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ARTICLE

Recorded incidence and management of dysphagia in an outpatient paediatric neurodevelopmental clinic

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In recent years there has been an increase in the number of children diagnosed with neurodevelopmental disorders. Dysphagia is believed to be a co-morbid condition in up to 90% of children with neurodevelopmental disorders, and is potentially life threatening.

Objectives. To describe the medical diagnoses of children attending a state outpatient neurodevelopmental clinic; to determine the involvement of allied health professionals in the management of children with neurodevelopmental impairments; and to compare the reported incidence of feeding difficulties with the number of referrals made for feeding assessments.

Setting. State hospital outpatient neurodevelopmental clinic in South Africa.

Subjects and methods. Retrospective audit of a systematic sample of 100 files from 1 472 patients aged 0 - 14 years attending the clinic between June 2008 and April 2009. Data were tabulated and analysed quantitatively using descriptive statistics.

Results. Diagnoses recorded in the files included developmental delay (32%), genetic syndrome (24%), cerebral palsy (19%), autism spectrum disorder (15%), learning disability (4%), microcephaly (1%), hydrocephalus (1%), dysmorphic features (1%), neuropathy (1%), traumatic brain injury (1%) and specific language impairment (1%). Of the sample 79% had been referred for at least one type of therapeutic intervention including speech and language therapy. Feeding difficulties were mentioned in only 29% of files, and less than half of these children (14% of the total sample) had been referred for a feeding assessment.

Conclusion. A minority of children with neurodevelopmental disorders and recorded feeding difficulties are referred for feeding assessments. This supports the suggestion of mandatory dysphagia screening in clinics and regular follow-up feeding assessments, as well as improved multidisciplinary teamwork.

Neurodevelopmental disorders arise from impairments to the developing nervous system from either exogenous or endogenous causes, resulting in failure to achieve appropriate functional capabilities.[1] In recent years there has been an increase in the incidence of neurological impairment, with more children being diagnosed with autism, attention deficit (hyperactivity) disorder (AD(H)D) and cognitive impairment than ever before.[2] The increased incidence of neurodevelopmental disorders has been attributed to increased survival of medically high-risk infants, improved diagnostic criteria, and a true increase caused by exogenous factors.[2,3] Furthermore, increasing poverty and limited access to health care services in developing countries have increased the risks of congenital and acquired neurological impairment.[4]

Dysphagia, which is defined as a disturbance in the active transport of food or liquid from the mouth to the stomach,[5] is reported in up to 90% of neurodevelopmentally impaired children, leading to compromised growth, malnutrition, dehydration and limited developmental potential.[6] Research shows that up to 40% of children with cerebral palsy present with dysphagia, while a further 75% have signs of gastro-oesophageal reflux disorder (GORD).[7] Furthermore, 62% of children with autistic spectrum disorder (ASD) and 45% of children with Down syndrome display signs of swallowing difficulties in the form of food aversion related to neuromuscular involvement and sensory integration impairments.[7] The sequelae of dysphagia diminish the individual's quality of life, while some consequences such as aspiration pneumonia[3] may be life threatening.[8] The prevention of aspiration is crucial, as chronic pulmonary aspiration may lead to pneumonia, respiratory impairment and death.[9]

Children with neurodevelopmental disorders are at risk of aspiration,[1] with greater risk being experienced by children who are not able to communicate their feeding difficulties to their caregivers. Aspiration may be audible, such as coughing and choking on food intake, or may present as silent inhalation of foodstuffs. It may be sporadic, intermittent and variable depending on the underlying medical condition.[9] Caregiver accounts indicate that 22% of parents of children with neurodevelopmental impairments report that their children vomit after eating, 56% report choking during feeding, and 28% describe mealtimes as stressful.[6] It is therefore vital to obtain a feeding history during consultations and to refer appropriately.

For the reasons listed above, a multidisciplinary team including paediatricians, speech-language therapists, occupational therapists, physiotherapists, otorhinolaryngologists, dieticians,

dentists, gastro-enterologists and social workers may be needed to address the complex needs of neurodevelopmentally disabled children and their caregivers.

The aims of this review were to describe the medical diagnoses of children attending a neurodevelopmental clinic, to determine the involvement of allied health professionals in the management of children with neurodevelopmental impairments, and to compare the reported incidence of feeding difficulties with the number of referrals made for feeding assessments.

Subjects and methods

Ethical approval was granted by the University of the Witwatersrand Medical Ethics Committee (clearance certificate M090464), while permission to access the files was granted by the hospital CEO and the director of the outpatient clinic where the study was conducted.

This was a retrospective audit of the files of paediatric patients with the diagnosis of a neurodevelopmental disorder. In a systematic sampling procedure every 15th file of all patients aged from 0 to 14 years who had been seen at the neurodevelopmental clinic at the hospital between June 2008 and April 2009 (1 472 patients) was sampled until 100 files had been selected for review.

