



CPLOL – Prevention Commission

Dysphagia Review 2004-2005

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1 Executive Summary

Introduction

The provision of services for individuals with dysphagia has been of interest to the CPLOL representatives for some time. A review of services across the member states was therefore proposed as a prevention commission project.

The number of people referred to speech and language therapists (and the effect on the provision of speech and language therapy services) with dysphagia has been increasing throughout Europe.

There is discussion about the roles of health professionals in dysphagia.

The timing of training for the diagnosis and treatment of dysphagia is also under discussion.

Aim of the project

The main purpose of the project is to share information about dysphagia services in Europe.

It attempts to reflect some of the practices and training of speech and language therapists/logopedists working with dysphagia. It does not attempt to be a rigorous piece of research with robust statistical evidence.

Rationale

For the purposes of the review of dysphagia services across Europe, the WHO (World Health Organisation) definition was interpreted as follows

1) Primary prevention

- informing carers, medical staff, other professionals
- helping patients and families to cope/with. understand about dysphagia
- explaining to other professionals about the problem of dysphagia, recognition/identification
- teaching other professionals about dysphagia management

2) Secondary prevention

- identification and screening of dysphagia
- reducing the prevalence of aspiration pneumonias/cost of medication/number of bed days spent in hospital

3) Tertiary prevention

- helping people regain some swallowing function and/or helping them manage the dysfunction

Background

Dysphagia has been described as difficulty moving food from the mouth to the stomach. Recently clinicians have widened this definition to include, behavioural, sensory, motor acts, cognitive awareness and visual recognition of food. Swallowing disorders occur in all age groups, preterm babies to the elderly. The problems may present acutely or worsen slowly over time.

Patients may be very aware of their problem or completely oblivious.

66% of patients in long term care and 30% of stroke patients may be dysphagic. As many as 33% of patients in acute care, 66% of patients in long term care and 30% of stroke patients may be dysphagic.

The referrals of patients with dysphagia led to services no longer having the resources to respond to patients with communication problems e.g those with dysphasia.

Method

A questionnaire, in English and French, was designed by a sub-group of the prevention commission.

The questions sought to reveal; the work setting, whether the slt worked alone, with other slts or in a multidisciplinary team, the percentage of the workload devoted to working with dysphagia, the types of assessment used, whether treatment was available, whether the problem of dysphagia was recognised by health professionals, whether training was included in undergraduate studies, whether CPD was available.

Results

The number of responses from each member state varied tremendously. This sometimes represented the level of involvement that speech and language therapists / logopedists had in working with individuals with dysphagia. In some cases a representative of the professional association responded on behalf of the members.

Therapists working with individuals with dysphagia worked in a variety of settings; hospitals, children's hospitals, rehabilitation centres, nursing homes, the patient's own home. The greatest number of therapists, over 50% worked in hospital settings.

The majority of respondents spent between 25 – 50% of their time working with individuals with dysphagia, but there were some therapists who spent between 75% and 100% of their time doing so.

Many respondents, between 40 and 50% in some countries, reported that the problem of dysphagia was not fully recognised or acknowledged by doctors and/ or health professionals.

Whether training enabling the therapist to work with dysphagic individuals competently is included in undergraduate education varies across the member states. Some countries, for example, the Netherlands, apparently have moved to providing this level of training, in other countries many therapists felt that the training they had had was insufficient to practise.

Discussion

In the majority of countries speech and language therapists/logopedists work with individuals with dysphagia and the amount of this work is increasing. In many of these countries knowledge concerning the assessment and treatment of dysphagia is taught at undergraduate level. However, in Denmark, for example, very few speech language therapists/logopedists (slts) work in dysphagia. Dysphagia was originally the province of the Occupational Therapists and not part of the education of slts.

From the information provided by the respondents it would seem that services for individuals with dysphagia are at different stages of evolution across the European Union. Also that in the majority of the member states it is the speech and language therapists/logopedists who take a pivotal role in assessing and treating/obtaining treatment for individuals with dysphagia, that is, cases of dysphagia other than those with a pathology requiring surgery.

Dysphagia Review 2004-2005

2 Introduction

The provision of services for individuals with dysphagia has been of interest to the CPLOL representatives, and their national speech and language therapy associations for some time. A review of services across the member states was therefore proposed as a prevention commission project.

At the CPLOL meeting held in Malmö, October 2003, the proposal to investigate the services for individuals with dysphagia, and the training of speech and language therapists to work with those with dysphagia, in the member states of the European Union, was accepted.

