and interventions.

Conclusions Adults with cerebral palsy may experience gradual changes in their swallowing and mealtime capabilities from as early as 30 years of age. Regular collaborative assessment and involvement of all stakeholders in decisions are important to facilitate compliance with recommendations, ongoing safety, and optimal well-being.

Keywords: cerebral palsy, adults, mealtime management, dysphagia, communication, qualitative research, lifelong disability

Introduction

People with cerebral palsy, particularly those with severe motor impairments, are at high risk for dysphagia in childhood (Calis et al., 2008). Furthermore, the disorder may be chronic, persisting into adulthood. There is evidence to suggest that adults with cerebral palsy experience a worsening of symptoms of dysphagia after the age of 30 years (Balandin & Morgan, 1997; Sheppard, 1991; Sheppard, 2002a; Sheppard, 2006). Dysphagia can undermine health and affect a person’s dignity, self-esteem, and quality of relationships with family, friends, and carers (Kaatzke-McDonald, 2003). In addition, dysphagia reduces social opportunities and the pleasure of mealtimes (Ekberg, Hamdy, Woisard, Wuttge-Hannig, & Ortega, 2002). Although the incidence of dysphagia is higher among people with lifelong disability than among the general population, little is understood about how people with cerebral palsy perceive the impact of dysphagia and the changes that they associate with ageing.

Dysphagia and ageing in people with cerebral palsy

Results of an 18-year longitudinal study of 627 adolescents and adults with severe and profound intellectual and developmental disability, including cerebral palsy, indicated that those who had a swallowing disorder at the beginning of the study tended to experience an increase in complexity and severity of symptoms as they aged. In addition, many of those who did not have dysphagia at the outset of the study acquired dysphagia in one or more of the phases of swallowing during the study duration (Sheppard, 2002a, 2006). Sheppard noted that participants with more severe dysphagia at the outset of the study began their decline at an earlier age than those who were judged to have less severe disorder. Specifically, the average age of onset of this deterioration commenced at around 33 years of age. Sheppard (1991) postulated that these changes might be due to deterioration in skeletal and neurologic status associated with age (Strauss, Ojdana, Shavelle, & Rosenbloom, 2004).

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Dysphagia can make mealtimes time-consuming and exhausting. This, along with risk of aspirating or choking on food, can result in difficulty with obtaining adequate nutrition and hydration (Stewart, 2003). Furthermore, people with dysphagia and lifelong disability, including cerebral palsy, are at risk of nutrition-related health problems in addition to other problems with health, safety, and well-being (Kaatzke-McDonald, 2003; Stewart, 2003; von Königsmark, 2000). Health problems experienced by people with cerebral palsy may be complicated by dysphagia and impact adversely on quality of life (Talley & Wiklund, 2005). These problems include being at greater risk for constipation (Balandin & Morgan, 1997; von Königsmark, 2000), gastro-oesophageal reflux disease, respiratory disease, and poor oral hygiene (Kaatzke-McDonald, 2003; Zaffuto-Sforza, 2005), along with difficulties with saliva control (Senner, Logemann, Zecker, & Gaebler-Spira, 2004) and taking oral medication (Sheppard, 2006).

Despite reports that people with cerebral palsy aged 30 years and over perceive that they experience changes in their eating, drinking, and swallowing as a result of their ageing process (Balandin & Morgan, 1997), there is no research on the self-perceived impact of dysphagia in this group. Consequently, the types of changes that adults with cerebral palsy may experience in their mealtimes as they age are not well understood. The purpose of this research was to gain an understanding of how adults with cerebral palsy experience and view changes in their eating, drinking, and swallowing, or mealtime management in the past two years. Participants’ severity of dysphagia disorder ranged from mild ($n=2$), moderate ($n=11$), severe ($n=13$), or profound ($n=6$); and current oral diet was regular ($n=19$), soft ($n=2$), puree ($n=7$), or gastrostomy tube feed ($n=3$). The 3 participants on tube feeds had regular oral tastes of puree or soft food. The majority (18) of participants lived in group homes, 5 lived in large residential accommodation, 3 lived with a spouse, 1 with parents, 1 with a sibling, and 4 lived alone. The participants had no difficulty in understanding the questions asked and were able to respond independently and appropriately. All were able to provide clarification of their statements if requested. Profiles of the 15 participants who contributed quotes to this paper are provided in Table 1.

### Method

#### Research design

In-depth interviews with a constant comparative analysis (Creswell, 2007) were selected as the central research strategy for this study. This method is well suited to gaining an understanding of an issue across multiple participants. By drawing interpretations from the data and continually refining the concepts emerging from the data, the researchers can identify topics and draw conclusions about the data (Creswell, 2007).