Data were collected on a standardised form and coded according to a system where the information from each file reviewed was recorded separately from identifying details. The data were tabulated in a nominal fashion and analysed using descriptive statistics.

As the primary source of data was a static document, the study did not include participants. This method of data collection eliminated the possibility of participant influences on the results obtained. Although the absence of participants may improve the internal validity of the study, retrospective studies by their very nature increase bias, since there was no uniformity in what was asked or done in each consultation. Nonetheless external validity was accounted for by the use of systematic randomised sampling that ensured representativeness of the sample.[10] As the population was defined without regard to geographical or socio-economic elements, ecological validity could not be ensured.[10] Since the research design did not allow for standardisation of documents, these could also not be verified for reliability.

Researcher reliability was ensured by employing a second rater with the same professional background as the primary researcher to evaluate a third of the sample for the characteristics listed in the data collection form. The correlation between the two was calculated, revealing 84% correlation between the two raters.

Results

Table I shows some patient characteristics in the study sample. Sixty-eight per cent of files belonged to male patients and 32% to female patients; the mean age was 6 years and 10 months (range 2 months - 14 years). There were 10 different neurodevelopmental diagnoses, but four primary diagnoses (developmental delay, genetic syndrome, cerebral palsy and autistic spectrum disorder) together accounted for 90% of the sample. Secondary diagnoses included cognitive impairment (*N*=67), motor impairment (*N*=41) and sensory impairment (*N*=19), with 41 files recording more than one secondary diagnosis. Despite the fact that none of the files contained secondary diagnoses of communication impairments, two-thirds (*N*=67) of the sample attended speech-language therapy, while half of the sample were attending more than one type of therapy (Fig. 1); 21% of the sample was not receiving any form of therapeutic intervention. It is noteworthy that referral to dieticians was not mentioned in any of the 100 files sampled.

Of the files sampled, 29% contained reports of children experiencing one or more feeding difficulties, with 14% reporting referral for a feeding assessment (Table II). There was an average of 4.5 neurodevelopmental consultations per child, with no identifiable relationship found between the number of medical assessments and referrals for feeding assessments. The most commonly referred feeding difficulty was food spillage, followed by referrals for vomiting after meals, food aversion, poor feeding, drooling and malnourishment (Table II).

Proportionally, children with cerebral palsy were most commonly referred for feeding assessments (35%, 6/17), followed by children with syndromes (21%, 5/23) and one child with a traumatic brain injury (TBI). All of the children receiving non-oral feeds (3 with cerebral palsy and 1 with TBI) had undergone feeding assessments.

An additional 15 files contained mention of feeding difficulties, but there was no evidence of referral for feeding assessments. Seven of these files were of children with genetic syndromes, 4 with developmental delays, 3 with cerebral palsy, and 1 with microcephaly (Table II).

No relationship could be identified between the age of the patient and the number of neurodevelopmental assessments that they had undergone (Table II). This is not surprising, since

TABLE I. DISTRIBUTION OF DIAGNOSES (*N*=100)

Primary diagnosis	No. of affected males	No. of affected females	% of sample
Developmental delay	23	9	32
Genetic syndrome	15	9	24
Cerebral palsy	11	8	19
Autistic spectrum disorder	12	3	15
Learning disability	4	0	4
Microcephaly	0	1	1
Hydrocephalus	0	1	1
Dysmorphic features	1	0	1
Neuropathy	0	1	1
Traumatic brain injury	1	0	1
Specific language impairment	1	0	1
Total	68	32	100

TABLE II. DETAILS OF PATIENTS WITH FEEDING DIFFICULTIES (*N*=29)

Reports of feeding difficulties in file by paediatricians	No. of reports	Diagnosis	Age (yrs) of child at time of data collection	No. of assessments in neurodevelop-mental clinic	Feeding referral	Recommendations made by speech-language therapist
Poor feeding	6	Developmental delay	13	3	No	-
		Developmental delay	2	1	No	-
		Developmental delay	5	3	No	-
		Cerebral palsy	3	6	Yes	Positioning/oral motor exercises/ change food consistency
		Syndrome	2	5	No	-
		Syndrome	3	6	Yes	Change food consistency
Food spillage	5	Syndrome	6	13	No	-
		Syndrome	7	12	Yes	Thicken feeds
		Cerebral palsy	3	6	Yes	Positioning/oral motor exercises/ change food consistency
		Syndrome	2	6	Yes	Oral motor exercises
		Syndrome	3	8	No	-
Vomiting after meals	4	Cerebral palsy	2	18	Yes	Positioning
		Cerebral palsy	2	7	Yes	Positioning
		Developmental delay	4	6	No	-
		Syndrome	1	4	No	-
Food aversion	4	Syndrome	3	8	No	-
		Dysmorphic features	14	10	Yes	Change food consistency
		Syndrome	4	7	Yes	Change food consistency and adapt utensils
		Cerebral palsy	7	3	No	-
Drooling	3	Syndrome	2	2	No	-
		Syndrome	2	5	No	-
		Syndrome	1	2	Yes	Oral motor exercises
Malnourished	2	Cerebral palsy	1	3	Yes	Non-oral feeds/PEG
		Cerebral palsy	6	8	Yes	Non-oral feeds/PEG
Gastro-oesophageal reflux	2	Cerebral palsy	4	1	No	-
		Cerebral palsy	4	5	No	-
Non-oral feeds	2	Cerebral palsy	5	3	Yes	Physiotherapy/ positioning/PEG
		Traumatic brain injury	9	1	Yes	Nasogastric tube
Sucking difficulties	1	Microcephaly	3	3	No	-