The number of people referred to speech and language therapists (and the effect on the provision of speech and language therapy services) with dysphagia has been increasing throughout Europe.

There has also been a great deal of discussion about the roles of the professionals involved with dysphagia and the interface with other professionals concerning the diagnosis and management of individuals with dysphagia.

The following were the agreed aims for the project:

- ❖ To share information about dysphagia services in Europe
- ❖ To look at the training for the diagnosis and treatment of dysphagia
- ❖ To look at the role of other professions in dysphagia
- ❖ To look at the slt role in teaching other professions about screening by nurses, assistants etc.

It attempts to reflect some of the practices and training of speech and language therapists/logopedists working with dysphagia. It does not attempt to be a rigorous piece of research with robust statistical evidence.

3 Rationale for the dysphagia review as a CPLOL prevention commission project

a) How the study on dysphagia fits into the concept of prevention?

Functional/practical application

Adult patients

- intervention prevents people from dying unnecessarily from aspiration pneumonia

Child patients

- intervention prevents failure to thrive, severe undernourishment, poor/slow development
- preparation/stimulation of oro-motor development helps to prevent difficulties later with oral intake and speech development

b) How does dysphagia fit the criteria of the WHO / CPLOL definition of prevention?

The **WHO (World Health Organisation) 1948** definition of prevention identifies three successive stages concerning the prevention of pathologies, therapy and, if possible, social re-integration of patients:

Primary prevention: covers all activities to “reduce the instances of illness in a population and, as far as possible new cases appearing”. In speech and language therapy this mainly covers information and health education, in addition to training of those involved with the population in question.

Secondary prevention: activities aimed at “reducing the prevalence of an illness and its duration”. This relates to identification and early screening in speech and language therapy.

Tertiary prevention: aims to “reduce the incidence of chronic incapacity or recurrences in a population, thus to reduce the functional consequences of and illness”. In speech and language therapy this relates to care provided, i.e. therapy, various rehabilitation techniques designed to assist the patient to return to educational, family, professional, social and cultural life.

For the purposes of this review of dysphagia services across Europe, the WHO definition was interpreted as follows:

1) Primary prevention

- informing carers, medical staff, other professionals
- helping patients and families to cope with / understand about dysphagia
- explaining to other professionals about the problem of dysphagia, recognition/identification
- teaching other professionals about dysphagia management

2) Secondary prevention

- identification and screening of dysphagia
- reducing the prevalence of aspiration pneumonias/cost of medication / number of bed days spent in hospital

3) Tertiary prevention

- helping people regain some swallowing function and/or helping them manage the dysfunction

4 Background

Dysphagia has been described as difficulty moving food from the mouth to the stomach [1]. Recently clinicians have widened this definition to include, behavioural, sensory, motor acts, cognitive awareness and visual recognition of food [2]. Swallowing disorders occur in all age groups, preterm babies to the elderly. The problems may present acutely or worsen slowly over time.[3].

Patients may be very aware of their problem or completely oblivious.

A more functional definition of dysphagia is that it is a condition resulting from an interruption in either eating pleasure or the maintenance of nutrition and hydration. It is recognised, by health care providers, that the maintenance of good health is dependent on adequate (oral) nutrition.

Disorders of the swallowing mechanism can result from a broad spectrum of disabilities. It is commonly a symptom of underlying disease, usually of a neurogenic or mechanical origin.

The consequences of dysphagia when it results in aspiration (entry of food or liquid into the airway below the vocal cords) are very serious. Dysphagia may result in pneumonia, malnutrition and dehydration.

a) Prevalence of dysphagia

Groher and Bukatman (1986) looked the prevalence in 2 large teaching centres and found that almost one third of those hospitalised were dysphagic. Cherney (1994) found that 32% of patients admitted to a rehabilitation institute were dysphagic (secondary to stroke). In Wade and Hewer's study, 1987, of patients admitted for stroke 45% evidenced some swallowing abnormality.