The qualitative research reported here was part of a larger mixed method study to explore mealtime changes experienced by adults with cerebral palsy that included quantitative clinical measures of severity of signs and symptoms of dysphagia, reported elsewhere (Balandin, Hemsley, Sheppard, & Hanley, 2008). Ethical approval was obtained from (a) the University of Sydney, and (b) two service organisations for people with cerebral palsy.

#### Participants

All participants were recruited through organisations that provide services to people with cerebral palsy. The managers were asked to only recruit people who in their opinion were able to provide informed consent. All the participants gave informed consent to be involved in the study. Fourteen women and 18 men with varying levels of severity of cerebral palsy participated in the project. Participants ranged in age from 30 to 69 years, with a mean age of 45 years. They all perceived that they had experienced changes in their eating, drinking, and swallowing, or mealtime management in the past two years. Participants’ severity of dysphagia disorder ranged from mild ($n=2$), moderate ($n=11$), severe ($n=13$), or profound ($n=6$); and current oral diet was regular ($n=19$), soft ($n=2$), puree ($n=7$), or gastrostomy tube feed ($n=3$). The 3 participants on tube feeds had regular oral tastes of puree or soft food. The majority (18) of participants lived in group homes, 5 lived in large residential accommodation, 3 lived with a spouse, 1 with parents, 1 with a sibling, and 4 lived alone. The participants had no difficulty in understanding the questions asked and were able to respond independently and appropriately. All were able to provide clarification of their statements if requested. Profiles of the 15 participants who contributed quotes to this paper are provided in Table 1.

#### Procedure

**Clinical dysphagia evaluation.** All participants were evaluated by a speech-language pathologist to confirm their clinical diagnosis of dysphagia. The Dysphagia Disorders Survey and the Dysphagia Management Staging Scale (Sheppard, 2002b) were administered to determine severity of swallowing disorder, and clinical signs and symptoms of dysphagia disorder.

**In-depth interviews.** All participants participated in an in-depth interview to describe their experiences of mealtimes. All participants were informed that they would receive a written summary of their data with our interpretation, and they could seek assistance in reading this and making changes or returning comments to us. Seven participants were interviewed a second time to confirm the authors’ initial interpretation of the data and to seek further clarification and expansion of the stories. All
interviews were conversational in manner, lasted from 30 to 90 minutes, and were conducted in a quiet location at the participant’s home \( (n = 7) \), day centre \( (n = 20) \), or workplace \( (n = 4) \); or at the interviewer’s workplace \( (n = 1) \).

**Interview guide.** An interview guide was developed and used to guide the discussion topics. The guide included the opening question, “Tell me about your mealtimes and any changes you have experienced over the past two years,” and probing questions (e.g., “Tell me about what kind of changes you have made to your mealtimes”). Other questions were asked throughout the interview to keep the conversation flowing as naturally as possible and to check and clarify the interviewer’s understanding of the participant’s experience as the interview progressed (Creswell, 2007). Ensuing questions depended upon each participant’s early responses to the opening question; consequently, questions were not uniform across the interviews and not all questions in the interview guide were asked of all participants. The information gathered reflected only the participants’ views about their mealtimes and the changes they had experienced. No information about the participants’ service providers or the services provided in relation to dysphagia assessments and mealtime management was collected.

**Transcription**

Each of the in-depth interviews was audiotaped and transcribed verbatim. Transcription rules were developed to protect participant identity and maximise the accuracy of the transcription. These were as follows: (a) each participant was identified with a pseudonym; (b) the dialogue of the interviewer, participant, and speech interpreter was fully transcribed; (c) any unintelligible speech was labelled “unintelligible word/phrase”; (d) fillers were included and typed orthographically; (e) non-speech utterances, such as laughs, were labelled (e.g., laugh); and (f) names of services, people, and places were replaced with general descriptor labels (e.g., service provider, hospital). Any information that might potentially identify participants was deleted or replaced with descriptor labels (e.g., town, illness, history).