PEG = percutaneous endoscopic gastrostomy tube.

such a referral should depend on symptoms not number of consultations.

Discussion

A retrospective review suffers from a number of weaknesses. The patient profile in this sample may not be comparable to that of studies showing a high incidence of dysphagia, as some of the neurodevelopmental conditions seen here may not be expected to result in dysphagia. In this small study, the proportion of cerebral palsied patients with feeding problems (35%) is comparable to the reported figure of 40%.[7]

The number of referrals for feeding assessments in this study is low in comparison with the internationally reported incidence of dysphagia. Even of those patients who had a file entry relating to feeding difficulties, less than half were referred. In spite of the report of feeding difficulties in 15% of files, there was no evidence of referrals for feeding assessments for these patients. It was of concern that neither the 2 patients believed to be suffering from GORD nor the child with

sucking difficulties had been referred for feeding assessments. Poor feeding, drooling, food spillage, vomiting and gastro-oesophageal reflux are serious risk factors for complications of dysphagia, with an impact on nutritional state and growth potential, learning capacity, parent-child interactions and quality of life, as well as medical complications such as aspiration pneumonia.[11]

Nevertheless, 79% of patients in this study were receiving some form of allied health care intervention (Fig. 1). These allied professionals may have made referrals to other team members that were not recorded in the neurodevelopmental clinic file. Significantly, 67% of patients had been referred for speech-language therapy assessments. It is hoped that feeding and swallowing were assessed during these consultations, despite the lack of specific referrals for dysphagia management.

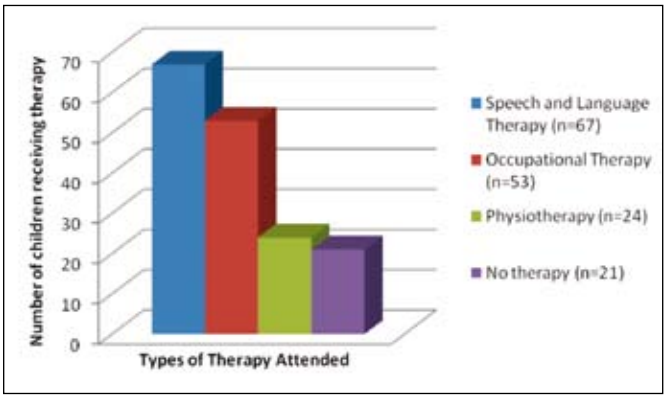

Fig. 1. Types of therapy attended (some patients attended more than 1 type of therapy).

Our study has identified gaps in multidisciplinary teamwork in our clinic. This is shown in the lack of referrals from paediatricians to speech-language therapists for feeding assessments, and also in the lack of referrals from speech-language therapists to other members of the multidisciplinary team (Table II). Of the 29 patients who had been referred for feeding assessments, only one had been referred by the speech-language therapist for physiotherapy. In one instance a recommendation was made for an adaptation in feeding utensils, which infers a referral to an occupational therapist.

The apparent lack of multidisciplinary involvement by all professionals involved in the management of children with neurodevelopmental impairments may be accentuated by logistic issues such as staff availability and pressure of work. The value of an audit such as this study lies in its ability to identify areas in need of improvement.

Conclusion

We conclude that too few children with neurodevelopmental disorders are referred for feeding assessments. Our study also suggests inadequate cross-referral of patients between the various professionals involved in the assessment and management of children with neurodevelopmental impairments. However, the results of this retrospective study must be interpreted cautiously since medical records may not provide a true reflection of the assessment and intervention process.

We highlight the need for improved multidisciplinary collaboration, particularly for children in this population, whose complex medical conditions may be life threatening. Furthermore, the use of a validated patient record system that allows for medical records to be accurately and comprehensively documented may improve the reliability of data for retrospective reviews.

Identification of feeding impairments could be improved with the introduction of mandatory dysphagia screenings at assessment clinics in order to identify children who are at risk, in order to intervene early. Where this is not a realistic option, the case history forms should include standardised and specific questions that would assist in the early detection of children with functional impairments of feeding. Furthermore, regular follow-up assessments of feeding should be implemented, as the nature of feeding and feeding difficulties may change over time.[11]

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