Research has shown that approximately;

- 40% of people in nursing homes have swallowing problems
- 45% of people over 75yrs have some swallowing problems

Oxford Research, on behalf of the European Study Group for the Diagnosis and Therapy of Dysphagia and Globus (EGDG), carried out a survey in 1999. Novartis Consumer Health funded the research with the focus was on elderly care. (The EDGD is an international society with over 30 members from a variety of specialties across Europe and the U.S.A. who are involved in the diagnosis and treatment of dysphagia.) The study stated that as many as 33% of patients in acute care, 66% of patients in long term care and 30% of stroke patients may be dysphagic.

b) Speech and language therapy and dysphagia

Dysphagia has become an integral part of the speech and language therapy caseload. During the past 10-15 years referrals of individuals with dysphagia to speech and language therapists (slts) in the UK increased at, what may be considered "an alarming" rate. Some services were overwhelmed by these referrals. The referrals of patients with dysphagia led to services no longer having the resources to respond to patients with communication problems e.g those with dysphasia.

Evidence from all the European member states (at the time of the project) revealed concern about the increasing workload of referrals of individuals with dysphagia and the need for increasing numbers of slts to be competent in assessing and treating dysphagia.

There is a continuing debate about "who" (which health professionals) should provide/be involved in the service to individuals with dysphagia, should the slt have the pivotal role.

A further important consideration was; what training was necessary for competence to practice? When should this training take place?

It is interesting to note that in the "**Definition and areas of competence**" of the orthophoniste/ logopedist/speech and language therapist identified in the CPLOL report "**1988 –1998 10 years of activity**" dysphagia is not mentioned in the core work of speech and language therapists/logopedists, but later "feeding and swallowing therapy" is included in the list of areas that speech and language therapists provide treatment. This probably reflected the situation at the time, i.e that at the beginning of

the period, 1988, there was less involvement by speech and language therapy services in dysphagia diagnosis and management than was the case in 1998.

The American- Speech- Hearing Association (ASHA) states that the practice of speech-language pathology includes providing services for individuals with swallowing and feeding disorders. (ref: ASHA "Scope of practice in speech-language pathology "). ASHA further emphasises the role of the slt in educating the healthcare team regarding this subject.

c) Outcome of slt intervention in dysphagia

Some research has shown that swallowing rehabilitation can be successful in returning over 80% of oropharyngeal dysphagic patients to oral intake. [4]

5 Method

A questionnaire was designed by a sub –group of the prevention commission. The questionnaire was provided in English and French as the official languages of the European Commission. The questionnaires were sent to CPLOL representatives of all the member states (as at 2004) who distributed as appropriate to members of their professional organisations.

Some of the representatives translated the questionnaire into their own language.

For the purposes of the questionnaire all aspects of feeding and swallowing behaviour were included.

Questions included -

- place of work, whether the slt worked singlehanded, with slt colleagues or a multidisciplinary team
- the percentage of the slts workload devoted to dysphagia
- the type of assessment used, who screened/assessed individuals with dysphagia
- whether the problem of dysphagia was recognised
- whether treatment was available
- whether training concerning dysphagia was included in undergraduate studies, what slts needed in order to be considered competent to work with dysphagia, if there was CPD

The member states involved were as follows:

Austria	Greece
Belgium	Italy
Cyprus	Luxembourg
Denmark	The Netherlands
Eire (Ireland)	Norway (observer member)
Estonia	Portugal
Finland	Spain
France	Sweden
Germany	Switzerland (observer member)

(i) Purpose of questionnaire

The discussions revealed a need to identify how each of the slt services in the EU manage dysphagia referrals, i.e.

- what is done for individuals with dysphagia
- what is not done
- what needs to be done
- where dysphagia services occur

Address issues such as

- use of/access to VFSS/FEES (videofluoroscopy swallow study/fibre endoscopic evaluation of swallowing)
- how and when dysphagia is taught to slts/logopedists

Identify

- what professionals are involved in dysphagia care
- what is the role of the speech and language therapist (vis a vis the other professionals)
- some of the problems created by the numbers of referrals

(ii) Responses:

Country (member state and observer member) and number of responses.

Austria	Belgium	Cyprus	Denmark	Eire	Estonia	Finland	France
20	3	1	1**	41	5	25	7

Germany	Greece	Italy	Luxembourg	Netherlands	Norway
84	2	2	2	8	3

Portugal	Spain(Madrid)	Sweden	Switzerland	UK
0	4	17	3	*

Note: Some countries decided to send in a few responses to represent the situation concerning services for dysphagic individuals, others countries requested responses from a large number of their membership.