**Data analysis**

**Constant comparative method and coding.** Interview transcripts and field notes were analysed concurrently with data collection. The first three authors identified the main themes occurring in each interview through direct interpretation of the data (Creswell, 2007). They identified the topics in the data, grouped topics to form categories, and created a code label that reflected the theme’s meaning (Creswell, 2007). As further data were collected, the researchers (a) identified new themes, refined the existing themes, and identified relationships between the themes; and (b) developed assertions and generalisations from the data that applied to the changes in the mealtime management that participants experienced. The authors achieved consensus

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**Table 1. Participant profiles**

<table>
<thead>
<tr>
<th>Participant pseudonym (Gender M/F)</th>
<th>Age</th>
<th>Severity of dysphagiaa</th>
<th>Dietb</th>
<th>Method of eatingc</th>
<th>Method of communication in interview</th>
<th>Accommodation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Miles (M)</td>
<td>42</td>
<td>Mild</td>
<td>Regular</td>
<td>Fully dependent</td>
<td>Dysarthric speech</td>
<td>With spouse</td>
</tr>
<tr>
<td>Anne (F)</td>
<td>55</td>
<td>Mild</td>
<td>Regular</td>
<td>Independent</td>
<td>Dysarthric speech</td>
<td>With spouse</td>
</tr>
<tr>
<td>Mary (F)</td>
<td>30</td>
<td>Moderate</td>
<td>Regular</td>
<td>Assisted eating</td>
<td>Dysarthric speech</td>
<td>Lives alone</td>
</tr>
<tr>
<td>Amanda (F)</td>
<td>32</td>
<td>Moderate</td>
<td>Soft</td>
<td>Fully dependent</td>
<td>Dysarthric speech</td>
<td>Group home</td>
</tr>
<tr>
<td>Angela (F)</td>
<td>46</td>
<td>Moderate</td>
<td>Regular</td>
<td>Assisted eating</td>
<td>Dysarthric speech</td>
<td>Group home</td>
</tr>
<tr>
<td>Carl (M)</td>
<td>53</td>
<td>Moderate</td>
<td>Regular</td>
<td>Fully dependent</td>
<td>Dysarthric speech</td>
<td>Large residential</td>
</tr>
<tr>
<td>Penny (F)</td>
<td>64</td>
<td>Moderate</td>
<td>Regular</td>
<td>Independent</td>
<td>Dysarthric speech</td>
<td>Large residential</td>
</tr>
<tr>
<td>Beth (F)</td>
<td>69</td>
<td>Moderate</td>
<td>Regular</td>
<td>Assisted eating</td>
<td>Dysarthric speech</td>
<td>Large residential</td>
</tr>
<tr>
<td>Richard (M)</td>
<td>65</td>
<td>Moderate</td>
<td>Regular</td>
<td>Independent</td>
<td>Dysarthric speech</td>
<td>With spouse</td>
</tr>
<tr>
<td>Tim (M)</td>
<td>35</td>
<td>Severe</td>
<td>Regular</td>
<td>Fully dependent</td>
<td>Dysarthric speech + Interpreter</td>
<td>Group home</td>
</tr>
<tr>
<td>Neil (M)</td>
<td>41</td>
<td>Severe</td>
<td>Regular</td>
<td>Fully dependent</td>
<td>Dysarthric speech</td>
<td>Lives alone</td>
</tr>
<tr>
<td>Monica (F)</td>
<td>44</td>
<td>Severe</td>
<td>Regular</td>
<td>Fully dependent</td>
<td>Dysarthric speech</td>
<td>With sibling</td>
</tr>
<tr>
<td>Jill (F)</td>
<td>54</td>
<td>Severe</td>
<td>Puree</td>
<td>Fully dependent</td>
<td>Dysarthric speech + Interpreter</td>
<td>Group home</td>
</tr>
<tr>
<td>Jacob (M)</td>
<td>43</td>
<td>Profound</td>
<td>Soft</td>
<td>Fully dependent</td>
<td>SGDd</td>
<td>Group home</td>
</tr>
<tr>
<td>Simone (F)</td>
<td>46</td>
<td>Profound</td>
<td>Puree</td>
<td>Fully dependent</td>
<td>CBe</td>
<td>Group home</td>
</tr>
</tbody>
</table>

Note. aAs measured on the Dysphagia Management Staging Scale (Sheppard, 2002b). bAs rated on the Dysphagia Disorders Survey (Sheppard, 2002b; Regular = regular/whole/unrestricted food textures; Soft = mechanical soft/fine chopped/ground food textures; Puree = puree food textures). cAs rated on the Dysphagia Disorders Survey. dSGD = speech generating device. eCB = communication board.
on interpretation of the data at each level of analysis through discussion (Creswell, 2007).

**Verifying and confirming interpretations of the data.** Each participant was sent a two-page written summary of his/her interview with an invitation to amend or add to the information contained in the summary. In addition, seven participants were interviewed a second time. No participants requested changes to their summary. These procedures helped verify that the identification of themes reflected the perspectives of the participants and was reliable, sensitive to the participants’ intended meaning, and plausible (Creswell, 2007).

### Results and discussion

Four main themes arose from the interviews: (1) awareness of changes in mealtime capabilities and experiences, (2) the impact of the experience, (3) mealtime changes associated with the management of the dysphagia, and (4) expectations for the future. Within each of these themes, subthemes were identified. These are presented and discussed below (Patton, 2002), and quotes are provided to support the thematic interpretation.

#### Awareness of changes in mealtime capabilities

Participants represented a range of ages, dysphagia severity, and diet consistencies. Selection criteria included that they perceived that they had experienced changes in their swallowing and mealtime capabilities in the past two years. Changes reported included increased occasions of coughing and choking during mealtimes and when taking medications ($n = 17$), and gradually increasing difficulty with eating, drinking, and managing their independence at mealtimes ($n = 14$). Over half of the participants ($n = 18$) reported that, as a result, they avoided foods that were hard to eat or associated with coughing (e.g., hard, crunchy, or stringy foods).

Angela (46 years) described modifying her usual foods to adapt to her increased difficulties with chewing: “I would have normal meals, like lamb or chicken, pork, it has to be quite tender, if it’s too hard I will choke, cough. They need to be cut up very finely, and I need sauce or gravy with them, because I find it hard to chew . . . and if it’s not cut up finely enough, I will choke.”

Carl (53 years) described experiencing muscle tension that impacted on the ease of eating. He said: “In the last couple of years, I can have a good day, and then a bad day. I was okay today; I can have the same meal tomorrow and probably cough all the way through it. It varies. I think some days I’m more uptight [in] the body muscles.”

All participants reported taking more time to eat and needing to concentrate more on eating now than when they were younger. Monica (44 years) stated: “I’ve got to concentrate more on my eating and swallowing. It goes down the wrong way or something.”

The changes described here have implications not only for the participants but also for their service providers and family members. The participants in this study described the changes that they had made to their diets, and 10 noted they were more reliant on others to support them in these changes by providing appropriate food choices. Furthermore, the changes meant that the participants required more time for both meal preparation and eating the meal.

Amanda (32 years) described needing to take more time when eating in order to enjoy her meal and prevent choking. However, she found that her support staff were not always willing to slow down to a pace that suited her. This resulted in problems during the meal. She said: “I have to take more time . . . Cause I can’t hurry . . . Yeah, and people hurry me on . . . I feel food in my mouth, and I’m choking.”

Eating rapidly, overstuffing, and reduced ability to chew foods are associated with choking risk in people with developmental disability (Sheppard, 2005). Services may need to review the amount of allocated support time as clients experience changes in their eating, drinking, and swallowing abilities.

#### Increased occasions of coughing and choking

Twenty participants described having “choked” on food in the recent past, having felt like food was getting “stuck in the throat” during swallowing, and coughing more easily or more often on food. Beth (69 years) described choking on a piece of meat as being both frightening and embarrassing:

> The other day I was trying to eat a piece of meat and it got caught in my throat. I managed to get it down but it was an effort. It was frightening; thank heavens it went down without me having to go to hospital. I felt awful because everyone was staring at me. I had two staff members trying to get it down, I eventually won, but it was a real fright.

Experiences such as Beth’s highlight the importance of ensuring that there is always someone available who is capable of providing assistance if a person chokes. Choking episodes are a risk factor for asphyxiation in adults with lifelong disability (Samuels & Chadwick, 2006; Sheppard, 2006). Indeed, Sheppard’s (2002a; 2006) observation that
dysphagia symptoms worsen with age indicates that regular monitoring of eating and drinking abilities, including those of adults who previously demonstrated competent swallowing at mealtimes, may be a reasonable health and a safety precaution. In addition, services may need to provide periodic assessment of adults’ mealtime abilities and management given that all the participants in this study described episodes of coughing or choking, yet some did not receive diagnostic testing to determine the cause of the problem, or advice and updated meal plans. 

Adults with cerebral palsy may require information about changes that they may experience and clear guidelines on who to approach if they have concerns that their abilities are changing and require new management strategies.

**Impact of the changes**

*Reduced social interaction during meals.* Changes in swallowing and eating capabilities may impact on social participation. McHorney et al. (2002) noted that the fear of eating that results from dysphagia is a major contributor to loss of well-being for adults with dysphagia. When talking about the suitability of food at meetings and social events, Mary (30 years) said: “Often the food is too difficult to manage . . . so I sometimes don’t eat it.” Other participants who were employed or were members of organisation committees noted this as a particular problem. Richard (65 years) said that he was “dreading” eating in public at work events due to his poor saliva control, recurrent coughing, and choking episodes that he found “humiliating” and “embarrassing.”