* The UK

- A few responses from UK speech and language therapists were used to test the questionnaire. There are no responses from the whole of the UK as from the other countries.
- This review co-incided with a large nationwide review of dysphagia services requested by the Department of Health in the U.K.: *“Development of a competency-based inter-professional consensus in the management of swallowing difficulties (dysphagia)”*
- The main author of this review has worked in a number of settings with dysphagic patients and continues to work with dysphagia.
- There are services for individuals with dysphagia in hospital, special school, child development centres, community hospitals etc. all over the U.K.
- During the 1990’s the number of referrals of dysphagic individuals in some hospital settings increased so much that the focus was on dysphagia and therapists had little time for dysphasia and dysarthria etc.

** Denmark: one response from the secretary General of CPLOL summed up the situation concerning dysphagia in the country (see later)

Portugal: Although discussions with representatives from Portugal at meetings had revealed concerns about dysphagia services and speech and language therapy, no completed questionnaires were received.

6 Results

(i) Working arrangements

The questions at the beginning of the questionnaire attempted to reveal what type of hospital, clinic etc the speech and language therapists/logopedists were working in and whether the speech and language therapists/logopedists (slts) were working single-handed, with other speech and language therapists / logopedists or with a multidisciplinary team.

Respondents in 8 of the countries worked in multidisciplinary teams. Respondents in 10 of the countries worked with dysphagic individuals in more than one setting. In ten of the countries respondents worked single-handed with individuals with dysphagia.

In some countries speech and language therapists / logopedists work privately but are recognised by and registered with the state health system. Therapists, nevertheless work in collaboration with others in certain settings.

Between 15 and 30% of respondents in some countries (7) were the only speech and language therapist/logopedist in the setting.

(ii) Settings where work with individuals with dysphagia is carried out

Perhaps predictably most of the work carried out with dysphagic individuals takes place in hospitals, general hospitals, University hospitals and children's hospitals. Between 50% and 70% of respondents worked in hospital settings.

In contrast, very few respondents worked with individuals with dysphagia in nursing homes or in the patient's own home.

Therapists working with dysphagia often worked in several settings, particularly the respondents in Italy, the Netherlands, Cyprus, Belgium and Greece.

Therapists were more likely to work with dysphagia in rehabilitation centres in Norway, Finland, Germany and Austria.

(iii) Percentage of time spent working with dysphagia

The question attempted to determine the percentage of their working time therapists spent working with dysphagia.

In 3 of the countries 50% of the respondents spent 50-75% of their time working with dysphagia (Italy, Luxembourg and Switzerland). In eight other countries between 5% and 38% of respondents spent between 50-75% of their time working with dysphagia.

In 4 countries between 5 and 20% of the respondents spent between 75% and 100% of their time working with dysphagia.

The majority of the respondents spent 25 to 50% of their working time with dysphagia. This represented all the respondents in Greece and Cyprus, 50% of those in Norway and Luxembourg, between 30% and 60% in 8 other countries.

(iv) Recognition of the problem of dysphagia by doctors and other health professionals

The responses frequently indicated that the recognition of the problem of dysphagia by doctors and other health professionals had represented a great deal of education, persuasion on the part of the speech and language therapists and that at the time of responding to the questionnaire a great deal of work had been done and that finally the problem was being acknowledged.

In 4 of the countries it was still considered by 50% of the respondents that these professionals did not recognise the extent of the problem. In one country, Greece it was still felt that the majority of these professionals were ignorant about dysphagia. In 4 of the countries between 20 and 30% of the respondents felt that the problem of dysphagia was not fully recognised.

In 4 other countries 40% of the respondents felt that dysphagia was not fully acknowledged.

(v) Types of assessments

FEES (Fibre endoscopic evaluation of swallowing) was used in about 45% of the countries, but often only by a small number of respondents.

VFSS (videofluoroscopy swallow study) was available and used in most countries with the exception of Estonia and Spain.

Pulse oximetry was used in 10 of the countries.

Auscultation was used in 11 of the countries; by more than 50% of the respondents in Eire, Belgium, France, Italy and Luxembourg.

(vi) Availability of treatment for dysphagia and where it takes place

Only about 50% of the respondents in 6 of the countries offered therapy, around 60% of respondents in 3 other countries offered treatment and between 80% to 100% of respondents in 5 other countries offered treatment. In 1 country, Estonia, the majority of treatment offered was for children with dysphagia with little therapy offered to adults.

(vii) Availability of advice to carers and other professionals

According to the respondents, the majority of countries provide some teaching, advice etc. to other professionals working with individuals with dysphagia. From the evidence from therapists in Belgium and France this advice was less readily available.