Participating in social occasions that involve eating and drinking with work colleagues is an important part of work relationships and team bonding (deRenzo, 1997). Consequently, people experiencing changes in their ability to swallow or increased coughing or choking episodes may benefit from advice, education, and/or intervention on how to manage these issues in the workplace (Cichero, 2006). Such support may assist them to maintain or regain employment independence and manage their dysphagia in a socially acceptable manner (e.g., by requesting soft food options in advance). Adults with cerebral palsy may also require counselling to accept the modifications of food textures or consistency necessary for safe ingestion of a varied diet while reducing the risk for coughing or choking (Cichero, 2006).

*Loss of independence.* Dependence on others for eating and drinking is associated with elevated risk for malnutrition, dehydration, and aspiration pneumonia in older adults (Barczi, Sullivan, & Robbins, 2000). Five participants reported that they had experienced a loss of upper body mobility as they aged. Their reduced mobility was associated with a loss of independence for eating at mealtimes and reduced opportunity to select food themselves. Miles (42 years) said: “Last year I noticed there was a slight change in how I feed myself, my movement in my wrist and my shoulder and my elbow, I’m getting more stiffer. If I’m very tired I can’t do it.” Anne (55 years) also noted that changes in her hand mobility had impacted on her mealtimes. She said “I’ve been very much aware in recent times because my fingers they just don’t operate as well as they used to, and just to pick up cutlery, it’s a different ballgame.” As adults with cerebral palsy lose independence in eating and drinking and their risk for health problems increases, it is important for families and support staff to understand the importance of compliance with dysphagia management recommendations for maintaining health and safety (Chadwick, Jolliffe, & Goldbart, 2003).

Fifteen of the participants noted that increased dependence upon others for assistance during mealtimes increased their concerns associated with health and quality of life. Penny (64 years) described her “greatest fear” as being the loss of the ability to feed herself “because while you can feed yourself you can gauge what you, how much you put on the spoon, but when you are being fed by somebody else they gauge it for you.” Nonetheless, as her need for assistance during meals has increased recently, she said: “Sometimes just now I say ‘can you give me help with the last bit.’”

Some participants accepted a loss of independence and a lack of control in selecting food with equanimity. Beth said without rancour: “Well, [I] used to pick what I like, I can’t do that anymore, I just get given what they think is best.” Penny said: “Don’t ask me why [my diet has changed] but they seem to advise it, so you just do what you’re told really.” However, not all participants were so accepting. Richard said: “The understanding of what I like—that’s a lot, the understanding—you’ve got to be able to enjoy your meal. Not to be told ‘you can’t have that,’ ‘you can’t have that,’ ‘it’s not for you to eat.’” Beth and Penny’s resignation and Richard’s resentment emphasise the need to involve all stakeholders in the development and modification of mealtime management plans. Case managers may have a role in ensuring that there is a forum for this to occur (Balandin, 2007).

*Other health concerns.* More than half of the participants (*n* = 17) experienced reflux and gastrointestinal...
problems (e.g., constipation and diarrhoea), saliva control difficulties, and weight management problems. These results support previous research findings that gastro-oesophageal and gastrointestinal disorders are prevalent for adults with dysphagia and lifelong disability (Kaatzke-McDonald, 2003; Sheppard, 2006; Stewart, 2003; von Königsmark, 2000).

Tim (35 years) illustrated how changes in his eating have resulted in several problems that may require intervention from more than one health professional: “I used to be able to eat a lot faster, but now I’ve found out I’ve got reflux. So I have to slow down a bit. If I get bad reflux, I get asthma . . .”.

Five participants described having problems maintaining a healthy weight, either through being overweight or underweight. Penny said:

I’m a diabetic so I’ve had to cut down on bread, and gravy. I’ve found out what the fatty things are, like pies, sausage rolls, pastry, BBQs, these are the things I’ve got to try and get around . . . I find it annoying when the staff don’t know, I’m checking for the staff, not for myself.

This highlights not only the importance of ensuring adequate nutrition and maintaining a healthy weight in adults with a developmental disability (Stewart, 2003; von Königsmark, 2000), but also the need for staff to be knowledgeable about diet and nutrition.

Impact of the experience

All participants described psychosocial consequences resulting from the changes they experienced at mealtimes in the past two years. These included emotional responses to the changes, communication barriers and concerns, difficulties in their relationships with their families and carers at mealtimes, and the reactions of the general public towards their mealtimes.

Emotional responses to the changes. Participants described a range of feelings associated with their difficulties with eating and changes in their eating. These included frustration at the loss of preferred foods, fear of coughing or choking, fear of future deterioration in mealtime abilities (McHorney et al., 2002), and embarrassment. They noted the importance of a good gag reflex and the ability to cough. Anne said:

I have [choked] a couple of times. I thought I was choking to death, but it’s a matter of getting it back up again. But the last time I remember doing it was a bit of egg or peas or something like that. It’s a very frightening experience.

In addition to fear, six of the participants reported feeling anger or frustration in association with their difficulties swallowing, mealtime management practices, and having their diet changed. These feelings arose from perceived lack of choice or control over foods to be included in their diets. Penny said: “It’s harder, when you gotta watch other people eat what you’d like.” Self-determination enhances quality of life for people with intellectual disabilities (Bowling & Gabriel, 2004; Lachapelle et al., 2005) and may warrant further exploration in relation to dysphagia.

Relationships with family and carers. Half of the participants stated that their interactions with family and carers over mealtime practices or decisions impacted upon their enjoyment of meals. For eight of the participants, eating with family members meant that they maintained access to preferred foods that they were not allowed to eat at the disability service. For others, mealtimes and their dysphagia were a cause of friction between them and their family members. The cause of this friction was specific to the individual as the following quotes about time taken over meals indicate. When explaining that she was a slow eater, Amanda said: “everybody at our house get angry” [when she eats slowly]. In contrast Mary said: “Mum gets annoyed, it irritates her. She gets annoyed that I don’t follow advice from the speech pathologist and my neurologist, not to rush.”

Our results indicate that some parents of adults find it difficult to relinquish control over their adult son or daughter’s mealtime management. This is a source of irritation for adults with dysphagia and may also contribute to their feelings of anxiety about mealtimes. Symptoms of dysphagia may be early indicators of the presence of a child’s developmental disability, and parents may find mealtimes with their child with dysphagia to be stressful and unpleasant (Morgan & Reilly, 2006; Reilly & Skuse, 1992). Therefore, it is possible that parents’ early negative experiences in feeding their young children with cerebral palsy continue to influence their interactions with their adult sons and daughters.

Participants whose speech was dysarthric (n = 20) reported that difficulties associated with both talking and eating meant that they either had to “talk” or “eat” at meals. This impacted upon the social aspects of mealtimes. Furthermore, although two of the three participants who used speech generating
At the same time. Monica said:

stretched when staff needed to assist many people

Positive relationships with staff were sometimes

changes for mealtimes. Angela reported her sup-

the difficulties for the adult when there are staff

familiarity of the adult with the support person and

could be a trial. This underscores the importance of

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mealtimes to be a social and enjoyable experience. In

good relationship with their support staff in order for

participants who relied upon others for assistance during

their meals spoke about the importance of having a

good relationship with their support staff in order for

mealtimes to be a social and enjoyable experience. In

the absence of this good relationship, mealtimes

could be a trial. This underscores the importance of

familiarity of the adult with the support person and

the difficulties for the adult when there are staff

changes for mealtimes. Angela reported her sup-

port staff showing frustration with her need for

assistance:

Even though I have a mealtime assistance plan and most

of them know how my meals should be cut up, some

people still find it hard to cut it up small enough for

me . . . I think some people get impatient.

Positive relationships with staff were sometimes

stretched when staff needed to assist many people

at the same time. Monica said:

I have a mealtime plan, but no-one looks at it. I think at

work they’ve got a lot to do at lunchtime, and the staff

wants to get it over and that’s it. That’s not good, I don’t

like it.

Mealtimes are a culturally important environment

for fostering social relationships. Older people

consider that good social relationships contribute

positively to a good quality of life (Gabriel & Bowling, 2004). A good relationship with family

and support staff is important not only for the safety

and enjoyment of the meal by adults with cerebral

palsy and dysphagia, but also for independence,

dignity, and recognition of adult status. Maintaining

a good relationship may be particularly difficult if the

adult is or becomes dependent on family and support

staff for assistance with eating and drinking and meal

preparation. In order to understand why certain

management guidelines are appropriate, it is im-

portant that not only the adult with cerebral palsy but

also families and support staff are involved in the

dysphagia management decision-making process

(Chadwick et al., 2003). The involvement of all

stakeholders is more likely to ensure that the adults

with cerebral palsy have their needs and preferences

met, and that the mealtime environment is safe and

enjoyable. Providing a forum for all stakeholders to

discuss their wishes and concerns facilitates the

involvement of the adult with cerebral palsy in

developing an individual mealtime management

plan. Speech pathologists have a role in ensuring

that the person with dysphagia, the family, and the

staff are aware of communication strategies that can

be used to facilitate safe and enjoyable meals. Service

providers who assist at mealtimes may need assis-
tance in learning how the person with dysphagia can

best communicate their wants and needs during the

meal.