(viii) Continuing professional training and undergraduate training of speech and language therapists to work with individual's with dysphagia

In the U.K. dysphagia used to be seen as a specialist area with training only being delivered at post registration (post qualification) level. Now a basic training is included at undergraduate level.

Replies from Estonia, Luxembourg and some from Eire stated that to pursue advanced courses in dysphagia it was necessary to travel to another country.

One of the respondents from the Netherlands suggested that there should be master classes as continuing education for those speech and language therapists/logopedists working a lot with clients with dysphagia. In the Netherlands the majority of the respondents were taught to work with dysphagia during their training

In Austria although 40% of respondents confirmed that they received dysphagia training as an undergraduate and others commented that they did not feel that this training was sufficient to practise.

In the U.K., in 1999, the RCSLT (Royal College of Speech and Language Therapists) asked all speech and language therapy training courses to modify their curricula so that students could be given the opportunity to acquire some basic theoretical knowledge and skills in dysphagia during their undergraduate studies.

The majority of the Dutch, Swedish and Italian respondents had undergone undergraduate training that was considered adequate to practise.

The majority of the Irish, Finnish and German respondents did not feel that any undergraduate training they had had was sufficient to practise and had attended other specific training courses in order to be competent to work with dysphagic individuals.

In Estonia, Spain and Cyprus there is no undergraduate dysphagia training.

7 Discussion

As previously commented, the number of responses from each member state varied tremendously. The level sometimes represented the level of involvement that speech and language therapists/logopedists had in working with individuals with dysphagia. In Greece and Denmark, for example, the professional association provided the examples as representative of the services in their country.

In Denmark, for example, very few speech language therapists/logopedists (slts) work in dysphagia. Dysphagia was originally the province of the Occupational Therapists and not yet part of the education of slts. The slts who work with dysphagia were described as doing so because of "coincidental" reasons and/or "personal" interest. In some hospitals and rehabilitation centres advice is given to head and neck cancer patients, and slts working in special kindergartens / nurseries with children with

cerebral palsy work on chewing and swallowing. Some research is being carried out and dysphagia is regarded as probably a growing field.

In Finland dysphagia is part of the basic training of speech and language therapists/logopedists (slts). However, it is not expected that all slts will be involved in this field. The slt is part of the multidisciplinary team working with dysphagia but plays the pivotal role. The slts working with dysphagia tend to work mainly in the University hospitals.

In Sweden dysphagia knowledge is part of basic training. It is common for slts working in hospitals to be involved with patients with dysphagia. Slts are known as the profession taking the main role with individuals with dysphagia. The dysphagia workload is increasing.

In Eire working with individuals with dysphagia is a major part of the role of those speech and language therapists working with adults, to such an extent that there is no longer time for slts to deal with communication difficulties. Dysphagia is part of some slts paediatric caseload.

In Estonia dysphagia is considered to be part of the speech and language therapist/logopedist (slt) role, but there is only one slt working with acute dysphagia in paediatrics.

In Germany, DBL (the association of speech and language therapists/logopedists) has promoted the teaching of dysphagia as part of initial training. Specialists carry out work with individuals with dysphagia.

In Austria there are lots of speech and language therapists/logopedists involved in working with adults and children with dysphagia. The speech and language therapist/logopedist takes the pivotal role.

In Cyprus dysphagia is a relatively new field but demanding more and more attention by speech and language therapists/logopedists in hospitals and "special schools".

In the Netherlands there are guidelines for speech and language therapists / logopedists working with dysphagia. They work closely with dieticians. A systematic review has recently been carried out.

In Portugal speech language therapists/logopedists are becoming more involved in working with dysphagia in all settings.

In Greece the professional association has a working group looking into dysphagia and the role of the speech and language therapist / logopedist.

One question raised by a member state that was not addressed was, "who pays for the nutritional supplements". This is a very relevant question as speech and language therapists reveal the need for these to be used, dieticians may recommend the use of nutritional supplements and advise the medical staff of the need to prescribe some supplements but in some countries the onus may be on the patient to pay for them.

Not all countries are like the U.K. where children's prescriptions are free, others who need supplements will probably get their prescriptions free as they will probably be considered "chronically" sick or will be pensioners.

From the information provided by the respondents it would seem that services for individuals with dysphagia are at different stages of evolution across the European Union. Also that in the majority of the member states it is the speech and language therapists/logopedists who take a pivotal role in assessing and treating/obtaining treatment for individuals with dysphagia, that is, cases of dysphagia other than those with a pathology requiring surgery.

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