Management of the dysphagia

Adults with lifelong dysphagia who are experiencing

changes in their mealtimes due to ageing are a unique population (Sheppard, 1991). They may be

facing the challenge of changing an already modified

mealtime; for example, by moving from chopped to

mashed or pureed food. Therefore, their dysphagia

should be documented and monitored regularly

across the life course to identify and appropriately

manage any age-related changes that occur (Shep-


In this study, the most common change made to

the diet was that of avoiding problematic foods. Carl

said: “I won’t attempt to eat what I ate before. Like

really crispy bacon, anything that’s rough, coarse

texture, I wouldn’t attempt peanuts now.” Very few

participants reported modifying the food texture to a

softer consistency to reduce coughing or choking.

Indeed, all but 1 of the 11 participants with moderate

dysphagia and just 7 of the 12 participants with

severe dysphagia had maintained a regular diet, some

with a narrower range of foods as a result of changes

in swallowing.

Neil (41 years) had not excluded foods that made

him cough but needed more time to eat. He said: “I

don’t have any problems, but sometimes when I’m

tired it’s a bit hard to eat, in the afternoon. Dinner is

a bit hard, the meal takes longer.” The reluctance to

change to a softer consistency expressed by these

individuals may indicate that clinicians and support

staff need to spend time discussing food options with

their clients rather than assuming people experien-
cing dysphagia will automatically comply with a

recommendation to modify food or drink consis-
tency. Adults with dysphagia who experience

changes in their swallowing or who are anxious

about loss of independence may benefit from

counselling to help them deal with their fears and

comply with the recommendations while maintaining

their self-esteem. In the present study, no partici-

pants mentioned having any form of counselling and

only one participant noted that she had seen a speech
Involvement in decisions about mealtimes. Although some participants like Beth reported being resigned to have someone make decisions about their meals for them (n = 9), 3 of the 7 participants on a puree diet had experienced the change from a regular to a puree diet as being sudden, radical, and unwelcome. These participants perceived this change as unnecessary and imposed by service providers. They stated the change had made little difference to their enjoyment of meals substantially. Simone (46 years) said she felt “angry” about changes to her diet. Jill (54 years) said: “It’s bloody awful—because I’m on a puree diet, and I hate it. I hate it.” These participants expressed anger that they were not permitted to eat “normal” texture foods. They took responsibility for their diet by reverting to their preferred diet on their visits to family members or friends who did not impose the restriction. Jill said: “When I go to (my sister’s) house, or like at my aunties—I have spaghetti, lasagne, cake.” Nevertheless, a willingness to oppose service providers’ “expert opinion” openly was rare. Only 2 of the 32 participants took full responsibility for all decisions made about their mealtimes. Monica explained how she would respond to future changes in her dysphagia: “In the future it looks as though I might have to have my meals pureed. Well you’ve got to eat, and you’ve got to eat in an easier way that you can. I’ll just see how it goes.”

Participants complained about not being involved in decisions about their meals. Decision- and choice-making are important components of managing health and dysphagia in older adults (Barczi et al., 2000). Adults with cerebral palsy and dysphagia may be at risk of not being involved in the management of their dysphagia for many reasons, such as in not being invited to the planning meeting, an unwillingness to participate in the change management process, a learned dependency on others managing their health, or having limited experience in making decisions and choices about health care. Further research is needed to explore how best to manage mealtime change and dysphagia in this population. A good relationship that involves true collaboration between all stakeholders (Patel, Cytryn, Shortliffe, & Safran, 2000) may help minimise risk and at the same time ensure that adults with cerebral palsy or, if necessary, their families or support staff, make an informed choice about individual management. Service providers and families need to respect the wishes of the adult with cerebral palsy and attempt to reach a mutually satisfactory solution.

Expectations for the future

All participants discussed their future mealtime management. Participants feared further deterioration of their swallowing and subsequent loss of function and/or independence, as demonstrated by the following quote from Carl:

Well, going by what I’ve seen from other people who have aged with cerebral palsy, I suppose somewhere down the track I’ll probably end up on a special diet. Maybe soft food or, at worst, puree. A person I lived with, he’s aged 63, and he used up until about four years ago, he was on a standard diet, and now he’s on puree diet and thickened fluids. So, I dare say that could happen to me, somewhere down the track. I’ll cross that bridge when I come to it. I try not to get too worried about the future. I could continue on the way I’m going for years to come, so I’m not, I’m not all that particularly worried about it.

Nine participants were concerned that deterioration in eating and drinking ability would result in the need for full assistance for eating, being institutionalised, or needing tube feeds. Jacob (43 years) acknowledged that if his abilities continued to deteriorate he would need to have “my food put in my stomach” (i.e., tube feeding), a prospect that “frightened” him. However, most participants (n = 24) hoped that their swallowing ability would remain stable in the future, as Stella said: “I hope to continue as I am.”

Clearly, service providers have a role in ensuring that people at risk of dysphagia have regular reviews and intervention that may help maintain eating and drinking skills. Yet to date, there are few reports on the efficacy of intervention in maintaining or prolonging mealtime abilities. Given the importance of seating and positioning, independent eating skills, nutrition, medication side effects, and comorbidities when considering a mealtime plan, we would argue that dysphagia assessment and reviews should be both multidisciplinary and collaborative.

Clinical implications

As discussed above, the results of this study have clinical implications for service providers working with adults with cerebral palsy. Service providers need to be aware that adults with cerebral palsy who are ageing with dysphagia require regular reassessment of their dysphagia and reviews of their mealtimes by a team that includes a speech pathologist about the increase in her symptoms of dysphagia.
pathologist to accommodate any changes they are experiencing. The adults themselves require information and support about their own dysphagia and how to manage it. In addition, they may benefit from counselling to help them accept and manage changes that they experience. Our results indicate that adults with cerebral palsy are concerned about the risk of being excluded from the short- and long-term decision-making about their mealtimes. Consequently, there is a need for greater effort to include them in discussions and decisions about meals. Adults with cerebral palsy may also need communication interventions to ensure that they have a satisfactory method of communication both during meals and in discussions about their mealtimes (Hemsley & Balandin, 2003). This is important not only for safety and independence, but also to support social interaction during mealtimes. Adults who experience a loss of function and independence during mealtimes will require additional assistance from family and/or support staff. Health professionals will need to provide these adults, support staff, and family members with information, education, and training to facilitate safe and enjoyable mealtimes.

Limitations and directions for future research

The results of this small qualitative study need to be interpreted with caution, as the findings may not apply to all adults with cerebral palsy. Furthermore, only the participants were interviewed; we did not attempt to verify the participants’ perspectives by reviewing their case notes or interviewing their service providers. Nevertheless, each participant was interviewed independently and many of the issues discussed were common to participants within and across different organisations.

Due to time and funding constraints we were able to interview only seven participants a second time. Although these second interviews indicated the information was reliable and that our interpretation of the data was accurate, we acknowledge that interviewing all the participants twice would have strengthened the data collection process and our interpretation of the data.

A larger group study is needed for further exploration of mealt ime changes that occur in adults with cerebral palsy. This should include an examination of the impact of dysphagia on their quality of life, health, and well-being across the life course and how best to include them in collaborative decision-making about dysphagia management. A longitudinal study would allow the changes in mealt ime experiences of this group of adults to be further investigated and understood.

Speech pathologists are trained to provide dysphagia assessments and to develop mealt ime plans, often in collaboration with a dietician. Our results indicate that research is needed to examine the qualifications and level of understanding of dysphagia of those who provide mealt ime support to adults with cerebral palsy on a daily basis. This research should include the views of service providers about mealt imes for adults with cerebral palsy, their perceptions of whether their clients are experiencing changes in their eating and drinking abilities, and what they perceive would be needed to improve dysphagia services to adults with cerebral palsy. Furthermore, research is needed to explore how best to include people with dysphagia and their family members, if appropriate, in decisions about dysphagia management and interventions.

Conclusion

Adults with cerebral palsy aged 30 years and over are known to experience changes in their eating, drinking, and swallowing (Balandin & Morgan, 1997, 2001). To our knowledge, this is the first report on their perceptions of such changes. The information provided by this group may be important when considering mealt ime management strategies for others with lifelong disability and chronic dysphagia, as well as those who are at risk for dysphagia as they age. In a population of adults who already have dysphagia and are on modified diets, any changes in eating capabilities, increase in coughing and choking, weight loss, or changes in respiratory health may indicate the need for further and regular review. Periodic reassessment will facilitate the identification of problems and the development of additional measures that might reduce the symptoms of dysphagia and increase health, safety, and comfort during mealtimes. Mealtimes are important not only for adequate nutrition but also for social interaction. Ensuring safe and dignified mealt ime management that maximises the independence and respects the wishes of adults with lifelong disability is a challenge that all stakeholders need to address collaboratively.

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